**[START OF TRANSCRIPT]**

**Interviewee:** Is the light okay? I mean I’m like…

**Interviewer:** Oh no, you’re fine. I mean I’m not in great lighting and this is all the lighting I have.

**Interviewee:** Okay, yeah, let me just see if this one’s…

**Interviewer:** Sure.

**Interviewee:** I just, it might not but…it’s a weird room that we have.

**Interviewer:** It looks beautiful. No, you look great, I can see you, you can see me. Not perfect. It’s not the point of it. And we’re not analyzing any visual features, it just helps for our social communication. But thank you. And during our conversation, I will be asking you about how you think your son’s sensory sensitivities and habits impact his transition to adulthood. And I’ll be doing something called a semi-structured interview which means I have my script in front of me with questions and they’re planned but I’ll also be adapting them to fit our conversation, so they actually fit for what we’re talking about and fit for you and your family.

**Interviewee:** Okay.

**Interviewer:** Any questions?

**Interviewee:** Nope.

**Interviewer:** Okay and later, if there are any questions you don’t want to answer for whatever reason, that’s perfectly okay. *“I don’t know”* is a perfectly fine answer, don’t feel pressured. And if there are things that come up from earlier later on, feel free to bring them up. This doesn’t have to be perfectly linear.

**Interviewee:** **[00:01:13]** Okay.

**Interviewer:** Awesome. Shall we?

**Interviewee:** Sure.

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

**Interviewee:** So, he’s a kid who wants pressure so as opposed to a child, like there’s sensory integration issues with kids that they either don’t wanna be touched or they wanna be touched, right? He’s on the other side which is the wanna be touched part, he loves being squished, he likes being in small spaces so one of the big things that he does is, I think I told you this before but when we go to a playground, he doesn’t want to be in the middle of the playground, he won’t go…he wants to be on the fence. He likes to be in the little kids’ area instead of the older kids cause it’s fenced in and he’ll just go around in circles on the fence so he won’t walk across a field or something, so it’s interesting so that’s like a visual thing that he has but he also has the touch thing. He’s *extremely* oral so he’s always chewing on something and he drools a lot because of that as well. He likes the deep pressure of like a chewy or what he’s been using is like the balls from the ball pit and we buy commercial grade ones so they’re like really, really hard and he breaks them in half just with his mouth. So he’s looking for this like intense sensory input. The other thing that he does, and I think this would fall under sensory as well, is he likes to flick lights on and off so he likes this... It’s not a strobing thing cause that would give him a seizure but it’s like he does it in a pattern so he’s very fixated on that pattern. It’s like up down, up down, up down, up down, up. So he does it in like a sequence and he’s getting something from the light because the whole time, he’s looking at the light so he looks at all lights and he loves to look at ceiling fans so there’s something about like that type of visual movement that he likes. Things that he doesn’t like, though, he has a hard time with when you’re not swinging, he doesn’t like to swing like that, he’ll go flat like this so if they have a…right now, they’re using this really funky swing thing at school but instead of going back and forth with it, they slide it on this rail back and forth. Does that make sense? There’s a name for that type of motion and I can’t remember…

**Interviewer:** So he likes kind of the flatness, the flat motion as opposed to kind of more of the curved up ending?

**Interviewee:** Yeah. The curving is the problem with that. He doesn’t…he has a thing with feeling secure so even though he’s like an extremely impulsive and you know he’s impulsive and he doesn’t follow directions, that type of thing but he’ll be overly cautious about stepping on things. He can’t perceive the depth of it maybe or something so it’s kind of interesting to watch him. I’m trying to think of other sensory stuff that he has. He has no food sensory issues, that’s for sure. He eats everything. He doesn’t have a color thing either, like with food. He does love the color blue and it’s this blue right here.

**Interviewer:** Like a nice cobalt blue.

**Interviewee:** Yeah. And I’m trying to think of other stuff that he does that’s sensory.

**Interviewer:** What about smell?

**Interviewee:** Smell, yeah, he doesn’t…he’s not big on overwhelming smells. **[00:05:17]** It’s kinda hard to tell if he likes them or not. He doesn’t like crowds either, that’s another, or loud sounds so we’ve only taken him to concerts that are outside, to give you an example, that are in a park or something or the town square or whatever it is because it’s like less people and it’s not as loud so... He’ll do this a lot when it’s loud.

**Interviewer:** Cover his ears?

**Interviewee:** Yeah.

**Interviewee:** Not cover them like that but he rubs on them, you’d think he’d have an ear infection but he doesn’t, it used to drive us crazy. So there’s visual, there’s no taste, and he likes the pressure part. He likes to be hugged really hard and he’ll hug you to hug him. And the other thing that he absolutely loves which I just remembered is he likes it when you do this. **[Makes farting noise]** So you make farting noises on his hand so the vibration of you doing that so he’s always putting his hand over my face which is fun with glasses. Like I don’t wear them all the time, I wear them for reading and the computer and stuff, they have a bit of a distance, but he’s just always wants that. Or he’ll do mouth things where he makes raspberries **[blows a raspberry]** the whole time. You’re like *“kid, please stop spitting in my face.”* The other thing he does is he’ll do fishy face we call it cause **[makes popping sound]** like that. Then he’ll also do grinding his teeth which is the worst. It’s absolutely the worst sound. It’s like when a baby grinds their teeth, I don’t know if you’ve had children or not, but babies usually grind their teeth for like two days and it drives you crazy. And then they realize *“oh, this isn’t fun.”* And usually, Alexay didn’t learn that lesson and he did it for like two years straight when he was probably around seven. And there are people in our family who couldn’t be around him because the sound was so horrible.

**Interviewer:** And it didn’t bother him, that sound?

**Interviewee:** Doesn’t bother him at all.

**Interviewer:** And the feeling doesn’t bother him? Cause like that’s…

**Interviewee:** No, he likes it. He ground his baby teeth down to like teeny weeny things, and I wear a guard for it cause I do it at night. He would never keep a guard in his mouth.

**Interviewer:** How are his adult teeth? Does he ground those down too?

**Interviewee:** No, he hasn’t because what we do now is obviously at night, we can’t do anything but during the day whenever he is grinding, we just keep putting a chewy in his mouth and he’ll stop doing it because either he doesn’t want the chewy or he gets annoyed at you for doing it. Keep putting it in, keep putting it in. He’ll just be like *“alright, I’ll stop”* or something. I don’t know what the stop process is but it does help to get him to stop doing it. He does have pica so that’s a sensory thing I think in some ways so his pica is…he is very specific in his pica so his pica is dirt, he’ll eat the dirt from flower pots or the ground or anything or the woodchips at the park. He also eats diaper gel and he’ll eat poop so we’ve had some major issues with him getting into his diaper. He has to wear putty pajamas or something that zips up cause we didn’t teach him how to use a zipper on purpose and because that way, we can keep the pajamas on him but we just found pajamas that they zip up the back so we’re gonna have to worry about that so that was an amazing find. They’re called *Little Keeper Sleepers* and they’re really well made and expensive. That’s the thing about having a kid with special needs is the expense is insane. They’re $38 a pair so obviously people who don’t… who are low income obviously are not buying these pajamas.

**Interviewer:** That’s not cheap at all.

**Interviewee:** Right, and that’s one of our issues as a parent is you’re like *“okay.”* We’re always buying new things for him to try and keep his interest. As far as toys, that’s another, he likes light up and spinning toys for some reason. And he likes anything that makes noise like a musical instrument type like bells, he likes the sound of bells. That’s really it, I think.

**Interviewer:** I was gonna say do you mind if I ask some follow up questions from what you just said?

**Interviewee:** **[00:10:27]** Sure.

**Interviewer:** So, going kind of in order of what you’ve just talked about, when you were originally talking about playgrounds and how he likes to kind of track the fence like on a kiddie playground, you talked about that being visual. Could you describe what you meant by that?

**Interviewee:** So, the way that he does stuff…he’s a side viewer so he’ll look to the side all the time and we’re not really sure…it’s gotta be something sensory I’m sure. He does look at your face so that’s something that’s an autism thing that he doesn’t have a problem with. He’ll look you in the eye all the time. But with the visualness of the playground, it’s almost like it’s too open for him. He likes to walk so his arm is touching the edge of the fence or he’ll just grab onto the fence or try to climb the fence. If he wanted to get from one side of the playground to the other side of the playground, he’s not gonna walk straight across. He goes all the way around and he also if you’re in a playground that doesn’t have a fence, he’s weird. He’ll like he won’t go on the equipment but he’ll stand next to the equipment so he has to have that feeling of closeness.

**Interviewer:** Yeah, definitely, thank you. And then when you talked about flickering the lights, does he flicker other things like a toy with lights or something or is it just a light switch?

**Interviewee:** Just a light switch. Other things that light up, he’ll just hit them once until they stop lighting up and he’ll hit it again. And sometimes, he won’t actually light it up, he asks by gesturing to you, like he wants you to do it cause you did it before or something, so that type of thing. I mean he functions on a really low level with certain things; he’s also extremely prompt dependent so he does things in a pattern where it’s like muscle memory so he’ll learn something and he only uses muscle memory it seems. So we have to teach him how to do things with… we can’t teach him how to put pants on, that’s one of the things that doesn’t work because you take your pants off and put them on the same way so he will always just put the pants on cause that’s what he learned. If you try to teach him to pull his pants down now, he’s just gonna keep trying to pull them up cause that’s what he’s learned so sometimes it’s hard to tell if it’s a sensory issue or but he’s obviously getting some sort of sensory from that light being on and off and he stares at the lights like we have to turn off lights like our kitchen, you can look out the door into the dining room. Well, there’s no door there but so it’s open and if you leave the dining room light on, he’s just staring at the light like from across the room and you’re like *“what are you looking at?”* because he’ll be like this.

**Interviewer:** Just staring at the light?

**Interviewee:** Yeah.

**Interviewer:** Got you.

**Interviewee:** Yeah. He likes to be upside down too, I forgot about that. He’s been like that since he was a baby. He stiffens himself up and he’ll like look at me like that. There’s something again with that being upside down feeling.

**Interviewer:** Yeah, absolutely. I mean if life feels different than being right side up. Thank you. And then you talked about loud noises. What type of loud noises or is it just all loud noises?

**Interviewee:** It’s not all loud noises so I mean like fireworks he’s fine with which sounds really strange. And thunderstorms, he’s fine with. But like really loud…if like a crowded room, that kind of loud, where people are all talking at once, I think that’s really where it is. That’s why we haven’t done the going into a building that way or when it gets really crowded. Like even in the mall where the food court or something where it gets louder, he gets a little rigged out a little bit by it. He gets quiet, that’s what’s weird. Or when he was a baby, he used to just go to sleep. He slept all the time. We had to wake him up to feed him. If you went to a party or something, when you brought him with us, he would just sleep because he’s overwhelmed by the sounds of everybody.

**Interviewer:** Yeah, absolutely, thank you. And then you briefly mentioned smell that he doesn’t like overwhelming smells. Would you say that’s more than the average person or just…

**Interviewee:** Pretty average, yeah. Although I’m sensitive to smell too so I don’t know, maybe it is an average…I have no idea. But yeah, even someone’s perfume or something like an old lady’s perfume or that type of smell where you’re just kind of like **[makes a gasping sound]** then he gets a little bit like sensitive like he’ll make funny faces so you’re just like *“okay, that’s a little weird.”* That one’s not a big one. The bigger ones are the oral, motor and squishing that type of stuff so.

**Interviewer:** Got you, thank you. And then how do you help your son manage his sensitivities?

**Interviewee:** Ohh, avoiding is one because obviously we don’t go to places that are really loud with him, or crowded cause I think part of the crowded part too when he’s in a group like that, he doesn’t generally when we’re in crowds, he’s not walking on his own. He can walk but he generally runs, not walk, so when we’re in places like that or in stores, any place that you would have like a surface that you have stuff on cause he’ll just like take it all off, you know. But those type of places he’s in a stroller, he’s in a giant stroller and I think part of what gets him is that he’s in a tunnel cause he’s short that way, like low, you know so he doesn’t like feeling trapped like that so I think that’s where…did I answer your question?

**Interviewer:** **[00:17:02]** Yeah, you talked about avoiding loud spaces.

**Interviewee:** Yeah. So I’m trying to think if there’s…ohh, the other things that we do, obviously, we give him things to chew on so we think about that. You have to have something for him to chew on and he’ll chew on anything so that’s why you need to have something that’s safe for him. And for sensory stuff, he has a reflection thing so he likes to look at himself in the mirror but he’ll look at any surface that has any amount of reflection on it like a picture on the wall so what we’ve had to do is we’ve replaced the glass in the pictures with plexiglass cause he tends to break them and then we also Velcro all of our artwork to the wall so he can’t take it down cause he’ll just knock everything off.

**Interviewer:** Will he knock it off so he can look at himself better?

**Interviewee:** Yeah, yeah. Or he’s banging on the thing…like he wants to look behind it or something. He doesn’t get it so he’ll pull it right off the wall so we’ve made those accommodations. We don’t keep a lot of things around our house because of him because he puts everything in his mouth so you have to make sure that the size of stuff is too big for his mouth and food and things you can’t. We don’t have food out, like fruit or anything, he’d either eat it or squish it I don’t know, like, stuff like that. We don’t have our knives out because he actually took a knife out of a knife block when he was 2 or 3 years old and put it in his mouth. Like he just took the blade and went like that. They were like *“holy God, put it back.”* I mean he’s done some really crazy, dangerous stuff. He climbed out his window when he was 2 ½, 2 when he was really little, it was crazy like what he would do but so we just keep a lot of things clear you know, give him the space to do it. Anywhere there’s a light switch that we don’t want him to turn on and off because he’ll leave it on and we have outdoor lights, you can’t see the one off our basement, there’s no windows on that side of our house so that used to be on for days and we wouldn’t even know so we put on these light switches that you… they’re safety light switches for kids. You have to actually push it in and then push it up so he won’t…those lights it’s to keep him from clicking the lights on and off. But we do leave the other half of that, though, is we know he likes using the lights so we leave some of the lights without that switch on them so that he *can* turn the lights on and off. We go through a lot of light bulbs that we shouldn’t be but like LED light bulbs or even the compact fluorescent, they’re like *“oh, they last so much longer.”* Not in our house! Cause people don’t realize is that it’s the number of ups and downs that turning it on and off which is the hours they’re talking about, well he does it, that shortens the lifespan of a light bulb by a lot so we’re constantly getting light bulbs because of it but it’s worth it for…you can’t take everything away. If it’s safe, let’s do it. If it’s one we can see, it’s the living room light, the dining room light, go ahead, flick it on and off all you want. I’ll just buy a light bulb. I’m trying to think of other stuff that he does that we accommodate for him. Well, he has his own space, that’s one thing, so he has a playroom, that’s in our basement so it’s a finished basement and we put mirrors on the walls for him so he can look at himself. There’s a TV which is behind, it’s an industrial plexiglass case that they use in jails and in psych places so we have that down there and then we have a giant ball pit because we know he likes the pressure so we built that and then we have giant balls down there so we’ll like either lay him on the floor and roll the ball over him with our bodyweight, stuff like that to try to have him calm. And we’ve used weighted blankets before…he doesn’t really like the weighted blankets or weighted vests. He does better with like lycra, I don’t know if you ever tried it but we have giant pieces of lycra that we’ll just tie onto him and it gives like a different type of pressure because it’s like an all over pressure that’s like pushing you in so it calms him down and there’s like this new, weighted blanket, kick people around and they’re not using them right so one of the things about weighted things is that you can only keep them on for 20 minutes. If you do it longer than 20 minutes, the effect of the weight is, your body gets used to it and the effect is not there. So people are like *“I sleep with a weighted blanket.” I’m* like *“you’re not supposed to sleep with a weighted blanket.”* You’re supposed to put it 20 minutes on and then take it off and if you’re sleeping all night, you’re not gonna get that effect and you’ll have to wait longer to be able to get that effect the next time so, yeah, it’s kind of weird. If you have them, he doesn’t use them. The one he does use is the lycra and that’s a thing like when we go to get his hair cut, we actually tie him in the lycra so he feels more comfortable sitting in the chair. It still takes three people to do his hair so but not because he’s not…the other thing about him which is interesting, he doesn’t have any issues with transitioning from one space to another space. He’s like whatever or going to the doctor’s office or the dentist’s office, those types of things do not bother him. You can say *“we’re going to the dentist”* and he doesn’t know what that means I don’t think. **[00:23:41]** He doesn’t connect that the dentist is that person who sticks their hand in my mouth all the time. He does okay and that we have used the weighted blanket for. The dentist’s office because that gives him more of an even weight on his body and the other thing we’re doing though is sitting on him so it’s like our dentist is awesome cause we sit on him, cause then he calms down, cause he’s got the weight and then she also goes like this around his head so she’s like cuddling him in a way so that also calms him down as well because he’s just like “okay.” He’s pretty fine.

**Interviewer:** That’s great. I’m glad she’s so helpful in that scenario. That’s wonderful.

**Interviewee:** Yeah, and she’s quick. That’s the other half. When you have a kid with special needs and you want the doctor’s to be quick, as quick as possible.

**Interviewer:** Has your son received any specific therapies for his sensory needs as opposed to his other needs?

**Interviewee:** Well, he was doing physical therapy, not in school but we stopped. We weren’t able to find an adult physical therapist cause he’s too big for pediatric physical therapy now but in school, they only do physical therapy for the safety of the child in the school so it’s different, right? So, when he was doing the physical therapy, she did a lot of things with him with pressure. She would do things with weight, that’s another thing we do is…he has a thing where when he pushes something, he over pushes so he wants that input, to be really hard, so he has a cart at school, they put 100 pounds of concrete on it to make it really heavy for him so that he has to have resistance so when she was working, the physical therapist was working with him, she, that’s my husband…

**Interviewer:** Hi!

**Interviewee:** Need a coffee.

**Interviewer:** Important!

**Interviewee:** …So he, what was I saying?

**Interviewer:** The weight and the cart, the concrete.

**Interviewee:** Yeah, and they put the weight on that so when he was doing physical therapy, she would do things where, cause they had like gym equipment there, she would do like this loop thing that she would put around him and have him walk away with weight and then walk back and forth using that weight to like ground him I guess, I don’t know so she did that and she did some other like squishing with the ball and stuff as well. I mean there’s some things that you would think he would like and he doesn’t. Trampolines or stuff like that, that again goes to that sensitivity of avoidance. He won’t go on a bounce house, he doesn’t want to go on those like blow up things because the ground is not steady, right? And he doesn’t go on a trampoline like what we’ve put on trampolines, we’ve thought *“oh, he would love this”* cause he can bounce around; he likes to bounce around, right? Put him in a trampoline, he sits in the middle, just sits there and you have to make him do it and then but if you put him in the ball pit which is the pressure again, he likes that so if you go to *Bounce* or one of those places, it’s kind of a wasted time for him, unless you go to the other parts.

**Interviewer:** Did the work that that PT was doing, do you think it helped him?

**Interviewee:** Yes, she was working…the other thing she worked on was his core, like core strength. He was low tone so that’s part of his thing so I think that it helped him with that and I think it calmed him down.

**Interviewer:** Having more tone calmed him down?

**Interviewee:** Well, going to the…

**Interviewee 2:** Sorry to interrupt.

**Interviewee:** We’re recording.

**Interviewer:** That’s okay.

**Interviewee 2:** How he behaves in a swimming pool, is at all relevant to this conversation?

**Interviewee:** Oh, that might be, yeah, the swimming pools.

**Interviewer:** Thanks. So he doesn’t like swimming?

**Interviewee:** No. Again, the bottom, it’s about the bottom so the behavior in the pool like they tried to do aqua therapy at his school with him, all he wanted to do was get out of the pool. The whole time, they were like *“this is pointless”* cause he’s just trying to get out and a lot of it has to do with he can’t judge that depth. If you go to a lake, he’ll walk in the water, he’ll be alright but he’ll only do it up to his thighs, he just likes to pick the mud up and try to eat it. But a swimming pool, we were always afraid he would fall into a pool and not know how to swim, he just won’t go in them, he’s like *“nope, it’s different, I don’t wanna do it.”* Maybe the feeling of it but he loves water, if you’re running water and it hits his hand, he’s like totally into that, like taking showers and baths, he loves the water, loves that but not pools.

**Interviewer:** Got you. But you were saying PT, you think it calmed him down?

**Interviewee:** **[00:29:19]** Yeah, so I think that when he was in it, the effect would be later on in the day so we would have PT usually at like 8 o’clock in the morning before school and then he would be calmer at school like probably around 10 o’clock, it kind of calmed him down like doing it was not calming in itself, but the fact that he had it I think helped him. She does a lot of the, I don’t know what they call that, compressions so you can do it on your hands and he likes it on his shoulders a lot so again that pushing motion, pushing type thing so she would do a lot of that stuff to keep him calm while we were doing it, but then it would help him a little bit later. And I mean those are things we do with him a lot anyway like if we see he’s agitated, we’ll give him a giant hug. I mean you’d be like *“woah, what are you doing”* cause you just squeeze him and then we might jump up and down with him because he likes the feel of his feet hitting the ground too, that compression. And then he’s calmer afterwards.

**Interviewer:** And how…do you think his sensitivities have changed overtime?

**Interviewee:** No. Well, actually I shouldn’t say that. He’s calmer now than he was when he was two, that’s definitely true. But I would say the sensitivities: the light switching things, the chewing, those things haven’t changed. It’s like the sensitivities haven’t changed but his behavior has since he’s gotten older. The sensitivities are maybe a little bit easier to handle, we can get in there faster, like especially with things like the grinding, that type of sensory input where it’s like we have about twenty chewies so they’re everywhere. We’ll get a ton of them.

**Interviewer:** So I just want to make sure… are you saying that you can manage his sensitivities better because his behavior has changed but the sensitivities themselves have not changed. Is that accurate?

**Interviewee:** Yes, yeah.

**Interviewer:** Perfect, thank you. And then when your son is in a sensory scenario that’s like aversive to him, say it’s too loud or something, do you think that causes anxiety for him?

**Interviewee:** Yeah. I think it does. I think he has a reaction to it and it’s not the reaction that…I feel like some kids with autism, when they’re in a loud space, they’re the type that you can put headphones on their head, it would be like *“okay, I’m good to go;”* it’s the sound that’s bothering them, right? So for him, well, he probably won’t keep the headphones on but it’s loud but it’s also confining so it’s more the confining that might be the problem than the loudness but even the loudness though, his thing to do like self-soothe type thing is he would cover his ear, play with his ears. The other thing he does is he sleeps; he’ll just sit there and you’ll see him fall asleep. That’s changed more now that he’s gotten older obviously cause you don’t need a nap, well, he does but he still naps actually; that’s part of his seizure problem. He has a really rare form of epilepsy so that his sleep is just…it’s called electrical status epilepticus during slow sleep.

**Interviewer:** Mmmmm.

**Interviewee:** Yes, yes and I think 4% of epilepsy might have it, if that and usually, people outgrow it but he hasn’t so he’s had that probably since he was born and we didn’t know it until he was 26 months. He was diagnosed almost exactly at the same time so he was diagnosed with autism first but then like 3 months later, he had epilepsy. They were like he has epilepsy so. But what was I saying about his sensory stuff?

**Interviewer:** I asked if that causes anxiety.

**Interviewee:** Yeah, so his anxiety like the look on his face…he’ll look a little distressed and then he’ll just shut down too like he won’t make noise. He’s constantly making noise, humming or going *“errgh”* or whatever you know, he’ll speak, he’ll do *“mm mm mm”* noises or whatever, just noise and then if he’s in a loud place, he doesn’t say or make any noise, trying to calm himself maybe or I don’t know.

**Interviewer:** And has that always been the case? Has he always had anxiety in these loud environments?

**Interviewee:** Yes. Yes, I would say that when he was a baby, I think it affected him even more cause he again slept so much when we would be around other people, it was kind of funny. We would be like *“oh, he’s sleeping again.”*

**Interviewer:** When did that stop you think, or become less?

**Interviewee:** Probably when you should hit puberty. He hit puberty later but probably around 10, 11, 10 or 11, 12, around that time. It got better. Like he, so you have neurological growths in your life, right? So you have them when you’re a toddler, a baby and then you have them when you hit puberty and then at least with boys, I don’t know with girls, they have it again when they’re around 18. You’ll have a brain growth that could change your seizure activity but it seems for him when he changed in those times, he was really, really, really maniachy and sensitive, especially when he was little and then when he got older, he got calmer and then also as his seizures have gotten more under control, he still has seizures everyday but and he has the ESES whenever he’s sleeping, that’s why he still naps, like you can’t get into a really good sleep so he’ll just nap during the day. He also does rhythmic like shaking his foot stuff like that as a self-soother, that’s another thing he’ll do.

**Interviewer:** Sure, thank you. And now thinking a little bit more broadly and more globally, what goals or hopes do you have for your son in terms of his sensory sensitivities?

**Interviewee:** One:never grind your teeth again. The first one right there, right? I mean I think for us, it’s more of an acceptance of what he is like so I would say that we accommodate him the best that we can. We know that he’s not going to be, I don’t know if the word, controllable like he doesn’t follow direction, not even like *“go there,”* he won’t, not even that simple of a thing. I mean he’ll follow the direction like *“pull up your underwear,”* but it’s not that he’s listening to you, he just knows these are the steps and it’s all muscle memory for him so even when you don’t want him to, like you’re not dressing him, you’re dressing him, say you miss the foot on the underwear, he’ll give you the other foot, not the one that I missed cause that’s what happens. **[00:37:27]** You do one foot, then the other foot but he still won’t have his foot in the thing so you’re sitting there like *“no, no, no, you gotta put your foot in the other side”* and he doesn’t get that so it would be nice if he would listen you know to try to find some sensory way or to help him with his sensory stuff that he would be able to say to us, we have a pointing program for him cause we’re trying to get him to point for things that he wants. It would be great if he could point to a chewy or he could point to like when he’s having a sensory issue for himself that he would know to… *“oh, I can do this like I can ask for this by pointing at what I want.”* And for him though any goal that we make for him we know is gonna take a very long time and I’m talking like 5-10 years to really learn an activity, like anything, so we tend to have very limited, like not very many goals for him in general. Just to be happy. We, also, in Connecticut, they’re doing a new model here I guess is how I describe it. They’re trying to keep kids with their families until the parents are over 70.

**Interviewer:** Yeah, I think you mentioned that.

**Interviewee:** Yeah so our goals have probably changed a lot because of that because we know that…I mean at this point I wouldn’t want him to be in a group home setting anyway but we now have a different goal. We’re not looking towards having him necessarily be on his own or be in a group home setting. He’s gonna be here so we tried to make the best **[phone goes]**.

**Interviewer:** Did you take that? We can pause.

**Interviewee:** No, it’s I keep getting spam from my car.

**Interviewer:** Oh yeah, me too.

**Interviewee:** Yeah, because we lease our car so I don’t care if it doesn’t…there’s coverage, believe me. By the time I…you know, just leave me alone. No, so he, our goal would be to have it not affect him as much I guess where you’re able to fulfil the need faster, I guess. And the people that work with him to make sure that they understand his sensitivities, like you’re not gonna take him to the park, we get that a lot. *“Go to the park with him,”* like no, cause he doesn’t enjoy it. It just stresses him out cause he wants to get away and find a place that’s calmer like his stroller, that I should say is we use his stroller a lot for keeping him calm and for the sensitivities because he likes…it’s one of those strollers that’s like a jogging stroller so it’s more of a sack feeling to it than like a structure so that keeps him calm, like when we go out into public, he’s generally in that stroller because we know it’ll keep him calm, he won’t be as destructive or he won’t be trying to get away from where we are.

**Interviewer:** Absolutely, thank you. We’re gonna move onto our next chunk of questions, but that was a lovely segue. So as your son has grown up and aged a bit, how has his and your community reacted to his sensory sensitivities?

**Interviewee:** I don’t know that the community, well, they’re unaccommodating, let’s put it that way. They’re not, no. As general rule, I don’t think any place is very accommodating to kids with sensory issues. I mean the school obviously has been, the public has not. So there’s a lot of staring and a lot of reactions to him still and they’re generally negative and people will walk away from us so they’ll guide their children away from you, they’ll stare, they’ll make funny faces so it’s difficult. You develop a very thick skin as a parent of a child who has such visible disability or the disability for him actually if you looked at him and he wasn’t making any noise, you wouldn’t…he’s gorgeous. You’d be like *“huh.”* I actually have a picture, like his school does a prom…

**Interviewer:** Oh, wonderful.

**Interviewee:** …for the kids and I’ll show you his prom picture, if it’ll show up. Right now, though, he’s got long hair so it’s a little bit different. He’s different looking. Yeah, so, I don’t even know how the public would actually do anything, maybe if you just don’t stare or ask questions or something, I don’t know.

**Interviewer:** Do ask questions or don’t ask questions?

**Interviewee:** I would like people to ask us questions as opposed to staring at him and a lot of times when people are staring at him, I just say something. What I do love is when kids are…here’s his prom picture from a couple of years ago…

**Interviewer:** **[00:43:27]** Wow, so handsome.

**Interviewee:** Yeah, I mean he is…it cracks me up he’s got his hands in his pocket. I was like *“how the heck did you guys do that”* because that’s not something he would do, he’s more like *“I’m gonna have my arms like this.”*

**Interviewer:** That’s a wonderful photo.

**Interviewee:** Yeah and they like stuck his hands in there, it was like that and then it was done.

**Interviewer:** Now you have that picture forever.

**Interviewee:** Yeah. Everybody’s always like *“he could be a model”* and I’m like *“yeah, models need to stand still;”* that ain’t happening and follow direction and I’m like *“no,”* he’ll be a what do you call it, oh whatever, I don’t know.

**Interviewer:** No worries.

**Interviewee:** Yeah, so I don’t know that the community, I mean I don’t really know what they could do except be more understanding of other people, that’s really the main thing.

**Interviewer:** Yeah, would you say the community was more accommodating or accepting when he was younger or less?

**Interviewee:** Well, when he was younger, yeah, because you’re looking at a 19-year-old in a stroller so they’re…you’re already getting a lot of people…when he was little and he was in a stroller, it didn’t matter. They’re like *“whatever.”* But as soon as he got to the point where he’s in a special needs stroller cause he’s so big, then it started to get worse cause they expect that because he looks like a typical person. It’s shocking sometimes, I guess the people and they realize *“oh, he’s not…there’s something going on there.”* But instead of asking, they just stare.

**Interviewer:** **[00:45:29]** Yeah, we’re almost done with this chunk of questions. But thinking about specific spaces or places, are more places more or less accepting of your son? You’ve just talked about school as accepting then talked about the general public, what about like family, friends, religious groups, things like that?

**Interviewee:** Well, we’ve had a couple of incidents with one church, with one person in a church. I don’t know if that was…cause he was being loud, I guess that was sensory, cause he was doing the stuff that makes him calmer or whatever. That’s like a sensory mouth thing. I actually had a woman in the church say that we shouldn’t bring him to church. I’ve had people, the bus driver tell us that shouldn’t he be with his own kind. Oh yeah, oh yeah! We’ve had people in public also say stuff like that. Family, the main thing with family, is the people who were most accommodating for us and at their most helpful to us were my husband’s parents. They’ve both passed away so when they passed away, he has three sisters…

**Interviewer:** Your husband does?

**Interviewee:** Yeah. He has three older sisters. The oldest one helped us when he was really little but she ended up in the hospital with him so that kind of was the last time she…the first and last time she basically helped. His one sister lives in China, she’s what’s called an expat, she doesn’t live in the US, before China, she was in Moscow and Ukraine. But she’s the one person that helps us which sounds really weird. She’s his godmother and so she does a lot of things for him and she’ll actually babysit for us because she comes home in the summer, usually in the summer and at Christmas, so she’ll actually stay with him and be with him where other people won’t. His youngest sister does absolutely nothing and she’s the one, her and her daughters, are the ones that they wouldn’t even be around him when he was grinding his teeth, like they didn’t. His behaviors and sensitivities bothered them so much that they didn’t want to be around us, it’s very painful. The other thing with the sensitivities to things, we divide and conquer a lot. Where one person will go, the other person stays home with Alexay because going to even like the… you can’t take him to other people’s houses because he’ll just destroy everything. We always make the joke, your house isn’t Alexay-proof. They’re like *“it’s baby proof”* I’m like *“no, it’s not Alexay-proof.”* And then when you go to places, like they’ve tried in the past…his family has tried to *“I’ll watch for him for 20 minutes”* or “*I’ll watch him for half an hour so you guys can enjoy the party”* or whatever. But then inevitably, they don’t watch him and that’s dangerous partially because of his sensitivity and partially because he doesn’t follow direction cause he’s very impulsive. One of the things about his thing is he’s so impulsive about it that he will walk through people to get to what he wants so we’re always afraid like he’s gonna step on a baby or he’s gonna step on the cat and he doesn’t care cause it’s a straight line, *“I’m going.”* Around the perimeter, though. And he does that in the house, too, it’s almost like he just likes walking in circles cause we have two circles in our house. We have a living room, dining room, kitchen have a circle. And then we have the slider, the door behind me, the French doors and then we have a family room, that’s on the other side, that has a slider and if he goes out, we have a beautiful backyard, wide open space, *never* goes in it. He *never* goes in it. He will not walk across that, he just goes from one outside door to the other outside door and I mean, he makes that circle. It’s like a door thing, I don’t know. Temple Grandin door thing, maybe? He has a lot of similar areas in her sensitivities and him, cause I read one of her books and I was just like *“wow, that’s our son.”* Small spaces, squishy, being squished, so she made that machine. He turns lights on and off and he likes going through doors so it’s like wow, but he’s not going to get a doctorate though unfortunately but…

**Interviewer:** That’s okay, not everyone needs one. So again, thinking more globally, a bit more broadly, what hopes or worries do you have in terms of how the community will continue to react to your son’s sensory needs?

**Interviewee:** I don’t know that…so, I don’t have great expectations, let’s put it that way. I don’t expect anything to really change and I think because of that, we just have these things and we’re just gonna keep using them. He has specific… the chewies, the ball pit, these things, he’ll have them for the rest of his life, he’s never gonna play with, he’s never gonna be age-appropriate at all and a lot of it has to do with sensitivities. He doesn’t sit and watch television. So we have to be…he will always need a space, have a playroom of sorts. He’ll need a space that he can just roam around like even his bedroom doesn’t have furniture in it; it has a bed, that’s it, we also have pillows, tons and tons of pillows in there and we put balls from the ball pit in there so that he can have that and we put stuffed animals in there and a chewy also so he can chew…he doesn’t chew the chewy though; he has the choice between the ball and the chewy, he chooses the ball on his own. I don’t know if it’s cause it’s bigger; he has something with the mouth obviously. And we’ll just keep doing that because that’s where he’s at and we want to meet him where he’s at. We realize like he does learn, we hope he’ll get better at communicating, but we’re also fine with how he is. He’s 19 so in that picture that you saw, he was 16 or 17, 16 I think or 17 and so he’s very young looking for his age. Right now, I don’t know, do you watch the show *The Umbrella Academy* by any chance?

**Interviewer:** I do.

**Interviewee:** Okay, do you know who Klaus is?

**Interviewer:** Yes.

**Interviewee:** Okay. I’m gonna show you his Halloween costume. See what he looks like now cause when the pandemic started, we stopped cutting his hair cause we couldn’t…is it saved in here?

**Interviewer:** I did too.

**Interviewee:** Yeah, I did for a while. I was like *“forget that, I’m gonna do my hair.”*

**Interviewer:** **[00:53:59 inaudible]** my hair so it doesn’t matter cause it’s so curly.

**Interviewee:** Oh you have curly hair? I don’t have that problem. I’m very jealous of the curly-haired people in the world. I have a friend, she’s Italian and she has the kinky-curly hair and she straightens it all the time, I’m like *“stop straightening your hair.”* I’m trying to…I don’t know what I did with this picture. I think I would really like it if he was able to just walk places, like the main thing I would really like for him is that his sensitivity would be less so that he would…you could go somewhere and not be in the stroller. That would be nice. That’s probably the extent of the goals we would have for him. Even in the community. Just that he could be there and not cause a scene, is that the right word? It’s like I don’t care. It’s weird. My husband cares more than I do about public appearances. At this point, I just look at people and I’m like *“he has a disability;”* if you can’t figure it out, it’s like whatever. Here you go. I’m not technically very…that’s what he looks like right now.

**Interviewer:** He does kind of look like Klaus.

**Interviewee:** He had the whole outfit on. He had the leather vest, I’m gonna see if there’s a leather vest picture in here. I don’t know if you can see that.

**Interviewer:** Oh yeah.

**Interviewee:** The leather vest, the dark tags and he had pants that were all like laced up the side and the whole deal, the umbrella, the whole thing. It was like he was Klaus.

**Interviewer:** That’s great. So just to kind of redirect us back to that question, are you saying that you hope you would be able to be in the community a little bit more easily? Is that your hope?

**Interviewee:** Yes. So one of the things that the community did do that is awesome, it’s nationwide though, is the *Caroline Cart*. I don’t know if you’ve ever heard of that.

**Interviewer:** Yeah, another participant told me about it.

**Interviewee:** Yeah. What a lifesaver, that stupid cart cause I can take him to a store where I used to not like I can handle him on my own okay if I have that cart or the stroller. But when you have to change because of that. You can’t go shopping, like I would like to be able to go shopping with him again. Like him to push a cart, that would be my only expectation is to have him push the cart, stop and I could say “*okay, we’re gonna go now”* and he would go, like that to me would be a miracle because he’s so impulsive. He’s like I’m gonna get my sensory fix, whatever it is. He will lunge for the blue balls like from the ball pit. He will knock you down to get to…cause I need to get that sensory so I was like I would love for him to be able to be somewhere and not have that overwhelming sense of I have to get to that sensory thing or whatever that he would actually just walk with you or I don’t know, that’s really it.

**Interviewer:** Do you wish more places had that cart that you talked about?

**Interviewee:** Oh God, yeah. Right now, in our area, we live near Danbury; Target is the first place that ever had those carts. Now Big Y has them, I don’t know if you…it’s a grocery store.

**Interviewer:** I kind of know it. Well, my sister’s in Connecticut so I drive down.

**Interviewee:** I just saw that this past like two weeks ago that Big Y has the *Caroline Cart* now and I was like “*oh my God, they have the cart”* I could come here with him now so that’s two places. Wooo!

**Interviewer:** Better than one.

**Interviewee:** Right. So as you see there are not very many of those carts around. So I mean if they had them, like say IKEA or someplace like that, their carts suck anyway. Yeah, but if you could accommodate him, bigger stores are fine, it doesn’t matter to me what it is as long as there’s something there. I have to say that because of his sensory issues, he’s in that stroller whenever we’re out so having A-A accessibility to places is another thing that is in the community, if they did that, that would be lovely. We were talking about that from before. There are places we can’t go cause his stroller’s just too big like going to the doctor’s office has started to become a pain because of that cause you can’t not have him in the cart, in the stroller cause he’ll just run through the place and they don’t want you to do that, not in a pandemic. And he’ll take all the pictures off the walls as he goes, kind of thing. **[00:59:54]** But the doors aren’t wide enough. You know they have to find the biggest waiting room with the biggest, it’s like you don’t even think that you’re gonna ever have a child that’s in a wheelchair, maybe the wheelchairs are really tiny so they don’t or whatever. There are places we just can’t go in. I’d just love to be able to go somewhere, go places with him.

**Interviewer:** For sure, that makes sense, thank you. We’re going to shift gears again, if that’s alright? In the quote-unquote transition to adulthood, where do you see your son?

**Interviewee:** What do you mean by that cause I need more clarification?

**Interviewer:** Yeah, definitely. So, could you talk about what stage of independence he’s at? Or could you talk about what are some things where he needs supports versus what are some things he can do by himself?

**Interviewee:** Alright, he needs supports for everything. So he’s still in diapers, he will always be in diapers. We’ve tried to potty train him before and it just didn’t…there was one that was very successful but we couldn’t get the school to do it because it involves nudity so it’s for institutions, it was designed in the 1960s or 50s or something for people who are mentally ill, in institutions, and it was a training program. Basically, you have the kid naked for like a week or two weeks and you’re going on the toilet, off the toilet, on the toilet, off the toilet, like the first three days is basically living in your bathroom with your kid kind of thing. We went through all that; he started to get it but then he had to go back to school and then he also has scoliosis so he ended up with a back brace so to potty train a kid in a back brace does not work cause you have to take, their underwear’s under the brace, so in order for them to go to the bathroom, they would have to take off the brace which by then, they’ve peed their pants. We were like *“this isn’t gonna work.”* He's had back surgery though so he has full spinal fusion so it’s from his T3 to the fourth L so they can’t do it lower than that because you wouldn’t be able to bend at the waist so yeah, he was at a 60-degree angle so and that was affecting his breathing. But, yeah, we never potty trained him. He’s not gonna be potty-trained. There’s so many things that he’s not at an independent level with like his intellectual disabilities which I think that they’re autism and intellectual disabilities, there’s so much overlap that it’s so hard for me to tell so because of those conditions, he just doesn’t grasp stuff. He doesn’t read, he doesn’t write, he doesn’t do computers. He can’t…we’ve tried PECS with him. That didn’t work. He does not discriminate, so if you’re looking at going into adulthood, there’s something I would like for him to be able to discriminate something because he just doesn’t give you that information. He doesn’t have a preference with some stuff too, so he’ll hold a toy for five seconds, he sees another toy, he chucks that toy, gets the other toy or he’s just always constantly throwing toys away and grabbing something else or, like he’ll grab a book, I don’t know, whatever. The cat, he’ll grab the cat which is funny. If we could figure some of that out, that would be great but developmentally that level, that’s why we say he’s at an infant to more like a 6-month-old cause obviously he sits. So he’s like a 6-month-old to a two-year-old; he’s got great gross motor skills but he doesn’t have fine motor, he has some fine motor skills…he can grasp a raisin or whatever, that’s one of them. But he’s more apt to grab it with his whole hand still so that developmental level, so he’ll never do anything independently. He’ll eat but you still have to sit with him. He can eat, he can put on his underwear but if you say to him, *“put on your underwear,”* that level of,like filling out that form was cracking me up, it always cracks me up. The Vineland, that one, cause we have to do that all the time. Yours was shorter though, yours was a lot shorter.

**Interviewer:** **[01:05:27]** That was intentional.

**Interviewee:** But those are the things where they’ll do the developmental levels and you’re just like *“okay, no, no, no, no, no.”* He’s in a program called DDS; it used to be DMR, Department of Mental Retardation, now it’s the Department of Disability Services in Connecticut so he gets services through them. What the hell was I just gonna say about that?

**Interviewer:** Are you talking about developmental levels?

**Interviewee:** Oh, yeah, so they have a thing called LON. It’s level of need assessment and what you’re trying to get in there is a high score and Alexay, I don’t know what the highest score could be, but it’s like 0 = they can’t do it, 1 = they do it sometimes, it’s like that level 4 thing or whatever. But he’s like zeros all the way through, except for gross motor skills so when you get to gross motor skills, he’s completely independent. He can walk, he can run, but developmentally, he can walk and run but he doesn’t know not to run in front of a car. He’s not safe. So I mean he’s pretty low functioning so he doesn’t brush his teeth. I mean the things he can do that you would look on a list as like, he can pull up his underwear, pull up his pants, he’ll put his foot into a shoe but he doesn’t necessarily step down, you have to shove it onto him. Can’t put a sock on, again, socks was one of those things that we just gave up on. Socks and pants because, again, you can’t change the way you do it. Where with a shirt, so he can put a shirt on, you hold the shirt in front of him, he will put the shirt over his head like this and then put his arms in like that, right? To take it off, he grabs the sleeve on this side and pulls it like that.

**Interviewer:** So it’s a totally different action?

**Interviewee:** So it’s a completely different motion. And then he’ll get it. So that’s so low developmentally that he can’t…most of us have figured out that you can put it on and off the same way but he doesn’t have that ability to remember that type of stuff so.

**Interviewer:** For sure. You mentioned that he’s able to feed himself but you need to be there, will he know to eat the food in front of him or do you have to prompt him with that too?

**Interviewee:** Well, it depends because he will try to eat it but usually with his hands so and another thing he won’t…recently we’ve been working with him more on it; he gains and loses abilities a lot like he’s learned to walk three times in his life so that’s all because of seizures, so bad, so we’re right now getting back into the mode of him feeding himself because we just got lazy, really lazy and when he had the back surgery, he couldn’t feed himself so that’s why it’s going back again. Actually, I need to go bathroom. I won’t talk as fast.

**Interviewer:** No, no, no. I’ll pause it till you come back.

**Interviewee:** I’m about to drink more coffee.

**Interviewer:** Story of my life.

**Interviewee:** Special needs parent: what do you live on? Coffee!

**Interviewer:** Understood.

**Interviewee:** Yeah. What were we talking about?

**Interviewer:** I asked if your son needs prompting to eat when food’s in front of him.

**Interviewee:** Right. Yeah, so, sometimes he’ll pick it up but most of the time, he’s gonna go with the easiest way possible which is *“I’m gonna try and grab it all with my hands,”* even if it’s not appropriate. Oatmeal with your hands doesn’t quite work. And the other thing that’s weird is if you were to give him a hamburger or something like that, he’s gonna try and shove the whole thing in his mouth. He’s not gonna hold the hamburger and be like *“oh, I’ll have a bite and put it down.”* He’s just like *“I want my mouth full”* and he’ll just keep shoving stuff in until he has to spit it out cause there’s too much in there.

**Interviewer:** Absolutely.

**Interviewee:** Again, that sensory issue with the mouth, it’s like *“I want it full,”* not... Two days ago, he did grab the spoon, we were laughing. The other thing he did which was hysterical is for his birthday, he doesn’t really know what a birthday is; everyday is the same to him. But for his birthday, we gave him cake, we were like *“okay, we’ll let him have fun,”* he’ll make a mess, right? He used a spoon.

**Interviewer:** That one day.

**Interviewee:** I had to actually take his hand and put it in the cake so he’d play with the cake which is so not like him. I was like *“okay, that would be great if that happened more often.”* You can’t just go and cook, like if you were making food for him, I tend not to do that though. I tend to make cause he’ll eat anything so I usually make a regular meal for him but he can’t eat meat. That’s another thing that’s a sensitivity, I think he doesn’t eat meat. He doesn’t necessarily like cold things either which is probably from the grinding of his teeth but it’s funny to watch him eat ice cream actually. Yeah, so, there’s that component. You can’t go and do something else or walk out of a room, he has a chair that he’s strapped into, it’s a *Rifton* chair, it’s a really nice all-purpose chair for him because he can rock in it which is one thing that he can do the bouncy thing where you’re like this, great. But it’s got a lot of adjustments you can make so you’re like *“okay,”* it works well for him to keep him seated. But you still have to watch him; he’ll take everything off a table. People always laugh *“can I set your table for you”* and I’m like *“no, not till dinner time.”* If you put a tablecloth on the table, he’s like *“wooosh,”* take everything with it.

**Interviewer:** That makes sense. And I know earlier in the conversation, you mentioned that you try to kind of minimize goals in a way, but do you think your son will be able to achieve more independence in the future whatever that may mean for him?

**Interviewee:** I don’t think so. I wish but I think that because of the developmental delays and some of the sensitivities as well because being wanting to fulfil the they’re just not appropriate for adults so I don’t know, I think he has them so much that it gets in the way of him being able to be more independent and I’m not sure though that the sensitivities have something to do with it but also the seizures so that’s one of the things for him that probably for the study is what might not help is the fact that he has seizures cause that’s affected him so much because of it. He has multifocal seizures so they’re all over his brain but they start in his occipital lobe and in his frontal lobe and it’s bilateral so it’s on both sides of his head so it’s like this.

**Interviewer:** That’s rough.

**Interviewee:** Yeah. I mean he’s had every type of seizure too so because of that multifocalness of it, and it being the frontal lobe, the occipital lobe is seeing so he’s affected there and then the occipital lobe is your short-term memory, going from short-term to long-term, right? So he loses it. It’s like every time he has a seizure, the slate’s been cleaned so that’s a part of why it takes him so long to learn stuff and why it’s probably more about muscle memory than it is about memory-memory. So, I think that because of that situation, he’s only gonna get so far with things.

**Interviewer:** Yeah, absolutely. And this question may not be so relevant given what you just said but do you think there’s anything that might help him like quote-unquote move into adulthood a little bit more?

**Interviewee:** **[01:14:53]** I don’t know. I lean towards no on that, I think. I don’t think there’s anything I mean we’ve tried it probably.

**Interviewer:** Yeah, absolutely, super fair.

**Interviewee:** The other thing that’s interesting about Alexay too is we’ve been doing, you talk about transitioning, in Connecticut, they start the transition when you’re 15 so 15 – 21 is they consider that you’re transitioning into adulthood. They start to try to give you things to do that will make you get a job, it’s like that cart pushing thing, he did it when he was much younger because we know that it’s going to take him so much time to have something into adulthood. One of the goals that they have for him is to push a broom and I mean it’s an adapted broom, he’d be able to do hallways or something somewhere. But that’s towards a job. There is stuff in place to try to have him be more independent, **[01:16:06 inaudible]** independent but be more adult, I guess. Have a job or something. That’s the stuff that they work on; they’re not working on much more than that I guess is really it.

**Interviewer:** Totally, thank you. And now putting these two things together, his sensory sensitivities, his sensory needs and this transition to adulthood, how do they intersect for your son, if at all?

**Interviewee:** Well, I think that the sensory stuff causes him to not achieve some of the goals because he’s so interested in the sensory part of stuff that he’s not paying attention to anything but that so that again, makes him take a lot longer for him to learn something cause maybe you’re trying to teach him how to eat, but he sees someone’s drink on the table or someone else’s food on the table, he’s gonna take that food cause he wants it. He’s gonna take that ball because he wants to stick it in his mouth. He licks things too, I forgot about that so that’s another oral sensory thing. He licks windows and pictures I think cause they’re kinda cold, I guess.

**Interviewer:** Yeah. But you said he doesn’t like cold food, though, like ice cream.

**Interviewee:** He doesn’t like ice cream. He likes it but he has a problem eating it and I think that’s the teeth, not the tongue for him so maybe licking things, he’s fine with because it’s the tongue, I don’t know. It’s kinda funny, another sensory issue. I don’t know if I answered your question.

**Interviewer:** That was a beautiful answer, that was perfect. Thank you. You’re doing great, we’re almost done.

**Interviewee:** Going off at a tangent so…

**Interviewer:** Tangents are great. This is why it’s a semi-structured interview. There’s space for tangents. And then relatedly, do you see his sensory sensitivities and sensory needs as an obstacle, a vehicle, a bit of both or neither towards whatever independence might look like for him.

**Interviewee:** I think it’s in between so it’s both. We’ve used the fact that he has oral sensitivity, well, I say sensitivity, but he likes it very intense, seeking behavior. We’ve used those seeking behaviors to try and help him transition. That’s again like that cart, putting 100 pounds on the cart so that he’s getting that resistance that he needs so he’ll actually be successful at pushing the cart cause if it’s not weighted down, it goes flying and he’ll just run with the cart and hit the wall or whatever. You have to guide him but if you put 100 pounds on it, he’s gonna steer it a lot better so those types of accommodations, that input that he needs, we’re always looking at input. *“Can we give him more; can we give him more?”* And then the other way around is his spaces become kinda sparce because you want him to be successful so his room at school, he doesn’t have a desk because all he wants to do on the desk is either be under it or on it, not at it, right? So, they made the space as open as possible with smushy things in it. They had a chair for him cause he likes to spin, he likes that motion, spinning, not back and forth so you can spin him in a chair and he likes that feeling. But he doesn’t play with lights, like you would think he would. He likes looking at lights from a distance like this. If you have those LED light things that they always have in sensory rooms, or LED light-changing, he doesn’t want to sit there and play with that. That’s not gonna interest him as much.

**Interviewer:** So you talked about how you think his sensory needs can be a vehicle because they can kind of help motivate him or modify his behaviors in a way that it can kind of modify them, but what’s the flipside for you cause you said possibly both?

**Interviewee:** Yeah, the flipside is the impulsiveness of it because if he wants it, that sensory thing, he’d kind of do anything to get it. So he’ll knock you down, he’s injured people; injuries are a big thing for us because that’s where it could get into that emergency placement of him not being able to stay with us. But it really is an impulsive behavior; he drops to the ground to get away from people, to get to the thing that he wants to get to. A lot of times that’s a window, or a door and now with COVID, it’s even more of a problem because before he would try to run into other classrooms and stuff. Now, you can’t so he’s a 2-1 also, you should know that. He has so many sensory things going on that create that impulsiveness from him that you cannot be by yourself with him. He’s extremely strong which is funny because he only weighs 106 pounds so, yeah, he’s very skinny, like you can see his ribs, skinny. He doesn’t gain weight cause he never stands still. I’m trying to lose weight, so I’ve been following him around the house. Like *“go for it kid, I’ll just walk around with you”* cause he never stops moving. I don’t know if that’s a thing for him that he just can’t sit still. Well, he can, never mind, he can sit still cause if you put him in the stroller, he’ll sit there all day and he’ll actually get into the stroller. He likes it so much. Otherwise, he’s either asleep or moving generally or in the stroller.

**Interviewer:** All three options.

**Interviewee:** Yeah, we got three options. Or in the car but that’s the same as the stroller really, right? Cause he’s in a vest, that’s another thing with him is he’s got child safety locks on the door but he won’t keep a seatbelt on so just a seatbelt would not be enough for him so we have this vest that he wears, it zips up the back and clipped in like this so he can’t…and there’s a seatbelt so he’s got both. But he loves the car; there’s another movement thing for you. He loves being in the car. We take drives to nowhere. The thing that we actually with the pandemic, we’ve had to do that much more because he’s in the house all the time, driving nuts so we were just making jokes that all roads lead to New Milford, I don’t know cause in Connecticut, and it’s probably about thirty minutes from here, North. But I’ve gone in every direction but South and ended up in New Milford and we’re just like what the hell, we’re like *“okay, guess what, we’re in New Milford again.”* We’re not even knowing where we are cause we don’t care. We’ll like end up in New Milford.

**Interviewer:** Well, at least you are good at navigating now; gained a skill.

**Interviewee:** To New Milford! He loves the car which is kinda nice to have some stuff that does work.

**Interviewer:** Absolutely, absolutely. And this question again may not be super-duper relevant for you but what do you anticipate as being challenging for your child as he does gain more independence or just perhaps as he gets older since you said you don’t think he’ll gain more independence?

**Interviewee:** Yeah, so, say that again.

**Interviewer:** I’ll repeat it. It’s a mouthful. What do you anticipate as being challenging for your son as he ages in relation to his sensory sensitivities?

**Interviewee:** So the concerns we have, if he were to go to a group home, what would they do with him? So that’s question number one. He’d need his own room, he’d need his own bathroom and he’s not gonna go on field trips or day programs, there’s another one for you. **[To husband]** No, thank you. **[To Rachel]** He’s, right now, anywhere you take him, he has to be in the stroller, right? So, yeah, okay, he’s gonna be in a day program but what are they gonna do? They gonna have him in a stroller to go out into the community? But he also has this energy that he needs to get out. How’s a place like that going to accommodate that energy? That need to have stuff in his mouth, that need to be moving all the time or turning lights on and off, or whatever that sensory thing he needs. I don’t see how they can fill it and that there are other people to consider, other than Alexay. Even have that problem now with him in schools, like the more impulsive he gets with the sensory stuff, the less he can do, without being in a stroller or they have a Tomato Chair or he rides a bike, well it’s a trike really, it’s a *Rifton*…I forget the brand. **[To husband]** No, not the chair, the bike. **[To Rachel]** The bike is huge and he gets strapped into it and he will actually steer so that’s kind of a cool thing but he’ll steer the hell wherever he wants to go, right? So that may be out that door or into that classroom, he doesn’t understand *“I’m on a bike”* type thing. I think it just makes it hard.

**Interviewer:** Yeah, absolutely. And then again, thinking about this intersection of sensory and this transition time period, is there anything that you think could help your child at this intersection?

**Interviewee:** My husband just said something while you’re…it’s *Freedom Concepts* is the bike. What was the question?

**Interviewer:** Yeah, no worries. No, no, don’t apologize at all. Thinking about this intersection, sensory sensitivities and this transitionary time period, what do you think could help your son in this intersection?

**Interviewee:** Well, I think that I may end up having to make a program, who the hell knows, right? That’s what ends up happening is that as a parent, you don’t see the need being met so you have to meet it. And if I were to do that, I would see it as he needs a place that has very minimal doors, maybe like a gym with no doors, I don’t know if that makes any sense, like one door which people don’t make but a space in which he can just…an empty space. **[01:28:13] That’s** our dream is to just have, like the day before, when we move all of our stuff out of the house, just lock all the doors and see what he does.

**Interviewer:** Yeah, like a safe spot?

**Interviewee:** Yeah, like an enclosed space that doesn’t have a ton of doors on it which that’s been an issue and that he can just explore; would have all sensory stuff in it, like the gym place with the giant pit of foam block-y things, like could have something like that or the swing. One of the problems at school was not so much stuff in there for the other kids cause he doesn’t use it, it’s for the other kids, that the space would be better for him. We’re thinking about the in-law suite type thing in the house but not with the kitchen, just a giant living room area that could be the sensory room and then the bedroom would have the bed and then a bathroom, but a very small bathroom, it would have to be a very specific type of space so that he can be successful and have stuff to do. I would love him to be able to go out into the community more, like as an adult but one of our fears is that people are just gonna try to keep him confined I guess, not do things with him because I bet you, they would love it if you would watch television, it’s like one of those things, you can’t just pop him in front of a television and like go and do stuff. There’s gonna have to be somebody always with him and there may be, need to be two people with him, depending on the place that he’s at, like a day program, he’s gonna need two people cause if they wanna try anything. But he’s also, and this is a challenge even now with school, he doesn’t do a lot of things that you would think he would, like he’s not gonna do arts and crafts, he’s not gonna cook, the minimal cleaning thing, whatever, that type of stuff. That’s the daily living stuff, he’s never gonna be independent and it would be great to have him be able to go somewhere, just be with people, do something. He’s a very low level so it’s hard to find other people that have children at the same level as your child and age. I think as we get older, as your children get older, then they have these issues that you end up becoming more isolated as they become adults because there’s not much out there for them. So I would just love to be able to have something be there for him.

**Interviewer:** For sure, thank you.

**Interviewee:** Not in our house. For him, he actually gets really quite ticked off after a while. He’s stuck in the house, keeps taking you to the door, that’s like one of those communication things that…his behaviors are part of his communication so we take that in consideration. If they want him to live with us forever, it’s gonna be a little bit difficult, we need something outside of our house.

**Interviewer:** Yeah, yeah. What would this be cause you talk a lot about creating your own environment in your home, what would this place or program or service be in your mind?

**Interviewee:** I mean I don’t know. If I had a place that he would go to, it would be, the whole thing would be sensory related because that’s his thing so I would like to see a facility like they have places like *Bounce*, they have places like there’s a place down in New Haven that is like a rocks thing or some crazy…there are these places around but they’re not geared towards our child. They’re the right size, that’s what…he needs the toddler area but built for an adult.

**Interviewer:** Yes, yes, yes. That makes perfect sense.

**Interviewee:** So someone out there needs to make a really, really large playscape with a giant ball pit and tunnels, and whatever that he can just go and have fun. But it has to be adult size, that’s the biggest thing cause that was actually a challenge when he was younger is he needed help on the Jungle Gym, the slide, the whatever, right? Cause you know those slides that are like a tube, he wouldn’t want to go in it, he would want to go on it.

**Interviewer:** Yeah, that’s not so safe.

**Interviewee:** So you have to be able to go with them and sometimes they don’t make it for adults and you’re like *“I don’t fit in this thing”* so he still has that issue. He’s tiny, he’s a little guy, he’s tall and very skinny but he’s tall, well not tall-tall, but he’s 5’6.

**Interviewer:** That’s not a toddler size.

**Interviewee:** Yeah, no, he doesn’t fit in that, he’s not gonna fit in the toddler hole which is where he wants to go so whatever.

**Interviewer:** Got you, that makes perfect sense, thank you. This is a bit of a gimme question but do you feel like there are gaps in the available services and interventions and places for people like your son?

**Interviewee:** Oh, definitely. Big time.

**Interviewer:** Tell me more.

**Interviewee:** Well, I mean because people, like even school, an example would be like school wanted to do, for the zoom stuff, right? So they do morning opening at school with him which is what you do in kindergarten, right? So are you aware like what it’s like?

**Interviewer:** Tell me what…I have an idea in my head of what I think you’re talking about but let’s make sure we’re on the same page.

**Interviewee:** Yeah, so they have this board thing that I think every kindergarten classroom has that I’ve ever seen and it’s like the weather and…

**Interviewer:** Oh yeah. It’s like the weather, the day, the month.

**Interviewee:** …the month, is it sunny, is it raining, the word of the day is, the letter of the day is and it’s like all of that stuff. The entire thing doesn’t help my kid but he has to do it because there’s other kids in the classroom that are more functional but they want him to have the group activity so they make him do this. **[01:35:32]** So he’s been made to do a lot of things and it would be great if he wasn’t, if there would be a program that like they wanted to do crafts and I was like absolutely not doing crafts with Alexay. There’s no frickin’ point. He’s what 19-years-old, he’s been in school since he was three. People are still trying to do crafts with him and I’m like I get it cause it’s a group activity; that’s him sitting with other kids and I understand what you’re trying to do. However, the activity I’m like why can’t you just give him finger paints instead or give him a sensory activity instead. But instead, they’re just like *“we’re gonna do crafts”* and then they would do a separate thing that was sensory. After one week, they realized that the craft part was a no; I said no but the sensory thing has been amazing so zoom sensory, I’m like *“oh, this is cool; I hope you guys do more of this stuff in school”* than you show me necessarily because he likes making a mess and that was the weird thing about the cake because we thought *“ha, I’m gonna kill the cake”* and he didn’t. But we’ve been doing these fun sensory activities; I am impaired with these things but he is not so cause I make the stuff; I won’t do hand-over-hand for these activities, that’s also a thing that I don’t get. He doesn’t need to make the Play-Doh, he needs to play with the Play-Doh, right? I mean I get cooking, that’s one that I would say is kind of interesting for him, again, because of the sensory stuff. You’re giving him something to do, hopefully that he can get his hands in it and it gets his mouth involved. Anything that gets his mouth involved is perfect for him. And those are the things like going into adulthood I, people keep telling me that there’s stuff out there, and I’m like I don’t see it, I don’t know what you’re talking about cause the day program that’s closest to our house and their day program is a lot of sitting and doing crafts and doing cooking or watching a movie, watching dancing; he’s not gonna do that, he’s not gonna do an activity, like the Hokey Pokey. He’s not gonna do that cause that’s following a direction; it would be hand-over-hand, put your left hand in and you’d have to put it in for him and what’s the point of this. He’s just gonna get mad at you because you’re making him do something and what he really wants to do is put balls in his mouth and run around the room, run around the perimeter of the room. It’s like how do you accommodate that? There was a gym teacher at his middle school, that was right before he was out of place, the place he’s at now doesn’t have a gym but what they did is they did an adaptive gym class for the kids and they would do things like bowling or different things. But they would let him run around the room, someone would just run around the room and then they’d have him participate when it was his turn. It wasn’t like he was being made to stand there while the other kids go and that was something they did at St. Vincent’s, the school that he goes to. They took him to an actual bowling alley, and I was like *“you guys are nuts”* like I thought they were crazy but they had a thing there which I’d never seen cause Bethel didn’t have it and it’s like for kids and people in wheelchairs so it’s a ball release thing, right? They used it with Alexay and he completely was bowling, I was like the kid’s bowling and they were smart enough. They only had him and one other person together so it was like an exchange was really fast. The hardest part about the bowling was waiting for the darn ball to come back coz Alexay’s not gonna wait so it probably is better to have two balls because he’s not gonna throw…he doesn’t care about the holes so he can go. He needs to keep going so, yeah it’s fun, those types of activities but I don’t know if day programs, maybe they do do that, I don’t know. I only see them doing shopping and going to the movies. He’s been to the movies once in his life. There’s a movie theater near us. I don’t know if you know our part of Connecticut but there’s in Ridgefield Connecticut, there’s a movie called the *Prospector Theater*.

**Interviewer:** I’ve heard of that from another participant from Connecticut.

**Interviewee:** Yeah, so the *Prospector Theater* is a woman whose nephew had Down Syndrome, she opened a movie theater so he would have a job. It’s pretty much one-to-one or maybe two special needs kids to one adult or whatever to one adult, typical adult and I actually was able to take…we never took Alexay to the movies because we’d need to bring the stroller obviously but we weren’t sure he would stay, like would be okay with it. But in order for us to go, we have to buy three tickets for him, who may stay for 10 minutes. It’s a very expensive…and we’d have to get food for him because that’s what’s gonna keep him interested in watching the movie as you’re feeding him popcorn, right? I actually talked to them at the *Prospector Theater* and they accommodated us so they only charged us for one ticket, his, right? They showed us in, they showed us how to get to the bathroom, and then they’re like *“do you need anything?”* They got us the popcorn, instead of us having to wait in the line. I was able to run out though, I had my helper with me from DDS. We were able to exchange like one of could go get more popcorn, he ate three large popcorns.

**Interviewer:** **[01:42:35]** That’s a lot of popcorn!

**Interviewee:** Well, a lot of it was on the floor which I was like *“damn you guys, you got a mess to clean up, sorry”* but he stayed. It was *Finding Dory* was the movie cause he loves those movies, if you put it on TV in the room, he’ll stop and look at it cause he loves that color blue, he loves Dory, the color blue and the movement I think because it’s fish. He liked that and he liked *Moana* cause of the water…

**Interviewer:** Also a great movie! I watched it recently.

**Interviewee:** …and blue, lots of blue! We’re like water movies, find them. He’ll watch movies for 5-10 minutes at a time or 2 seconds, it could be that fast but he’ll watch things that have singing in them and he’ll watch ones that have blue like fish, that type of movement or whatever. *Finding Nemo*, *Finding Dory*, the other one he loved was *Sing*, he loved that movie and he likes the troll movies for some reason I don’t know, they’re horrible but whatever. Singing and blue people, I think. But again, if he were to go in an adult program, out into the community like that, they need to be able to accommodate the fact that he won’t stay. These group activities for him are not really group activities because he’s always the one that’s having to leave, like the church, going to the church. One lady was like, *“why are you bringing him here?”* which was horrible and I told them I was never coming back to that church again cause they’re not being very Christian and then they told me she was crazy and I was like I don’t really care if she’s crazy or not. At churches, we were always out of the church with him. At a certain point, I just stopped going to church because I wasn’t in church. I was in the room where you have coffee but I wasn’t actually in the service. I was like what’s the point. We’re Russian Orthodox too so generally the churches don’t have seating which is really good for us, people stand in church most of the time, but some churches do now have seats so then that would make it more difficult for us because that stroller. We’re always in the back anyway cause we have to leave cause he starts making noise and our church, the church that we didn’t go to anymore cause of that lady was not our church. Our church was extremely accommodating and they don’t really care if kids make noise and stuff; that’s not a big problem for them but again you still don’t wanna bug everybody with your child making lots of noise. There’s a lot of places like that where you end up saying *“why am I here, I’m not really here, I’m in the parking lot or I’m walking around the block.”* It’s like I’d rather just stay home and have him have his space where I don’t have to be on him or feeding him like I don’t really care about feeding him the whole time in that he’s always hungry so whatever, he’s extremely underweight so go for it, eat all you want. But, for him, he doesn’t want to sit for hours and hours and hours, right? Even though he will, it’s just not fair to a kid who wants to be moving all the time.

**Interviewer:** Absolutely, thank you for sharing that. So now thinking again a little bit more broadly again, a little bit more globally, how have your child’s sensory needs and sensory sensitivities impacted your goals, hopes and expectations for him as he does navigate adulthood, or independence to a degree?

**Interviewee:** You wanted to know how it’s impacted in what way?

**Interviewer:** Impacted your goals, hopes or expectations for him as he ages into adulthood, whatever that may look like for him.

**Interviewee:** Yeah, so, the sensory stuff is a big issue because you can’t stop it. For him, the sensory things that he wants are, I mean they’re not inappropriate per se, they’re very messy cause it’s all the oral motor stuff, I mean his hands are a mess, his face is a mess, he’s always wet, you’re like *“ergh,”* and that impacts some of the goals. His goals have been really impacted like they ended up having to be around food a lot because that’s the thing that will make it successful so trying to give him a choice between food and a toy, but he doesn’t discriminate so you don’t really know if he’s picking it because he really wants it or not. He’ll just throw it away, not the food, that’s why you use it, because the food he’ll just eat it, but if you were to just give him a field of toys or something, he may pick one but you don’t know if he wanted it because he might throw it immediately and then pick another thing. That impacts a goal like how are you gonna get him to actually meet a goal. The fact that that sensory movement thing impacts him all the time because he doesn’t pay attention because he wants to leave *“I wanna move around and I wanna look at my reflection, I wanna ring bells,”* I don’t know, whatever the sensory thing is for him at that time.

**Interviewer:** Absolutely, thank you. We’re gonna move onto our last chunk of questions, it’s the shortest one. We’re almost there. So, finally, as a caregiver, as a mom, as a parent of someone with autism but also these sensory needs that we’ve talked about, what does it mean like transitioning to adulthood? What does that mean to you?

**Interviewee:** It’s changed a lot.

**Interviewer:** How so?

**Interviewee:** When you have children in general, so we have a typical son and we have Alexay’s special needs. At first you think *“oh everything, what will they be able to do?”* and you’re trying to figure all that stuff out and then for him, it only gets so far, because of, especially the oral sensory issues because again it gets in the way of him being able to actually achieve anything. So as a parent, your goals keep changing cause you start off saying *“I want him to get married, have children, go to college”* and then you start finding out they have these special needs and you’re like *“oh wow, that is not happening now so I have to rethink.”* I want him to just be healthy at this point. I want him to be able to find some sense of a community. And these sensory things for him are so dominant in his life that I don’t know it’s going to happen so you stop having expectations. That’s how we’ve handled it anyway is like our goals have become smaller and smaller so you start off with the big goal and then it’s like well, maybe he’ll be able to do X and then you realize he’s not gonna meet that one so then you pull it back and you start planning. If you want him to have a goal for transitioning to adulthood, people thought we were crazy because we were saying to them when he was 10, *“we have to start now.”* And they’re kind of like *“what are you talking…”* [you’re] like *“no, no, no, it’ gonna take him that long.”* It’s gonna take him 11 years, it may take him longer than that so you start making your goals, bring it back, like that pushing the cart thing started, he did it at regular public school, it wasn’t exactly the same, he would take his lunch to the cafeteria. The new school doesn’t have a cafeteria; they eat in the room so they started that when he was really young, well, he still will not push a cart correctly if it’s not weighted down because it’s that sensory input for him. He has to have that weight so you’re always making accommodations to the goal, to make him successful so then after a while, you’re like is he actually making progress because we keep pulling this back. The progress is extraordinarily slow; that and his physicalness. I’ve been trying for years to get in shape but now I’m like I’m 52, I’m gonna be 53 in September and I realize if I’m expected to do this until I’m 70 at least. I mean I know people in their 70s and their special needs kids are still with them because they don’t consider it an emergency, that 70-year-old can take care of that guy cause he doesn’t have much that he needs or something and like God, please help me so I’m trying to get into shape because he’s so strong, I don’t wanna get hurt. I keep getting hurt and I don’t wanna get hurt. I have depression, I’ve been diagnosed with major depressive disorder, I have fibromyalgia, I have high blood pressure and I’m overweight. I have fibromyalgia because I was so stressed out, I developed it when he was around 7 or 8, when I was around 36, 37. I was like *“I’m too young for this”* but because of that stress of trying to keep him safe with his impulsive sensory stuff, you just get to a point where your body can’t take it. I’m doing a lot better though now cause I’m not as stressed. We ended up doing for ourselves is we weren’t the parents that embraced this as well, especially for my husband, it was much harder for him to embrace where he’s at. He still had like these massive hopes and stuff and that made our marriage a lot stronger because of all this because we had to really fight through a lot of things to get to where we’re now on the same page with most stuff or we can now communicate better with most stuff. Therapy helps a lot, especially for people with kids with special needs because everything does change. My goals have gone from *“yeah, it’d be great if you went to the bathroom or toilet,”* to he’s never gonna go to the bathroom or the toilet and I really don’t care cause even if he did, I’d still have to wipe his butt so what’s the difference, right? I was talking to and so many people, like it’s a goal for every person to say does your son go to the bathroom, you know, use a toilet? And I’m like why do you care kind of thing like I don’t understand because it’s not gonna make a difference to how I am in my life now, like I still have to wipe his butt so I’d rather him be in a diaper and have no accidents cause I’ll tell you that was like the hardest part about trying to do that was like going through that entire thing and then there’s accidents and how would you stop that if…he doesn’t care, first of all. And your life just gets so weird, like the other half. It’s just so weird. People just *don’t* get it. The extent to which you change things to accommodate it and the effect that it has on your other children, on your marriage, on your relationships with your family. I don’t even talk about my family cause my dad, it’s just me and my dad so I had a brother, I lived my entire life going to hospitals because my brother had cystic fibrosis. He died when he was 25 and then my mother passed away when she was 50 from breast cancer so it’s just me and my dad. There’s an extended family, none of which have done anything. I haven’t seen a lot of my extended family in years because they won’t come to my house. My dad’s from Albany, his family is from Albany and that’s only 2 ½ hours away, not a big deal, right? None of my dad’s family has been here. Oh actually, my dad’s sister came here once. He also has two brothers, they’ve never been here. One of them passed away. His sister came because we did a service for my mother; she was cremated and she wanted her ashes spread in our garden and so we did the service and I invited everybody from the family thinking it’s my mom, she was like a big deal to…once my grandmother passed away, my mom kind of took over the holidays and stuff so it’s like *“come to our house.”* My one aunt was like *“no, it’s too far to go”* and that’s my dad’s brother’s wife and yet they would go to Hartford area to go to some big auction and they drive right by our house. I literally live right off of Exit 8, of 84. And they would take 84 to go to this thing and it’s just that’s the life you have so your world just starts to get really tiny and that’s really hard to handle. I see my mother’s family more than I see my father’s family and they live in Lions, New York, it’s out by Rochester but going there, they’ve never met my sons, they’ve never met either one of my sons because I didn’t see them for a long time but then I started seeing them once a year. I go there once a year. But they too don’t come down here. We’re like on the outskirts of everything, I guess just because where we could move to at the time. We’re still in the same house that we started…it’s our first house. We’ve been here for 19 years.

**Interviewer:** **[01:58:58]** It looks beautiful from my angle.

**Interviewee:** The thing about that though again, you can’t move so I think about my own future. I don’t wanna live the rest of my life in Connecticut, right? But I will be living the rest of my life in Connecticut because we happened to be one of the lucky people our son started off when he was seven years old getting services. He got DCF voluntary services when he turned nine, supposed to be when they’re eight, but he stayed in it till he was nine, then DDS took over and he gets services from them. He gets about $50,000 a year at least for the services now, I think it’s like 42 and that’s just for stuff for after school and weekends. When he turns 21, he’ll then get more money for the day program part which is what the school is doing now. They’ll have to pay for that part as well and if we went to another state, we have to start that process over from the beginning and I wouldn’t be guaranteed that, especially like I wouldn’t move here, but especially like in places like Florida, Texas, you have to really look at all the states and there are very, very, very few states that actually do anything for kids with special needs. One of the things I am very glad is that he has the autism spectrum disorder diagnosis, even though to us that’s not his major diagnosis, even though it was his first, I mean we’re glad because that’s where the money is. He also gets Husky which is the medicate; in order to be in DDS, you have to be unmedicated. And because he’s unmedicated, there’s a program for kids with autism for behavior issues so we get that service as well. That stops at 21 though. So that’s just for kids. And that’s another thing, it stops at 21, cause he’s not gonna not need, he’s not gonna stop needing a behaviorist. They deal a lot with the sensitivity issues and as it relates to behavior, there’s a bit of that with Alexay, his behaviors are very much determined by his sensitivities so that’s gonna have to continue cause it’s just not gonna go away and then we’re gonna have to try to figure that out, right? But all this stuff limits us. When I moved to Connecticut, did I think it was gonna be the place I was gonna live in for the rest of my life? No! Right? I would love to move West, I’d love to maybe move to Denver, to Colorado, you know Washington State. We like cold weather so Canada would be great too but I don’t think they’d take us. But that kind of thing, you change that view, your life just gets much smaller for you. We don’t travel because he can’t travel, like you could never put our son on a plane. You’d have to knock him out, they’d have to put him to sleep to be on a plane. He’d be trying to open the door, he’d be banging on the windows, he would drive everyone insane on the plane and he wouldn’t understand either like what is going on? You couldn’t say to him *“we’re going on an adventure;”* he doesn’t understand that. He’s not gonna get that concept of *“see that thing up there, that’s a plane, we’re gonna go on that”* or whatever. We would *never* think of that.

**Interviewer:** Thank you for sharing all that. I just have two more questions. We’re almost done. You’ve alluded to this in not so many words but what do you see happening in your son’s future?

**Interviewee:** It’s the scariest thing that I can think of is that. I’m a realist, I’m not an optimist, I’m not a pessimist, I’m a realist and people don’t get that. They immediately think you’re a pessimist because when you say stuff to them, I don’t have goals like I did or saying about the moving or whatever, those things change for you. His future, one of the scariest things I think a lot of special needs moms have this but I especially have it for my son, because he’s non-verbal that no one will ever hurt him. That’s an actual concern that in his future, he could be hurt. Those are the things you want to try and prevent and eventually, kids with autism, their life expectancy is normal, it’s not like Down Syndrome kids, their life expectancy is less generally, right? Now that might not be the case anymore cause the advances in science and stuff, they could probably live as long as everybody else. Cystic fibrosis, at least I’m aware of what it means to lose somebody really young and that from my brother, they’re now living a lot longer. Alexay’s expected to live a normal life expectancy. His brother, because of my brother and my upbringing, I chose, my parents, they treated my brother and I much differently because my brother was ill. One of the things with people with cystic fibrosis is they tend not to be very big. Alexay and my brother are exactly the same bodies; underweight. My brother and him were both the same height, well my brother’s 5’6, Alexay’s 5’6 with 106 pounds. The most my brother ever weighed was 114 pounds. When he passed away, he weighed 80 pounds, so he went down to like nothing. But Alexay is like that so I think about that. I think about like what’s going to happen to him once I’m gone. Hence why I’m trying to get into shape; I want to live to be 99,90. I just can’t imagine that because of my brother, the other part I was trying to say is our son, David, is named after him. David, I was made to do a lot of things for my brother, even though he was a year younger than me, I was babysitting him when I was 15. He was typical, except for CF, but because he was so small, everyone was like *“you gotta babysit your brother, he might burn out.”* I’m like *“he’s a year younger than me, he’s smart, he’s not a baby”* but I would end up doing all that stuff. We overcompensated for that and David didn’t have to do anything with Alexay, right? But because of that, and Alexay, because of the seizures and stuff like all of it, takes a lot of attention so David didn’t get enough attention so there was a period of time where he really hated his brother. It’s going away now more so, it’s more of a tolerance though than a love but not a *“hey, I wanna hang out with him”* kind of thing. Well, what happens when we’re gone? We don’t expect that David’s gonna take care of his brother. He actually recently said I’ll take care of him but I won’t live with him, like I’ll make sure he’s okay but he would have to somehow get into a group home situation. How does that happen right now? It’s so up in the air so you end up being very realistic about it, right? It’s like I’m gonna get in shape and we’re gonna have him here for as long as we possibly can and we have to put stuff in place for later.

**Interviewer:** Do you see him finishing his school program?

**Interviewee:** Yeah. Yeah. I mean we see it but they’re already now talking to us about the fact that he has behavior issues that they can’t handle; the impulsiveness of him, the dropping on the floor, those types of things, afraid someone’s gonna get hurt. We’re still talking about finding ways of him being able to be in the school cause the school actually, and they’re gonna bring in an outside person to evaluate or something I don’t know because there aren’t any other places that he could go to that are near us. The school is actually trying to be very accommodating, they’re like *“no, no, no, we’re not trying to have you go to a different school. We want him to graduate here.”* So we hope, unless it gets worse, so he may end up somewhere else, I don’t know where or what they would do cause I think the rest of the places are like over an hour away, he’s 45 minutes from our house.

**Interviewer:** That’s a good drive.

**Interviewee:** Yeah, but again, [he] loves to be in the car. If he didn’t love to be in the car, that would really stink. He loves to be in the car so we actually had a huge issue with busing with him. That was difficult. Now we have a really great bus driver. We had a bus driver who was too old to be driving buses and was also racist which is a problem for us.

**Interviewer:** Those are both not good things for very different reasons.

**Interviewee:** No, no, generally the staff that you get is predominantly people of color because it’s like the nature of the business, I guess really. It’s rare that there are white males. There was one at Alexay’s school, two males worked there and you’re either gonna get a giant Jamaican lady, a Haitian lady or you have to get a guy cause he’s so strong. You think about that kind of thing with it and you’re just kind of like *“oh, alright.”* One guy left and so now they’re down with one person, one guy which is difficult, but hopefully they can keep him. That’s the goal, I hope. The scarier part for us though is actually the after school, the day program part, I’m like *“what are we gonna do”* although this year has been very helpful with that, trying to come up with ideas and stuff to have.

**Interviewer:** **[02:11:01]** So last final question. Thank you for sharing all that. So you just spent a long time articulating what it means to transition into adulthood from your perspective, what type of a role did your son’s sensory sensitivities play into that perspective?

**Interviewee:** I think that they play a major role for him because of the fact that these behaviors, these sensitivities that he has, some of the accommodations for them are not group friendly and they take up a lot of his time cause there’s not very much stuff that he likes to do and so 90% of it is sensory at least. Well, if you include food, it probably is at, try 95 and then the other 5 is sleeping, or whatever, so it’s a huge thing for him. I mean that’s part of that major concern about cause as far as I know, there are not very many or any programs that are dealing with sensory things like kids who are low functioning sensory kids. It’s always been the problem and even school, even DDS, we have to have goals at DDS, it’s like well, okay, their idea of a goal and our idea of a goal are two different things. In school, the sensory stuff has made meeting goals as like difficult. Well, now, we’re gonna be going into transitioning into an adult situation that doesn’t even care I guess that your kid has sensory things. There isn’t a beautiful sensory room that I know of; they have a room with a bunch of tables I think and a kitchen and maybe a laundry room where they’re gonna teach you how to do laundry but…

**Interviewer:** Not quite the same thing.

**Interviewee:** Not quite. And they do laundry at school with him now and it’s a put in thing so I get that *“put it in”* so, but like he’s never gonna fold laundry and he would put dirty laundry in the dryer if somebody wasn’t standing there. You could say, *“this is the dryer, the washer and this is the dryer…”* So, again, sensory.

**Interviewer:** Absolutely. Thank you for sharing all that. That was my last formal question. Would you like to add anything else?

**Interviewee:** I don’t know. Again, you’re dealing with transition and it’s our worst nightmares in some ways for a parent. I think it brings you back to the day when they were three cause that’s when kids with special needs go to school. Alexay went to school before David did cause of the cut off so David’s birthday is in September. In Connecticut, they cut it off at September 1st. New York State, I think does it at December 30th so he could have gone to school so he was older when he went to school cause he had to wait that year. But Alexay turned three the day after your kid turns three, they go to school on a bus. A three-year-old! You’re like *“bye!”* So that kind of a feeling, that’s what transition feels like to me. I was like I have all these years behind me but it’s still like putting your kid on a bus when they’re three years old. It’s still like *“wooo, what is gonna happen here.”* And there really aren’t a lot of people that specialize in transition for the parent. There’s no one out there that’s telling you what you’re gonna do except for your other friends, like we’re still trying to get social security forms cause you’re doing it by yourself kind of thing.

**Interviewer:** Absolutely. Well, thank you for sharing all this. It’s been such a pleasure to learn from you, it’s been truly invaluable. We couldn’t do without you so we appreciate it.

**Interviewee:** Thanks, thank you so much.

**Interviewer:** **[02:15:45]** No, thank you. Do you know anyone else who might want to participate by any chance?

**Interviewee:** I probably do actually. I have a bunch of people that I could probably, I have one friend. How old does the cut off, I forgot?

**Interviewer:** It’s 25 and 11 months, right under 26.

**Interviewee:** 25 and 11 months. Okay. So I have a friend, her son transitioned right in the middle of the pandemic.

**Interviewer:** That’s rough.

**Interviewee:** I mean what I can do is I will put together…would it be good if I put together a little email and I put your information in there?

**Interviewer:** I mean I have that stuff. Would you like me to send it to you so you can just distribute it? Would that be easier?

**Interviewee:** Yeah. That’d be great. I have my friend, Randy, her son is named, what is her son’s name? I can’t remember.

**Interviewer:** No worries.

**Interviewee:** My friend, Lola, her daughter’s just turned 18. She’s very high functioning but she does have some sensory stuff.

**Interviewer:** Wonderful. We don’t, in terms of our eligibility, we don’t discriminate based upon language abilities or functionality, just autism and sensory and the right age, that’s all we’re looking for so we get a big range of responses which has been…

**Interviewee:** The lowest age that you had was 18, right?

**Interviewer:** Sixteen.

**Interviewee:** Sixteen?

**Interviewer:** So it’s just that beginning to in theory, the end of the transition, in theory.

**Interviewee:** And are you taking people from anywhere in the United States?

**Interviewer:** Anywhere in the world as long as we can find a time at which we are both awake and present and an internet connection.

**Interviewee:** Okay, right off the top of my head, I have five people, I call them the *“ladies,”* so we have a support group, we all have children with special needs. I think all this group, they all have children that are on the spectrum, ranging from one that could possibly go to college but maybe not live on her own, down to Alexay is the least functional. Three of them have children that talk some, they use the echolalia though a lot. One of them just says *“chicken.”* My friend Melinda’s son is absolutely hysterical cause he’s a limited food eater and he like walks around *“chicken, chicken,”* and he decided, she finally got him to eat some vegetables and it’s salad. Of all things, the kid eats salad. It’s a little weird, right? But now, he walks around the house going, and this cracks you up, *“salad, salad, salad.”* It’s like you never thought in your life that you’d be having someone, a kid, walking behind you going *“salad, salad. I want salad, mom.”*

**Interviewer:** Sure, here, eat vegetables. That’s wonderful.

**Interviewee:** Yeah, but, I’ll reach out to these women once you send me the stuff and I’ll email the ladies and I’m sure someone will probably be interested.

**Interviewer:** We would love to have them. Thank you. No, but truly, thank you so much for your time and effort. It’s been a pleasure. So as soon as this video renders and the audio’s all good, I’ll send you a follow up email. It will have a gift card as compensation for your time and effort and I’ll also embed all that information that you can distribute to the ladies.

**Interviewee:** Oh, awesome, great.

**Interviewer:** Yeah. Do you have any final questions for me? Can I do anything for you?

**Interviewee:** No. When is your research project gonna be over with?

**Interviewer:** Our grant technically ends in about 6 months; we can probably get a no-cost extension but we only need about 10 more participants so we’re getting really close to the end and so we’re starting to do our data analysis. I have no doubt we’ll get it done before 6 months, so soonish.

**Interviewee:** I’m sure that it’s concluding pretty similar stuff to what I just told you, I can’t imagine that there’s much of a variety in what people are saying.

**Interviewer:** Most parents do feel like there’s an intersection but the response, it’s actually pretty variable sometimes, depending on the kid’s functionality or depending on their sensory needs, it’s been really exciting to learn from people.

**Interviewee:** Are you going to look at how functional they are and their sensitivities? Are you gonna, say Alexay would be one end of the spectrum and my friend’s son or Lola’s daughter, Emily would probably be the other end? Do you find that there are big differences between?

**Interviewer:** It depends. We’re trying to figure out, cause this is such a huge amount of data, these interviews can be really long and we get all these surveys too, so we’re trying to figure out a way to frame it in a way that makes sense. One of our ideas is to look at the spectrum of independence as a way to figure out how do some kids deal with their sensory stuff versus how do they not? Is there a particular sensory thing, touch for instance or hearing? So we’re trying to figure out the best way to make sense of the data and that’s definitely a contender but we’re not really sure yet cause there’s so much.

**Interviewee:** I know, I was like, it’s very broad. I would be interested to find out if there’s a correlation at all between the intellectual abilities of the person versus if they’re less functional, do they have more sensitivities or specific sensitivities like there’s a part of it, I think that more functional kids have, and I could be completely wrong on this, have sensitivities to sound and they may have sensitivities to some places more so but kids that are lower functioning, their things tend to be more about touch, touchy-feely but also…

**Interviewer:** Honestly, I don’t know yet. I’ll let you know when I know. That’s a really interesting thought. I don’t know, I’ll find out and then cause you, in one of the forms, you said that you want to know about our results. Then when we get results, you’ll know too.

**Interviewee:** Cool, cool. I definitely would be interested.

**Interviewer:** This has been a pleasure. Thank you so much and thank you for giving me so much of your morning. It’s been wonderful.

**Interviewee:** No problem.

**Interviewer:** Have a good rest of your day and I will talk to you via email soon.

**Interviewee:** Okay, great. Thanks.

**Interviewer:** Alright, bye.

**Interviewee:** Bye.

**[END OF TRANSCRIPT]**