**[START OF TRANSCRIPT]**

**Interviewer:** We are recording and I will be asking you questions about your perspective regarding your son’s transition to adulthood in relation to his sensory sensitivities and we’ll be doing something called a semi-structured interview and that means I have my planned questions in my script but I’ll also be adapting them a little bit to follow our conversation so they actually make sense for you and for your family. Any questions?

**Interviewee:** No.

**Interviewer:** **[00:00:26]** Okay and if there are any questions you don’t want to answer for whatever reason, that is perfectly okay. *“I don’t know”* is also a perfectly okay answer and if anything pops up from earlier, feel free to bring it up.

**Interviewee:** Okay

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

**Interviewee:** Okay. The biggest one of John Henry’s I think is probably noise where he really doesn’t enjoy loud noise unless he’s the one who’s picking it. Noise and maybe after that, it’d be, I’m not really sure, maybe touch because there’s a lot of activities with touching he does not enjoy, although some of them are kind of folded into that noise. He doesn’t like getting his hair cut because we use the clippers so there’s a lot of things going on there that could be bothering him. He is very specific about who he lets hug him, I guess. He will ask for hugs from me and he’ll spontaneously hug me and his brother and sometimes his father. I should probably make, I’m not sure if this came up in the initial interview or not, but my husband and I are divorced so his father actually lives separate from him and at the moment, is a little bit too sick to really engage in any parental care really so he hasn’t seen his father much. Plus, because of quarantine issues, he hasn’t seen his dad much this past year at all so that’s kind of a little bit of, sorry, a sidebar there. My current husband and I live separately so it’s just a weird living arrangement, so I’d say probably that the noise and then touching and then I’m not sure if transitions are part of that, like a sensory thing because he’s very, very bad at transitions.

**Interviewer:** Got you. Well, first of all, thank you for sharing that about the background. I’m sorry to hear that your son’s dad isn’t doing well. It can’t be easy.

**Interviewee:** It’s not easy. No. It’s not been an easy year at all.

**Interviewer:** I’m sorry. You initially talked about noise and you talked about loud noises that your son doesn’t pick, so he’s okay with noises that he has picked that are loud?

**Interviewee:** Yeah, he is. I think sometimes he startles himself with how loud his computer comes on sometimes but he, for the most part, keeps his noise in his room to a minimum, like sometimes it gets a little bit loud but most of the time, it’s at a decent level. He doesn’t like, like if we’re in the car and I put on certain music, there’s music he just can’t, he will cover his ears and kind of go into a stress position if we’re playing certain…and it’s all over the place, it doesn’t matter. There’s very few types of music I can put on the radio that he’ll immediately just be quiet about and not complain. Even music that he likes which is like I said all that Nickelodeon music, he doesn’t like me playing it in the car for him so I don’t know if some of his sensory issues are just weirdly situational or what, but that’s one big thing is if I put on a show that he likes in the living room, he runs away from that too so I’ve never really been able to understand where he’s coming from.

**Interviewer:** Got you. Thank you. What about non-human noises, like maybe like sirens or cars, how is he with those?

**Interviewee:** We live very close to train tracks and a train just went by and he loves train noise. He doesn’t mind the horn and if we happen to be at a railroad crossing when the train is going by, cause we live near freight train tracks so they go by for a very long time sometimes, he always wants me to roll the window down and hear the train noise go by.

**Interviewer:** Got you. Awesome. Thank you. And then you talked about touch and you talked about hugs specifically, does he have other preferences about touch, like is he okay with light touch or like certain clothing fabrics?

**Interviewee:** So, he will not wear a piece of clothing that has a tag. I have to cut all the tags out of his clothing and if he had his way, I would also be cutting all the seams out of his clothing but that’s not really possible, so he just has to deal with the seams for now. Or pockets, he has pants that have pockets, like sleep pants that have pockets, he doesn’t like the pockets really. So, most of the time, I’m watching him in the shower and he doesn’t like to have his face touched at all so washing his face is problematic. He doesn’t like the toothbrush in his mouth really so there’s been some issue with brushing teeth and he’s always been almost I would say violently opposed to having his hair brushed so we just don’t brush his hair here or he also doesn’t really like the whole process of having his hair washed either so he doesn’t get his hair washed very much here either. Usually his dad would take care of that because I’m sure he doesn’t mean it and actually this goes for his hands too where he doesn’t like to have his hands touched so at night, I have a fingernail brush in the shower that I’m trying to get him used to, like slowly trying to, *“well, let me just do one finger”* and build that up there because he gets…there are some other issues here that his fingernails get pretty disgusting but he won’t let me cut his fingernails and he really doesn’t like me washing his hair and that has ended in him more or less accidentally punching me in the face a couple times so I kind of left that up to his father but since his father hasn’t been around for this year, it’s been a little spotty.

**Interviewer:** Yeah. How about toenails? Is he okay with you cutting his toenails?

**Interviewee:** I don’t know what he does to his toenails but they’re fine. They seem to be fine, fine length. I don’t know if he just grinds them down cause the other thing is he does not like wearing shoes and socks. It’s really hard for me to get those…he won’t wear socks in the house and a lot of times when we leave to go run errands, he just goes barefoot really, well, especially since we don’t get out the car anymore. This past year’s been pretty much a free-for-all. He also doesn’t really like wearing underwear although he would wear it to school. This past year’s been pretty much whatever, just gets us through the day really.

**Interviewer:** Totally. What about other clothing, is he okay with pants versus shorts, things like that?

**Interviewee:** He’s okay with shorts cause in Texas, it gets pretty hot so in the summertime, I like to send him out in shorts and he gets used to wearing shorts. He would prefer to wear sleep pants at all time but the funny thing is when he wears shorts, he asked me where the rest of the pants are, like *“where’s the pants?”* and points at his legs. He’s okay with long-sleeved shirts if it’s really cold out, like wearing a jacket, I’m not gonna die on that hill, if he’s just going from my house to the bus, I’m not gonna force him into a jacket cause the bus is warm and he’s probably not going outside at all because he hates putting on jackets. We’ve never been able to get him to wear hats, deliberately when we need him to wear a hat, however we will put hats on as a funny thing like, *“oh look, I put a hat on ha”* and any other outdoor type clothing like mittens or a scarf is just not gonna happen.

**Interviewer:** **[00:09:33]** Do you think that’s because he doesn’t like the feeling of those other pieces of outerwear?

**Interviewee:** Well, to be honest, I never really pushed a scarf because he’s not always coordinated and I was a little worried there could be some problems there, catching on something and mittens we just never tried really. He used to like going outside a lot more; we used to have a swing set back when we lived in Connecticut; we haven’t had one since we’ve been in Texas. But we never really pushed him to wear gloves or anything.

**Interviewer:** Got you. Thank you. And does your son have any sensitivities towards certain tastes, things like that?

**Interviewee:** For instance, something like ice cream, I think it’s too cold for him so he likes the concept of ice cream. He’s very much a concept guy, not as much a follow through guy so he doesn’t understand that trade-off between my teeth hurt because I have very sensitive teeth so I probably know where he’s coming from and ice cream is delicious so he’s never made that leap like *“I’m gonna eat ice cream even though this hurts me”* so cold stuff is, although he likes cold drink and he likes ice in his drinks. He loves spicy food and I don’t really know…he’ll try almost any food but he won’t incorporate that into his diet necessarily so I can get him to try a bite of something but then he’ll just put it down and not want to eat any more of it.

**Interviewer:** Got you. What about smell?

**Interviewee:** I think he might be sensitive to it but not in a way that causes him any real distress. I’m not really sure because we moved into a much smaller apartment and they’re teenage boys and so sometimes this place kinda stinks and so we started buying scented candles and he seems kind of opposed to them. But I’m not sure if it’s because of the smell or because of birthdays, he thinks all candles should be blown out.

**Interviewer:** Got you. Fair. And what about anything visual? Are there any visual stimuli that he is sensitive to?

**Interviewee:** Not that I know of no. It’s hard to say. I think it’s more of a routine thing with him where there are certain lights that he wants to have on and certain things he wants closed but I don’t think it’s a sensitivity to light as much as *“this is just the way it should be.”*

**Interviewer:** Got you. That makes sense. Perfect, thank you. And these sensitivities that you have described, particularly touch and sound. Have those changed over time?

**Interviewee:** Yes. There are some things that he’s become tolerant to. When he was little, for instance, we’d go to the supermarket and we couldn’t go down the freezer aisle because the sound of the compressors made him crazy. We went to buy a fish one time and we couldn’t actually buy a fish because he couldn’t stand the sound of the aquarium filter running. Although he got used to that later on, we did have fish for a while and he was okay with it. But I don’t know what happened, eventually he just became more tolerant and we were able to go down. I can’t really think of anything that’s changed much. He’s pretty consistent in the things that he’s really sensitive to since he was a kid.

**Interviewer:** Mm-hmm. Perfect. And the change related to the sounds of the compressors going down the freezer aisle, do you think that change might be related to any independence that he’s gained over time?

**Interviewee:** I don’t know. In stores, he’s supposed to stay pretty close to me but I don’t know, I think it was just a gradual tolerance of it over time.

**Interviewer:** That makes sense. And when your son is exposed to a sensory experience that he doesn’t like, whether it’s too loud or a touch-feel he doesn’t enjoy, does that cause or increase anxiety for him?

**Interviewee:** It does, like I said, if he’s listening to music in the car, he’ll go into that stress position where he has his hands over his ears or he will throw himself to the floor and start yelling if we’re someplace that he, like let’s say in the case of the compressors, he would throw himself to the floor and not move and start yelling. And that’s pretty much his standard response to anything that is not what he wants to have happen is that he’ll throw himself to the floor and start yelling.

**Interviewer:** Got you. And so he’s always, has he always had that type of anxiety response to aversive sensory experiences?

**Interviewee:** Yeah. Yeah.

**Interviewer:** Got you. And then how do you help him manage and cope with and handle his sensitivities or how does he manage and cope with them?

**Interviewee:** Well, I try and keep him out of situations where that’s going to be a problem. If we’re somewhere where music is playing, I try and play music that won’t bother him because there is some stuff that won’t bother him or he seems strangely fascinated by. Mostly, I just try and help him avoid the things that are gonna give him stress, just because forcing him into situations over and over again really hasn’t worked. I just prefer not to have him be stressed out like that.

**Interviewer:** Yeah, absolutely. Makes total sense. And then has he ever received specific therapies or interventions for his sensory sensitivities?

**Interviewee:** I mean the word “sensory diet” has been tossed around at some of our IEP meetings but I don’t know if anything specific has been ever implemented per se. I know at one point it was recommended he see someone that was a sensory specialist but nothing ever came of that because it was in Connecticut and they were over an hour away so it’s just hard to schedule that stuff.

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

**Interviewee:** I don’t know. I mean I would hope that he could overcome them to some degree but we’ve gotten this far with school and that hasn’t really happened all that much. He still has the same issues at school where going into really loud rooms doesn’t work out for him. I mean I would hope that he could at least sort of make peace with some of it enough to function a little better when we’re out in public but I hate to be pessimistic but I don’t, I just hope he has some semblance of a normal stress-free life when he gets to be an adult but I don’t know.

**Interviewer:** Got you. Thank you. We’re going to move onto our next chunk of questions. So as your son has grown up and aged a bit, how has his and your community reacted to his sensory sensitivities?

**Interviewee:** To be honest, the community at large, they’re pretty clueless. I don’t think there’s been any reaction to much of anything here in Texas regarding autism. This particular year in school, last year and this year, well, last year, he moved to a facility at the high school which I really was very weary of because it was a wing designed specifically for special needs students so I thought *“oh, this is just a way to exclude him from interaction”* but I mean he went from an interior room with no windows, or floors and lights and like no furniture to, this place is amazing, it’s very high ceilings so you don’t have that claustrophobic feeling, especially in the interior room that he was in all middle school. It’s got beautiful, huge windows in every classroom, the walls in the hallways have acoustic baffles so it doesn’t get really echoey, there’s a beautiful courtyard that they designed where they grow vegetables. It’s just a beautifully set up place for him so the fact that the school responded in this way and created this facility for kids was just amazing to me. In Connecticut, I always say the school was a little bit better. In Texas, we’d had nothing but trouble until he got to high school so this is amazing that they actually put this much thought into designing a wing like that for special needs kids and I wished they’d do that everywhere.

**Interviewer:** **[00:19:53]** Yeah. That’s wonderful. I’m glad you’re getting a more positive experience. That’s great.

**Interviewee:** It would be nice to go back to it.

**Interviewer:** Hopefully soon.

**Interviewee:** I get my first shot March 4th so we’ll see.

**Interviewer:** That’s awesome. I don’t know when I’m getting mine and I’m not holding my breath but I’m hopeful. Would you say the community was more or less accepting of your son and his sensory sensitivities when he was younger?

**Interviewee:** It just would depend. Some places were absolutely fine; some places, I’d get the stink eye because he’d be a little loud or jumping on something that he wasn’t supposed to be. I would say it was a mixed bag with school where I don’t think a lot of my typical son’s parents really understood the difficulties we had, and in that respect, because Max didn’t ever invite anybody over. I think parents got a little tired of just always having Max at their house and we never reciprocated, not because we didn’t want to, because John Henry can be unpredictable and we didn’t know if he would hit other kids or things like that so…I mean, it’s kind of been a mixed bag all the way across. Everything is situational dependent.

**Interviewer:** Got you. Thank you. Were there specific aspects of the community that were more or less accepting, like certain spaces or places or again, was it all just a mixed bag?

**Interviewee:** I would say mostly it was other parents who had autistic children who were very accepting and once a while, you’d hit someone out in public that was understanding because they had a relative who was on the spectrum or they had some other experience with Down’s or something but any other non-autism or intellectually disabled parents, you just never knew. Even at the school level, especially in the upper, like the superintendent and like the board level, I’d always run into problems; problems there.

**Interviewer:** And then again thinking a little bit globally again towards the future, what hopes or worries do you have for how your son’s community will continue to react to his sensory sensitivities in the future?

**Interviewee:** Well, I mean I have all kinds of fears about where he’ll be after I’ve passed away or his dad has passed away, even though I know his brother is a good soul and will take care of him. People just react in such weird ways sometimes to intellectual disability and autism and I just hope that he winds up somewhere…I mean my hope would be he would wind up in an intentional community setting but those are kinda hard to find. And that way, he could experience interactions with people cause he is fascinated by people. He knows when someone’s on the spectrum, it’s very weird, like he has an eighth sense and he takes to those people even if they don’t want to take to him. But he still takes to those people so I would hope he would wind up someplace where he could make the little connection that he can make with people other than his family. But I don’t know. I’m pretty cynical about American society at large right now so I don’t have much positive hope for him, I guess.

**Interviewer:** Got you. I appreciate you sharing that. I’m sorry you feel that way but I do appreciate your thoughts. We’re going to move onto our next chunk of questions again. So in the transition to adulthood, where do you see your son?

**Interviewee:** Well, practically, I see him living with me or if his father makes it through this illness, kind of switching back and forth between the two of us and then, I’m sorry, I’m getting like 5 different people are texting me right now.

**Interviewer:** Do you need a respite? We can take a break.

**Interviewee:** No, it’s okay, I can get back to them afterwards, it’s just been a busy day. I lost my train of thought. Could you…

**Interviewer:** No problem. I was asking you where you see your son in the transition to adulthood.

**Interviewee:** So where he will be after he gets out of school?

**Interviewer:** Like where is he now…would you say that he is gaining skills so that he can become independent or I can ask some more specific follow-up questions if that would be easier?

**Interviewee:** He’ll never be able to live independently. He still needs help with hygiene from bathroom issues, although he has proceeded to a point where he can sort of clean himself after he uses the toilet but he still doesn’t quite always get everything. But he needs assistance with all sorts of hygiene. He can’t make his own food, for instance. He can’t arrange his own transportation to anywhere. I don’t see him having an attention span long enough to complete any sort of job task sort of, unless it’s a very, very supportive workplace. He likes sorting things, I guess.

**Interviewer:** In a non-COVID world, is he able to help you with shopping and things like that?

**Interviewee:** To some degree, we can be in a store and I can say *“can you hand me this thing”* and sometimes, he knows what I’m talking about, like if I was like, *“can you get me a bag of Doritos,”* he could go and get his own, the brand of Doritos he prefers or *“can you get me popcorn,”* things that he really likes, he’s more able to pick up. But if it’s something that I need, I’d have to explain it to him a little bit more what it is. But he does pretty well. When we were still going to stores, he actually did pretty well. Although there was some stuff he did that was a little…he has a game he plays with his brother where he throws something on the floor and then he’s like *“Max, pick it up”* and that can get a little old but yeah, he does alright.

**Interviewer:** That’s good. What about can he help with simple household chores, like loading a dishwasher, unloading a dishwasher?

**Interviewee:** **[00:27:47]** I’m very fussy about the way my dishwasher’s loaded so he doesn’t really help with that very much but he can fold stuff. He can sort silverware so he can put silverware away. Plates are a little bit too high up for him to reach successfully. He will pick stuff up if I ask him to. To tell you the truth, his room is slightly more, although he has so many stuffed animals, they wind up everywhere but he puts his clothes in the hamper, he has no clothes hanging around his room at all. He does pretty well. He picks up his books usually and puts them away so and unprompted now too which is great.

**Interviewer:** That is wonderful. Absolutely. And then in his previous schooling, did they ever help him with money management skills or what money is?

**Interviewee:** They tried back in Bethel, it was just a smaller school so he was trying to do stuff like go to the cafeteria and buy an item with lunch every day. Here, it was not as successful because there were always bigger schools and I don’t know what the deal is but down here they put music on in the cafeteria or a TV show really loud so that became just impossible for him to deal with so they kind of phased that out. I think they might have tried something; I think he can identify money but I don’t think he has a real grasp of entirely what it does, although if you handed him money and walked him through the process, he’d hand the money to the person and stuff.

**Interviewer:** Got you. And then in his own way, does he ever express interest in wanting to have a job or some type of daily task like that?

**Interviewee:** No.

**Interviewer:** No. And what about living more independently? Has he ever expressed a desire for that?

**Interviewee:** He would certainly like it if I left him alone but no. I mean it’s just reactionary stuff like *“I don’t want to take a shower,”* like normal teenage stuff that just… *“Well, you have to take a shower.”*

**Interviewer:** Yeah. And what about friends? Does he have any group of friends that he manages to some extent?

**Interviewee:** At school, he has kids he has a connection with but I don’t know if it would be friends per se. Back in Connecticut, he had a kid who was definitely his friend and I think if we were back in Connecticut, they’d still be friends but that kid was a little bit more advanced than him. He just liked looking out for JH and apparently, he still asks after him and John Henry will ask about him too once in a while.

**Interviewer:** And back in Connecticut, would the two boys try to initiate some type of interaction or was it more parent-led?

**Interviewee:** No, we didn’t have a lot of playdates, but when we did, they would do stuff on their own, like go to the swings or they had a little wading pool. My favorite one was when they snuck back into the house after we had gone out in the backyard and they ate all the leftover pizza together for a playdate. And then there was vomiting. They kind of enjoyed looking out for each other and hanging around and to tell you the truth, that’s John Henry’s primary interaction with kids I think is that he wants them to be in the place that they’re supposed to be when he thinks they should be there so he kinda is like the person telling the stragglers to get going and things like that.

**Interviewer:** Got you. And then do you think your son will be able to achieve more independence than he currently has?

**Interviewee:** Not really. No. I don’t see him really taking on a lot more of his daily routine himself.

**Interviewer:** Got you. This question probably is not quite applicable then but do you think there would be anything that might help him move into adulthood a little bit more or might facilitate this transition?

**Interviewee:** I honestly don’t know. Maybe if there were more resources available to kind of give him daily living activity skills or communication skills but everything right now is pretty limited and school is definitely limited in what they can do with him.

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

**Interviewee:** I mean I think in order for him to transition to adulthood in a traditional sense, they’d have to be really kind of managed much better than they are now by him. But he has no vocabulary right now to express his feelings really…really he doesn’t so I’m not entirely sure how to make those behaviors more managed until he has the communication skills to let us know when something is bothering him and how something is bothering him.

**Interviewer:** When you say ‘manage’ regarding his sensory sensitivities, what do you mean by that? Could you provide an example?

**Interviewee:** Well, for instance, instead of him dropping to the floor, or reacting to something by going to that stress position, it would be better if he had language to say what was happening to him so we could make attempts to mitigate that or show him ways to mitigate that himself. At this point, sometimes it’s like having a foreign exchange student living with you that has no grasp of the language, we just have to guess what’s going on with him.

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

**Interviewee:** It’s definitely an obstacle.

**Interviewer:** In what way?

**Interviewee:** I don’t know how his independence can be achieved if he can’t manage his own hygiene or if he can’t be able to be out in public without creating a stress response if something goes wrong or suddenly there’s loud noises or something out in public. I just don’t, until we have ways to get him to communicate how he’s feeling, I just don’t see any way that those problems are gonna be anything more than an obstacle for him.

**Interviewer:** Got you. Thank you. And then relatedly, what do you anticipate as being challenging for your son as he does gain more independence or just transition in regards to his sensory sensitivities?

**Interviewee:** You mean what’s gonna be an obstacle for him?

**Interviewer:** What will make this challenging for him as he becomes older in regards to his sensory sensitivities?

**Interviewee:** Well, I mean not everything can always be the way he wants it to be. Right now, he wakes up and just gets on his computer for most of the day so me asking him to get off the computer and come do something with us, usually leave the house, requires so much prep work. I have this thing where you have to wait to pull the John Henry trigger before you get ready to go somewhere, like you have to be absolutely ready to walk out the door because once we start that process, there’s no halting it so I mean, he would have to be able to learn how to manage his response to those situations in order to be more independent.

**Interviewer:** And how does his sensitivity to sound or touch play into that?

**Interviewee:** Well, if we’re going to an environment that could be unpredictable in sound or if we want him to get a haircut from someone who’s not one of us or if we want to go take him out to a restaurant or see some sort of outdoor music or something like that, any of those things. Or if he was working at a job and they have like a fire alarm or some other loud thing happens, he’d have to manage those better to be independent.

**Interviewer:** **[00:37:23]** For sure. And do you think there’s anything that could help your son at this intersection of sensory and his transition?

**Interviewee:** I honestly don’t know. I mean I know that there are people who do more work in sensory…I’m not sure what to say, like acclimation or managing your responses, but I’m not sure where we are at this point in time on getting him to that sort of a resource.

**Interviewer:** Are there any specific services or interventions that you think could be helpful? Or is it just this individual you described?

**Interviewee:** Honestly, I’d have to do more research into it. The problem with him has been, and it’s probably wound up in sensory thing[s], is his transitions, his transitions away from what he’s doing to something else that have been really something we’ve tried to focus on with little success, so maybe a sensory approach would be something I can bring up at school. I don’t know.

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

**Interviewee:** Absolutely. 100%.

**Interviewer:** Tell me more.

**Interviewee:** Well, for instance, in Connecticut, they were one of the first states that allowed you to or that made it a provision in insurance offered in the state to provide ABA therapy for your child or occupational, whatever kind of therapies you needed for your child and Connecticut is a small state, it’s not a big state, but it’s really hard to get places in Connecticut. Are you from Massachusetts?

**Interviewer:** Yeah but my sister’s in Connecticut so I do understand the geography to some extent.

**Interviewee:** So it’s not just as easy as here in Texas, I’m like *“oh, something is this many miles away, it’s gonna take…”* likeit’s pretty easy to calculate but in Connecticut, I had to drive 15 minutes to get to the highway and then it was an hour on the highway to get anywhere and the place that I lived in Connecticut which was the southwestern corner, there was nothing there; nothing. There were no services at all there and when I got that insurance together and got that piece together and was like *“okay, now, I’m gonna go out and find him ABA therapy,”* I had to go way north in the state to get an agency that would do it and at the time, I was the first parent, apparently, to ever use my insurance to try and pay for therapy. I tried a bunch of different agencies, all of which were very far away for me, and they were all like *“we don’t provide services to parents, we’ve never had this come up before”* so I finally found one that would work with me and that’s a whole different story. It took six months from the start of initiating services with them to get someone actually in my house.

**Interviewer:** A long time.

**Interviewee:** Yeah, Yeah. I don’t know how Connecticut is cause I haven’t lived there since 2013. Here, in Texas, I think that there’s more resources for kids on the spectrum and IDD kids or kids with any sort of learning disability but not kids like mine so I would find a place that looked promising and then eventually you get to the point where they have to be able to do their own toileting or other stuff which kind of eliminated him or he wouldn’t have exactly the verbal skills to be in a social skills group so it’s really hard to find those services and he’s also limited because the transitions to get him into the car into a place that is going to give him those services is so time-consuming, so we’d get him through the door. In Connecticut, he did have occupational therapy at a facility which of course was in the middle of the state so we had to drive an hour to get there and then we’d get him into the room and it would be 20 minutes before he would actually settle down enough to actually attend. So, at that point, I was like *“well, we just have to do the services in the home”* and then that’s a whole other thing is to find someone who would come into the home. And that the other thing, I’ll say too, is that trying to find someone who can attend with him or be there for respite care is another just huge stumbling block where it’s just impossible to find people who have either the level of experience or the level of caring to actually come here and help with him so even though a lot of these things are offered to me, I’m like *“well, what am I gonna do.”*

**Interviewer:** Got you. Thank you for sharing that. I appreciate it. And now thinking globally once again, how have your son’s sensory sensitivities impacted your goals, hopes and expectations for him as he does navigate adulthood or begin to navigate adulthood?

**Interviewee:** I mean I think it’s just made anything approaching, what everybody thinks that **[phone goes]** sorry.

**Interviewer:** No worries.

**Interviewee:** I think that it’s made even approaching the idea that he could live independently…everyone thinks that well, if someone has Down’s or autism, they go live in a group home and everything’s fine. Even that kind of situation is not going to work for him I don’t think.

**Interviewer:** Because of his sensory stuff?

**Interviewee:** Yes. And the way I think the sensory stuff affects transitions and that whole piece so it makes him even able to function in a way that he could even partially take care of himself gets a little difficult.

**Interviewer:** Got you. Thank you. We’re going to go onto our last chunk of questions. We’re almost done. So finally, as a caregiver, as a mom, as a parent of someone with autism but also these sensory sensitivities, what does transition to adulthood mean to you?

**Interviewee:** Well, honestly, it’s a little depressing. No, there’s this concept in…I think it generally applies to anyone who is a caretaker for someone who is either chronically ill or who has some sort of intellectual disability, it’s called “chronic sorrow.” So, it’s this kind of constant presence where everything can be moving on fine and then suddenly something’ll hit you and it kinda knocks you back a little bit. That’s kind of the way it is for him, like there’s lots of stuff I wish and lots of expectations I had coming into this as a parent that are just out the window so you kind of have to rearrange a world view to include the difficulties that he’s going to face as an adult. So I’m not entirely hopeful that he’ll be able to live anywhere independently unless I can find that sort of intentional community for him. I just assume he’s going to live with me until I can’t take care of him anymore.

**Interviewer:** **[00:45:59]** Thank you. You just alluded to this but how has this perspective changed over time for you?

**Interviewee:** I mean it’s been pretty present since he was diagnosed. I knew that probably that he would not be a typical kid. At the beginning, I had a little bit more hope that we could get him into a better place but it just never, no matter what I tried at the time, it never seemed to work out. Except for that one kid that I mentioned, I’d have playdates with other autistic kids and there was never any interaction really. He’s not a kid who played with toys or anything so probably about the time he was approaching his tweens, I was like *“well, I think that this is probably just the way he’s going to be and there’s not much we’re going to be able to do to mitigate this.”*

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

**Interviewee:** Well, like I said, I think he’s probably going to live with me or possibly part-time with his father and I hope that there are reasonable programs that I can get him into, like a day program that actually has some activity involved. I’m a little worried because I’ve heard stories about day programs, they’re just nothing; there’s no direction provided there. I don’t know if he’ll ever, in fact, I really doubt he’s gonna be able to hold any sort of job really in the future so he’d be living with me and trying to get him out into the community a little bit and doing some activities hopefully and keeping him in some sort of a therapeutic situation because I don’t see that when he turns 21, suddenly he’s going to lose the need for behavioral interventions or continuing speech therapy or any of that. I just see that going on forever.

**Interviewer:** Do you envision him completing his school program?

**Interviewee:** Yeah, I think that he will. Texas is a little weird where they like to kind of push them into day programs at 18. I have a little bit of a fight brewing with them right now about that especially since we lost this whole year of school and part of last year so he turns 18 next January and I’d like him to stay in school in the classroom until he’s at least 20 and then see what we can transition him into at that point.

**Interviewer:** Yeah. Do you see him having a family of sorts, whatever family may mean?

**Interviewee:** I know his brother will always be in his life. Unfortunately, we’re such a small family. It’s essentially me and his dad and his brother for the most part. My current husband is also a very small family and I assume that I’ll be, and he has a brother who has Asperger’s, so I assume that at some point in time there’ll be some sort of living situation where we’ll all gather in some respect if we can find the right building.

**Interviewer:** Got you. That is important too. Last question, how have your son’s sensory sensitivities impacted this perspective you just articulated in terms of what it means to transition into adulthood?

**Interviewee:** Well, just knowing that he won’t be able to mitigate situations where his sensory problems start overwhelming him or even communicate what is overwhelming him that when he’s out in public with someone who doesn’t know him well enough that that will be a problem so without those skills, I just don’t see him being able to move into, at the very least, that kind of life that people envision that intellectually disabled people have, right? The group home or the day hab job somewhere, something like that, it’s just probably not gonna work out for him that way.

**Interviewer:** Got you. Thank you. That’s all I have on my end. Would you like to add anything else?

**Interviewee:** No, I think I’m good.

**Interviewer:** Okay, well, thank you so much for sharing your perspective and your experiences. It’s been absolutely wonderful and truly invaluable so thank you.

**Interviewee:** Thank you and good luck with your study. I hope you get some good information out of it.

**Interviewer:** Thank you. I think we will. Do you know anyone else who might want to participate? I know you heard about this through a friend I believe.

**Interviewee:** Yeah, I can post it on my special needs…if you send me a proper link for it, I can post it on my Facebook groups that I’m in for this area. I was thinking that well, my friend who referred me to this referred the moms that I knew up there so they were all on that group but down here, I just forgot because I haven’t been out anywhere, I just forgot I belonged to these other parent groups.

**Interviewer:** Yeah. We actually have a Facebook post, so I’ll just share that with you directly. I’ll send you the link so you can share that directly if that is easier. Is that easy for you?

**Interviewee:** Yeah.

**Interviewer:** Cool. I want to make your life easy. But again, thank you. So as soon as we’re done talking and this video and audio renders, I will send you a follow-up email as a thank you and it will include a gift card as compensation for all of your time and effort.

**Interviewee:** **[00:52:10]** Thank you.

**Interviewer:** Of course. Can I do anything for you? Any final questions? Anything I can clarify?

**Interviewee:** No. Everything is pretty straightforward.

**Interviewer:** Okay. Well, if anything comes to mind, if you need help with anything, you know where to find me. Please reach out.

**Interviewee:** Okay.

**Interviewer:** Have a great day.

**Interviewee:** Thanks. You too. Bye.

**Interviewer:** Stay safe. Bye.

**[END OF TRANSCRIPT]**