**[START OF TRANSCRIPT]**

**Interviewer:** I'm sorry. Oh, there we go, we're recording now. Sorry about that – computers **[laughs]**.

**Interviewee:** No problem.

**Interviewer:** So, I will be asking you questions about your perspective regarding your son's transition to adulthood in relation to his sensory sensitivities. And I will be doing something called a semi-structured interview, which means I have my planned questions in my script, but also be adapting them to fit our conversation to fit your family.

**Interviewee:** OK.

**Interviewer:** Any questions?

**Interviewee:** Ah, no.

**Interviewer:** OK, cool. And if there's any question for whatever reason you don't want to answer it, perfectly fine. ‘I don't know’ is perfectly fine. And if something comes up from earlier, feel free to bring it up, no pressure, this is a nice casual conversation.

**Interviewee:** OK.

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

**Interviewee:** So, when you're referring to sensory, he really keys on sirens. If we're out and about, and a siren happens to go by, he pretty much kind of stops what he's doing and maybe just freezes for a little while and analyzes what's around him and can slowly be redirected.

**Interviewer:** Is it with all loud noises or just sirens in particular?

**Interviewee:** Well, if there's a startling loud noise, he will put his hands to his ears and kind of cower down, but for the most part, it's sirens that he does that.

**Interviewer:** Got you. And what about any other sensory things? Like any tastes or textures?

**Interviewee:** Well, taste is limited to his very small diet, he has a very limited diet. My wife does introduce new things and he does try new things, but for the most part we stick to the regular diet that he's used to.

**Interviewer:** What is he used to?

**Interviewee:** He eats pizza, chicken quesadillas, we make those at home and try and slip in things that are good for him, like peas and corn and stuff like that. And then he likes french fries, milk, water juice and ginger ale and Sprite.

**Interviewer:** And for things not within that repertoire, or not within that diet, do you know what he doesn't like about the other food? Is it like a texture thing, a flavor thing, a new thing?

**Interviewee:** It's for convenience for him. It's finger foods that make a difference. So, a knife and fork you rarely see him use, but he has been…I have seen him use it, it's just easier access of finger-type foods.

**Interviewer: [00:03:18]** Absolutely, thank you. And then does he have any textural preferences like for clothing or things he does or does not like to touch?

**Interviewee:** Clothing, he has a tough time with a button down jammie, you gotta have the pullover type. He's not one to wear no hats or gloves or boots or any other appropriate stuff in the cold weather, he does not want anything on his head at all and doesn't like to have his head touched.

**Interviewer:** OK. Even by you or your wife?

**Interviewee:** Myself and my wife can get away with it, I do a get away with it 'cause I have to wash his hair, but a barber has a tough time giving him a haircut, with the hand on the head.

**Interviewer:** Yeah, totally. And with those buttons you described how he doesn't like them, is that like a convenience thing, or is it a textural thing?

**Interviewee:** I think it's a textural thing, 'cause I have had it pre-buttoned and slipped it over and sometimes he'll take it, but 50-50 he’ll reject it.

**Interviewer:** Got you. What about smell, any really strong likes are strong dislikes for particular smells?

**Interviewee:** That's hard to gauge with him. I can't really pinpoint anything that sticks out on smell.

**Interviewer:** That's perfectly fine. And what about any visual stimuli? Does he like or dislike anything in particular?

**Interviewee:** He's extremely video engaged, constantly on YouTube with the iPad, the iPhone. For a while he was into the portable DVD player. He won't let me put headphones on. Once again, nothing on the head or around the ears. But very video stimulated.

**Interviewer:** OK. And in those videos, is it like a particular image that he's drawn to or is it just the screens in general?

**Interviewee:** He has his routine, which he pretty steadily watches from – Alvin and the Chipmunks to Shane and David, to a lot of…very keen on infomercials, anything with a phone number on the screen, loves to read the 1-800 numbers. And he's into also religious channel, the EWTN. He likes Mother Angelica and talks about the Bible and Moses and…it's surprising what his interests run to that degree of religion.

**Interviewer: [00:06:35]** Yeah, thank you for sharing that. And these sensory sensitivities that you've described, like not liking things in his head, disliking certain loud noises, having a limited diet, or palate rather, has that changed over time?

**Interviewee:** Well, some things have changed. Early on he had pica, and that kind of disappeared the last four years when he was at the Meyer Institute. So the pica went away. You asked about textures?

**Interviewer:** Oh yeah, you said he doesn't like his head being touched?

**Interviewee:** Yeah, my wife always buys him a jacket with a hood on it and she's always putting the hood on and he's always taking it off.

**Interviewer:** And that's always been the case?

**Interviewee:** Yes.

**Interviewer:** And what about sirens, has he always been bothered by loud noises like that?

**Interviewee:** You know, it doesn't have to be a loud siren, it could be a very faint noise in the distance and he picks up on it. And that has been going on for – I want to say age 12-13.

**Interviewer:** OK, so he didn't always have it?

**Interviewee:** Not younger, I don't recall it being younger.

**Interviewer:** Yeah. And when he had pica, what were things that he would try to ingest?

**Interviewee:** Cardboard, paper, puzzle pieces. And for the longest time we thought it was an attention getter, but that's something they were able to do away with when he was at the Meyer.

**Interviewer:** That's great. And then some other changes you described, like perhaps the pica going away, or the sounds increasing or the sensitivity to sound increasing, do you think those changes are related to any independence that he's gained overtime?

**Interviewee:** I don't think so. The reason I say that is 'cause the independence overtime is very limited.

**Interviewer:** That makes sense, thank you. And then when your son is exposed to say a siren or a sound that is startling to him, does that cause or increase anxiety?

**Interviewee:** No, it appears to have a calming effect. And something that he just kind of slows down and just kind of looks around and analyzes. He's very good at walking into a room and pretty much eying the place as he walks in and knowing what he’s getting into. He’s very observant in that way.

**Interviewer: [00:09:30]** Yeah, sounds like it. What about if someone touches his head? Does that cause anxiety?

**Interviewee:** Not really. I mean, he would push your hand away and leave it at that, something like that. But when you talk about anxiety, there was a time earlier before I retired that my wife's anxiety would feed off his anxiety. They would kind of work against each other as far as the anxiety part goes.

**Interviewer:** Yeah. And this was when he was younger?

**Interviewee:** Well, when he was…I wanna say from the last six or seven years.

**Interviewer:** OK, got you, thank you. And has he always…has there always been a lack of anxiety during the sensory experiences?

**Interviewee:** Did you say a lack?

**Interviewer:** Yeah, yeah, 'cause I usually ask, ‘has anxiety changed over time’, but you're saying there was no anxiety.

**Interviewee:** Yes, there has been a lack of anxiety to now, from then. And we do a lot of things to manage that. One of them is volume control on devices and overdressing him to stay warm and things like that.

**Interviewer:** That was a great segue to my next question, thank you. So, my next question is, how do you manage and help handle your son's sensory sensitivities. So, you just mentioned bundling him up, you mentioned volume control. Are there other things that you or he does to manage those exact those sensory sensitivities?

**Interviewee:** Yeah, some of the YouTube channels we…for the longest time certain shows would set him off. Barney in particular and Blues Clues, and I can scroll through the history and delete those. But he usually brings them back up and he's been bringing them *both* back up lately without any problems.

**Interviewer:** That's good. And are there other techniques that you or your wife employ regarding his head or the sirens or anything like that?

**Interviewee:** Not really, we just let them…the sirens take their course, once they're off in the distance, we go back to resume normal activity. As far as reducing anxiety and stress, one of the better things that we've introduced early on, I taught him how to swim. So, swimming was relaxing and then he kind of would rather spend more time in the hot tub next to the pool than go in the pool because it's warmer and more inviting. So that's going way back – swimming. And then we've recently added a small hot tub in the backyard, and I introduce that at 8:00 o'clock at night, and we go sit out there and then I shower him, I get him in his jammies and pretty much like clockwork, he's in bed at 9:00 o'clock.

**Interviewer: [00:13:11]** sounds like a great system, it’s what I like to do.

**Interviewee:** It works.

**Interviewer:** And has your son ever received specific therapies or interventions for his sensory needs?

**Interviewee:** Oh yeah, he was targeted at the Meyer with applied behavioral analysis. Before he went to the Meyer, he was at Melmark, New England, and the different teaching models between Melmark and Meyer was the Meyer is a consult model, where the Melmark is…the BCBA was actually in the classroom working with them one on one. So, he was at the Meyer for 12 years.

**Interviewer:** And do you think the ABA at both schools, do think that helped him with his sensory needs?

**Interviewee:** We did our research early on. The other method is the Higashi method, and I did not like that model for…taking a tour of the school, the students come in first thing and they're in their gym clothes and they basically run their tails off for the first half hour in the morning. And then as I toured the school, I saw the kids still in their sweatpants and sweatshirts throughout the school day. Like I would think there'd be a period to clean up and destress, to swim or something, and then start academics. But I went with ABA at the Meyer, I think that was our best bet. Some of the Meyer ABA was really rigid with the…I think there might have been a better benefit if James could have been exposed to more normal kids around him, but that's not the case at the Meyer.

**Interviewer: [00:15:19]** Yeah. Do you think the ABA did help with his sensory sensitivities though, like the touching or like the lack of liking being touched in the head or the sounds?

**Interviewee:** I do, I do think so.

**Interviewer:** So, you think it decreased a little bit because of that?

**Interviewee:** What decreased?

**Interviewer:** The sensitivity of being touched, did you say that decreased? Or the pica, maybe. Sorry.

**Interviewee:** It could…it definitely helped on the pica, 'cause that went away and that was from day one.

**Interviewer:** But…yeah…I don't know how to answer that.

**Interviewee:** That's OK, that’s a great answer right there.

**Interviewer:** Thinking a bit to the future, what goals or hopes do you have for your son regarding his sensory sensitivities?

**Interviewee:** Well, our number one goal is to get the vaccine **[chuckles]**. Our second goal after that is to get into a day program, and we're taking our time with the state program 'cause nothing is going on with the COVID, so we're just looking at a model that would…it's hard to put him back in a situation where it's a rigid ABA **[00:16:50 inaudible]** with academics and more of a setting of relaxation and acceptance for his behaviors that are typically autistic, jumping, loud noises, stuff like that.

**Interviewer:** So, for the vaccine, is that your goal because he won't wear a mask, because he’s sensitive to things on his face?

**Interviewee:** Absolutely, he won't wear a mask, and we've stuck to this routine since COVID started, and 85% of it's outside in the mountain. We've been lucky and we just…we want to get it going before this…you hear about these strains coming out that are stronger or more potent. So, the sooner we can get him vaccinated, the better chance I have getting him in a day program and getting out of the mass scenario and maybe traveling with him, getting back to traveling with him as he was requesting that today – as he refers to traveling as a suitcase.

**Interviewer:** Yeah, that must be hard. It's hard for everyone else to travel right now.

**Interviewee:** Yes

**Interviewer: [00:18:08]** We're gonna shift gears a little bit to our next chunk of questions. As your son has grown up and aged a bit, how has his and your community reacted to his sensory sensitivities?

**Interviewee:** For the most part, the community's been great. I was a member of the pact here in Quincy when it was a bit of a struggle to get him out of district, we had to get an educational lawyer involved, and once that's established, they kind of give you what you want. But the community as a whole has been supportive. We've had maybe one or two incidents that was misread or didn't go our way, but it was minor.

**Interviewer:** I'm glad to hear it's been overall positive. That's wonderful. And what do you say the community was more or less accepting when he was younger?

**Interviewee:** Probably less.

**Interviewer:** How so?

**Interviewee:** He was louder and more agitated as he was frustrated in his ability to communicate.

**Interviewer:** Super fair. And were there specific places or spaces in the community that were more or less accepting of him and his sensory needs?

**Interviewee:** Well, yeah, we have a limited place we go now because certain people know us and overlook the mass, but it's very limited. So, we do lead a sheltered life in that sense, but I didn't see any real boundaries before COVID. Maybe one incident where I was trying to take him into a place that – in Cambridge, it does have the hot tubs and the lady was like, *“I don't think he can come in here, 'cause he's too loud* *and we got people doing massages…”* and it's a big…aromatherapy and all that. And the owner overheard and said, *“no no, it's fine.”* And once we got him in the tub, he was very happy.

**Interviewer:** That's great. How has family been? Or if you both belong to any religious groups, have they been accepting of him and his needs?

**Interviewee:** He doesn't get outside as much unless he's in a school setting. And the reason is we have medication we have to deliver on time in the evening now. My wife is very strict about that, but…what was the question again?

**Interviewer:** I was asking if there were like certain spaces or places that were more or less accepting, and I asked about family or like a religious group if you belong to one.

**Interviewee:** Yeah, no, he doesn't belong to any groups. For the most part, everybody's relatively accepting. It's hard…he likes to go to library, it's hard to take him in there when he's doing his echolalia talk and people are trying to study, but we're working on that.

**Interviewer: [00:21:24]** That's good, I'm glad it's been so positive overall, it's wonderful.

**Interviewee:** Yes.

**Interviewer:** And then again, thinking to the future, what hopes or worries do you have about how his community will react to his sensory needs?

**Interviewee:** Well, one big hurdle coming up in the next 5 to 8 years is getting him into a group home, 'cause my wife and I are not going to be able to take care of him for the rest of our lives. So, I'm looking at that setting in the long term. And the short term is getting him into a day-hab program once this mask…vaccine occur.

**Interviewer:** And for those goals for you, the short term and the long term, what role do his sensory needs play into that?

**Interviewee:** Well, quite a bit. I mean, he's…with this video stimulation, it's going to hold him back from holding a job. We did pursue the vocational aspect of it when he turns 14 – let me just get a little water here.

**Interviewer:** Yeah, take your time, please. Thank you for meeting with me so late, I don't think I said that in the beginning. I appreciate it.

**Interviewee:** Yeah, this is perfect 'cause everybody settles down at night. Now, where were we?

**Interviewer:** Yeah, you had just described your short term and long-term goals for your son, the day program and the group home. And I was asking what role do his sensory sensitivities play into these goals for you? And you mentioned the vocational program when he was 14.

**Interviewee:** Yeah, we started that early on with Kelly Challenge and with Rafael Castro's group and he was pushed from that point, age 14 to when he aged out at 22 and he was deemed not really viable for a vocational program, 'cause it's very competitive and he just didn't have the skills to do a certain task and stay on task and that sort of thing.

**Interviewer:** Got you. In his sensory, what role does that play in that? You started mentioning the video game stimulation?

**Interviewee:** Yeah, he rarely goes anywhere without the device and he's…it's interesting if you take the device away, he's louder, boisterous and with the device he’s more normal and mainstream.

**Interviewer: [00:24:20]** You say that device is kind of interfering in vocational activities?

**Interviewee:** I don't think it interferes, because two of the…there was two things that we did were very telling; we participated in a gene study, and then one of his doctors, Dr. Kolter, his neurologist, did a whole-body MRI. So, the whole-body MRI showed us a brain area in the frontal lobe where there’s brain damage. So, we never knew about that till this whole-body MRI came around. And the next question is, well, where did that brain damage scar tissue come from? And it could go back to birth, it could go back to a virus, it could go back to a physical altercation with aggression. Who knows? So the gene study revealed a propensity, a delineation of one of his genes for a propensity for diabetes, and that coupled with the medication he's on for aggression – Risperdal and Benzatropine, we screen for diabetes with a blood test every year, before we didn't know about doing that, had it not been for the gene study. The gene study also picked up on the…he had a kidney problem when he was born, a blocked ureter, and soon after he was born he was operated on. And they did have a rough birth. So, there was a lot of things that we learned from that gene study, as well as the target marker for the autism and a couple other things. But it was those two things [that] showed a lot.

**Interviewer:** Yeah, I'm sure, that's wonderful. I'm glad you got to learn those things. We’re gonna move on to our next chunk of questions. So, in the quote unquote “transition to adulthood,” where do you see your son?

**Interviewee:** Well, he's aged out of the system at age 22, so at that point you lose all your entitlements. And then we're in the day-hab program setting with DDS, and we're trying to find the right day-hab that would eventually lead to the possibility of hopefully getting work of some kind, but upgrade his self-help skills, and then eventually lead into some type of group home.

**Interviewer: [00:27:21]** That's wonderful, thank you. So, thinking about things that he can do independently and things where he needs some support, could you describe those things?

**Interviewee:** Yeah, independently he can put on his pants, zip it up and do the button. He needs help putting on his shirts overhead, he needs help in the bathroom, and he needs prompting to go the bathroom. You can see a little anxiety or agitation or jumping around and, *“hey, let's go over here to the bathroom,”* and that nine times out of ten solves that problem, so. He can swim, not that many autistic kids know how to swim. We ride a tandem bike together. I tried for my many many years to get him to ride a bike on his own and we ended up with a tandem bike. What else? He can complete fairly – I don't want to say elaborate, but a fairly good size puzzle, he likes puzzles. What else can he do? He's very limited verbally, they did teach him his name and his address and his phone number, but I don't think he would be able to recite that now.

**Interviewer:** Got you. Is he able to do some small household tasks like put dishes away or like put them in a dishwasher or something like that?

**Interviewee:** He's got the ability to pick up glasses if you put it on his computer table, somewhere he doesn't want, he'll bring it in the kitchen. As far as loading a dishwasher, I don't think so. I've tried to do the laundry with him and he's more interested in the television or the computer. But I don't see him doing a whole lot on his own, I don't.

**Interviewer:** Yeah. That's super fair. I have a few more follow up questions if that's OK with you?

**Interviewee:** Sure.

**Interviewer:** Is he able to prepare simple snacks for himself up the things that he does consume?

**Interviewee:** No. No.

**Interviewer:** And you mentioned a vocational program when he was 14, did he get a chance to learn some job skills through that?

**Interviewee:** Oh yeah, they introduced him to table wiping, sweeping, sorting, filing, recycling, he did quite well stacking silverware, and other chaining things he did well on, but yeah, he's limited.

**Interviewer: [00:30:27]** That's fair. In this vocational program, did they introduce any concepts of money at all?

**Interviewee:** They did, they did, actually. He would identify bills. I'm not sure how he did on the coins, but he would do the one and the five and the ten. But he…I don't think he has a concept of money or where it goes. A lot of times before COVID – he likes to go to Faneuil Hall and see his street musicians, and then I would give him some money to put in their basket and sometimes he would walk by and put in the trash. So, he didn't really…he doesn't understand that.

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

**Interviewee:** No, no. I've been grooming him verbally to go back to a day program. I drove him…I’m working with that one up in Lexington that he…not Lexington, Wellesley. And I drove him just by the building and was explaining to him, and he looks directly at you and takes it all in, but doesn't say much.

**Interviewer:** For sure. Do you think, again, in his own way – I know he doesn't have many words, but in his own way, does he ever express an interest in wanting to live more independently, like, say, in a group home or a day program?

**Interviewee:** No.

**Interviewer:** No. And do you think you'll be able to achieve more independence in the future?

**Interviewee:** I think he's going to be forced to. I think a lot of things will change when he moves out of the convenience of living with mom and dad, who probably overdo things that they shouldn't do. There is the ability to make him do certain things pertaining to getting out of the pajamas in the morning, brushing your teeth, which he won't do, I have to do that, and then getting dressed. And it could play out a great deal of time, and he will eventually complete it with several prompts and several redirects. But there's a quality-of-life issue that life goes on before we get out the door at noon versus 9:00 o'clock.

**Interviewer:** Yeah, absolutely.

**Interviewee:** So, a lot of things are done for him for time sake reasons.

**Interviewer: [00:33:11]** That's super fair. And what do you think will help move him into adulthood a little bit more or move into a little bit more independence?

**Interviewee:** I'm not sure, he's…when he was at the Meyer, he was quoted as being one of the smartest, laziest person there was there, doing the bare minimum to get by, the *very* bare minimum. You see that with his mannerisms in public or versus going through a door and maybe holding it for the guy behind him, and that's not happening. He's really focused on him and himself only.

**Interviewer:** Got you. Do you think there might be any services or interventions that could help him gain some more independence or move quote unquote “more into adulthood”?

**Interviewee:** I do, I do. I think with the right trained staffers, and he would do well. But it would have to play out overtime where this person would stay with them for more than a year. And one of the biggest problems we had with staff at the Meyer was the high turnover rate and their policy that a teacher wouldn't stay with him for more than six or three or six months before they rotate out. And that, I think that has a lot to do with their methodology of not getting somebody too comfortable with them or overdoing it for him, such as happening at home.

**Interviewer:** And do you think he would benefit from someone being with him longer? Or do you think that kind of turnover was beneficial for him, or would be beneficial for him?

**Interviewee:** Well, I think he would benefit with somebody [with] more lengthy connection.

**Interviewer:** Got you, thank you for clarifying. Sorry, going back a little bit thinking about independent skills or things where he needs more support. Perhaps pre-COVID, did he have any sort of friends from perhaps the Meyer or the other schools that he was in?

**Interviewee:** There was one instance where we were alerted to a friend that he had in a classroom. When we learned about it, we were trying to get in touch with that family to see if they wanted to do something after school to see for ourselves what they were talking about. And we never made a connection there with the parents, so that fizzled out. And then he just aged out from the Meyer in September and some of the staff has come by to see him, but he really doesn't give them the time of day, he doesn't give anybody the time of day unless he wants something. If somebody got up and said, *“hi James, how you doing and how you been?”* He would just kind of look away and look down at his iPad and go his way.

**Interviewer: [00:36:33]** Got you, thank you. Now we're gonna put these two things together. So, thinking about his sensory sensitivities and then thinking about his transition to adulthood, how do they intersect for your son?

**Interviewee:** Well, I think the sensory things are…he's grown into without any kind of sensory sticking out other than what I described with the sirens. He enjoyed…the street musicians was a sensory thing for him where he could sit on a park bench with his iPhone and listen to his favorite street musician. Same with the stores, he's very keen on what's playing over the intercom music wise. And it's kind of easier to read his face now with reaction to what's going on or things like that.

**Interviewer:** You just said ‘grown into’, what do you mean by that?

**Interviewee:** I think with age, the sensory issues have died down.

**Interviewer:** Got you. So, because of that, do you think they impact his transition less?

**Interviewee:** Yes, I do, they impact his transition less.

**Interviewer:** Thank you. Then my next bunch of questions may be a little bit less relevant, so my apologies.

**Interviewee:** OK.

**Interviewer:** But do you think his sensory sensitivities are an obstacle, a vehicle, a bit of both, or neither towards his independence?

**Interviewee:** I think neither. I think neither.

**Interviewer:** Why neither?

**Interviewee:** Well, I don't see him gaining much independence. And sensory really doesn't have a role in that. I think it has to do with…all his deficits are where that brain injury is, and that's what we're doing now.

**Interviewer:** Yeah, absolutely. Well, my next question probably won't be applicable, my apologies **[both laugh]**. So, what do you anticipate as being challenging for your son as he does gain a little bit more independence in relation to his sensory sensitivities?

**Interviewee:** I think it's just following general safety guidelines, you know. More and more, we’re doing more things without the device, and that gains his, a little more cognitivity (sic) on his end to see what's going on around him. So, I think there's a balance with that and him being more aware of his surroundings.

**Interviewer: [00:39:43]** Perfect, thank you. And then in this intersection of sensory and his transition, do you think there's anything that could help him?

**Interviewee:** We're working on one day of work of speech, for [a] half hour day at Alternatives ABA in Norwell. And I see him interact with the teacher, 'cause I'm always with him. And I see him throw up a facade of the echolalia talk, his hands over his ears, him kind of zoning out on her when she's trying to engage him and I think he's always had that from the Meyer and I see it in speech class.

**Interviewer:** When you say facade, what do you mean by that?

**Interviewee:** He just wants to get in and out of there. It's only half-hour session, and he gets whatever he asks for and they do the puzzle together and they take turns - my turn, your turn. And he's fairly verbal with that and then he can request to go to the gym, and there's a trampoline and a swing, and he likes the swing, but when she's trying to get in his face and get him verbal and show – she wears a mask that he can see her mouth – he’s blocking her out with that echolalia talk and the hands over is [ears], like he's over stimulated.

**Interviewer:** Thank you, that makes sense.

**Interviewee:** And I think that's a show.

**Interviewer: [00:41:36]** You just mentioned speech, do you think there are other services or interventions that could help him in his intersection?

**Interviewee:** I do, I do. One of the hurdle blocks of getting into the day program is his behaviors. I'd like to work with a behavioralist with the Laurie Center, he's connected with some couple doctors there, and I think we could better treat his behaviors with a behavioralist.

**Interviewer:** And by behaviors, could you describe them briefly?

**Interviewee:** You get the typical autism behaviors of the jumping when he's happy, the echolalia talk and the hands over the ears. But when you really want him to do something, he won't. Like I’ve been trying to test drive new cars and I took him with me, and he wouldn't get in a new car. So, he's definitely got a sensory issue with new cars and getting out of his routine. He's in a very regimented routine and it's hard to change.

**Interviewer:** Yeah, thank you, I appreciate that. And then do you feel like there are gaps in the available services and interventions?

**Interviewee:** Are you talking pre 22 or after 22?

**Interviewer:** I'm talking both so, however you prefer to answer that.

**Interviewee:** Pre-22, I think we had everything we needed service-wise, he had OT, PT, behavioralist. And then everything changes at 22, you lose your entitlements and the best you can do is a very robust day program that has a medical component which would address behaviors with a behavioralist. He's very easily talked [or] directed into situations and can do it, but he's not going to be pushed, else the behaviors come out. Like we were in a situation where he ran into a restaurant that we walked by and they have to wear masks, and the staff didn't know him. Ultimately, he was ended up dragged out of there, and that set him off into behaviors, 'cause he just wants to go and watch what's on the television, that's only risk he’s there. He doesn’t want to buy food or eat, he just wants to…had they sat him down and let him watch a TV, it would have been fine, but that's what causes behaviors.

**Interviewer: [00:44:46]** Got you, thank you. And now thinking again a little bit more broadly, how have your son's sensory sensitivities impacted your goals, hopes, and expectations for him as he does navigate adulthood?

**Interviewee:** Well, we’re stuck with the sensory issues we have, they haven't changed at all other than the pica, and I don't see them changing to benefit him in the future.

**Interviewer:** And has that lack of change impact how you see him become an adult?

**Interviewee:** I don't think it impacts him that much, he would be in a very specialized program wherever he was or group home wherever he was, I think those cater to the issues that you're referring to as far as sensory.

**Interviewer:** Thank you. We’re in for our last chunk of questions, we're almost done. So, finally, as a caregiver, as a dad, as a parent of someone with autism and some sensory sensitivities, what does it mean to transition to adulthood for you?

**Interviewee:** Well, everything changes at twenty-two, the resources dry up dramatically, you’re kind of left to sort out the day programs that would benefit him. It's just a very narrow group of people that you're dealing with in a very specialized field.

**Interviewer:** And has this perspective changed over time?

**Interviewee:** You know, I don't think his has. He's very – like I said, as long as that routine is there and he can call out the next location, he's happy. There was some confusion a while back on locations, and we've since cleared them up verbally. He would request to go to the laundromat, which turned out to be the Curry Ace Hardware, and that's all fixed now. But he does confuse Lowe's with BJ's. So, I think we're getting back to the brain injury.

**Interviewer:** Yeah, that could definitely be it. Has this perspective changed for you, though? I know you just described your son.

**Interviewee:** Not really, it's been a learning curve since we've aged out, and the real curve is the COVID, 'cause we have to exist in a society that doesn't **[00:47:37 inaudible]** with someone that won’t wear a mask. And we got the letter from the doctor and we got our people that we hang around with and are routine that know him. And the routine can't really change for the better until this goes away. And then I think the ultimate reward after this goes away is some travel and a day program.

**Interviewer:** Yeah, absolutely, thank you. And what do you see happening in your son's future?

**Interviewee:** I see him not really gaining much more cognitive ability or intellect. I think you kinda know what you got after age 22 and I just don't see a lot changing for him, I think everything is gonna end up getting catered around him to live in a group home eventually.

**Interviewer:** Absolutely, thank you. And then last question, what role did your son's sensory sensitivities play in this perspective you just described about what it means for him to transition into adulthood?

**Interviewee:** Well, I mean it's changed a lot since he was very young. I think the older we both got together, the more we realized, I realized that he's got deficits that aren't going to change and that have to be managed and we're just gonna have to cater to those needs.

**Interviewer:** Absolutely, thank you. That's all I have. Would you like to add anything else?

**Interviewee:** No, I'm just enjoying doing the study. We'd worked with summer before, do you know where she ended up?

**Interviewer:** I don't, but I could ask around if you'd like?

**Interviewee:** I didn't know if she was local or moved on.

**Interviewer:** I will do some digging. I don't know, she I think left before I came, but I definitely know who she is, people still talk about her. So, I'll let you know. I'll see if I can find it for you.

**Interviewee:** That's great.

**Interviewer:** Yeah. But truly thank you for your time, it's been so wonderful to learn from you and to hear about your experiences, it's been valuable.

**Interviewee:** All right, very good, you're welcome, thank you.

**Interviewer:** Do you know anyone else who might wanna participate in our study?

**Interviewee:** You know, we're very limited on who we socialize with, so at the time, no. If it wasn't COVID, I could have somebody, but.

**Interviewer:** No worries, I ask everyone, so no pressure. But again, thank you. Tomorrow after this video has rendered, I will send you an email and it will include a gift card as compensation, an electronic gift card as compensation for all of your time and effort, ‘cause we do so appreciate it.

**Interviewee:** OK, thank you.

**Interviewer:** Thank you. If you have any questions, please let me know, you know where to find me.

**Interviewee:** OK, very good and keep us apprised of your studies.

**Interviewer:** Yes, absolutely. I have you down that you want to know about results. So as soon as we have them, they'll be in your inbox.

**Interviewee:** Alright, thank you so much again.

**Interviewer:** Thank you, have a lovely evening.

**Interviewee:** You too, bye.

**Interviewer:** Bye.

**[END OF TRANSCRIPT]**