**[START OF TRANSCRIPT]**

**Interviewer:** OK, we are recording. And I'll be asking you questions about your perspective regarding your son's transition to adulthood in relation to his sensory sensitivities. And I'll be doing something called a semi- structured interview, which means I have my planned questions in my script, but I’ll also be adapting them so they actually fit for your family and for what we're talking about.

**Interviewee:** OK.

**Interviewer:** Any questions?

**Interviewee:** No.

**Interviewer:** OK. And if there's anything that you don't want to answer for whatever reason, that's perfectly OK, *‘I don't know’* is also a perfectly okay answer. And if you think of something from earlier in the conversation later on, you're welcome to talk about it, it doesn't have to be perfectly linear.

**Interviewee:** OK.

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

**Interviewee:** George has always had sensory sensitivities. So even when his…before he got the formal autism diagnosis which he got at Texas Children's Hospital, and it took like nine months to go through its battery of tests that they…hold on, just a sec.

**Interviewer:** Oh, no worries, not a problem.

**Interviewee:** That's my alarm telling me that he needs his meds.

**Interviewer:** Do you need to go help him? We can pause…

**Interviewee:** No no no, my husband’s here, Tim's here. His dad will get it.

**Interviewer:** OK, perfect. We can always pause if anything happens.

**Interviewee:** OK. So, anyway, even when he was, PDD NOS, which is basically the label they gave you when they didn't know really what it was, and he started speech therapy at…then actually he started speech therapy and then immediately the speech therapist said, *“wow, he's got so many oral issues, we've got to get him into some kind of like OT as well and PT…”* and everything else. So, he's always been very…he was always very oral and highly sensitive to sounds and touch, textures. So, that was one of the early things. That and just not talking as we expected him to at the age of two, there was just real sensory issues for him.

**Interviewer:** Got you. Do you mind if I ask some clarifying questions?

**Interviewee:** Sure.

**Interviewer:** Awesome, thank you. You said he had a lot of oral stuff when he was younger. What did that look like for him? What was that?

**Interviewee:** Well, for one, looking back, you know, even when he was an infant, he would – and I breastfed him – he would nurse and nurse and nurse and then just literally *throw up,* and then just began nursing again. It was like he just…the sucking was just so…it was like he wasn't even sucking on my breast because he was really hungry anymore. And he actually sucked his thumb so badly he had calluses on his thumb from sucking his thumb so badly. So, in retrospect, you know, it was kind of like wow, I guess that was all part of the oral. He would also then, as he got older and was no longer just an infant or even just even as a toddler – and he sucked his thumb until he was about five years old, I think he was. And then one day he just quit and he never sucked it again; no idea why. Never gave him a pacifier, so it was always his thumb. But he was oral in the sense that he would put inedible objects in his mouth. We had to be very careful about plants and things, he loves the smell of plants. So even though we eventually got him to stop, he would take a plant and put it in his mouth, chew on it and then spit it out into his hands and rub it and get the smell and then maybe put it back in his mouth. So that was clearly not…we had to be very careful what he was around. But even if we went to some place, even as he got older, there would be – like I very vividly remember, we could go someplace, let's say like a museum, and there'd be a handrail that was metal, and he would just put his mouth on it and run it all the way down because it was *cool*. It was something that none of us would ever have thought of doing. And yet he would do that. And so you're just like, *“oh my gosh!”* He *never* got sick.

**Interviewer:** That's great. That's really good.

**Interviewee:** He *never* got sick. And we were convinced that the Center for Disease Control should have studied his immune system because he clearly showed that if you let your kids put everything in their mouth and do all this – although we did try to protect him, there was times he would just do it so quickly, and you're like, *“oh my gosh! I didn't anticipate him running his mouth along the handrail at the museum that was packed with all these people.”* And you knew that was completely unsanitary.

**Interviewer:** But as long as he's OK, that's what matters, ultimately **[chuckles].**

**Interviewee:** No, he didn't. He never got sick.

**Interviewer:** Great, I'm glad. You mentioned that he was also sensitive to sounds. What type of sounds?

**Interviewee:** Well, any high-pitched sounds, like a…even if it's not even nearby. So, a lawn mower, leaf blowers, anything, [it] could even be outside that would be very distracting. I mean, he would be covering his ears. So he was covering his ears a lot. I actually – and this actually really helped, I don't even remember when it was that I went up to Connecticut with the boys…**[to Tim]** remember when I took him? **[To Rachel]** He got some auditory integration training. I think it was 2006, maybe he was about six or seven years old. Now he hated wearing *anything* on his head and still does, he would never wear a baseball cap or anything. And yet to have auditory integration training, he had to get comfortable wearing headphones, right? So, we worked with him and his ABA therapy. They worked with him just wearing the headphones, just so he would tolerate having them on his head. That took quite a while, but once we finally got him tolerating it, he was…I took him up for auditory integration training to a specialist I had found out about up in Connecticut, and he was trained by the original guy. Are you familiar with auditory integration training?

**Interviewer:** I'm not. Could you tell me about it?

**Interviewee:** Well, what they do…gosh, really going back in my 14 years ago or whatever. But it's…there was a French doctor whose name I can't remember, who came up with this theory, and it came from…there was an Opera singer who could no longer hear the notes, and she clearly was a professional, and she couldn't quite hear the note. And he developed this auditory integration trying to re-calibrate her ears to hear. And so, and it really helped get her hearing back to where it had been. And let's just assume that she had very sensitive hearing 'cause she could hear the last, least little bit that was off, right? And so this woman had actually studied – this woman in Connecticut had actually studied under this this gentleman in France, and now she was in Connecticut, so she was doing this training herself. And it really did help. So, George listened to…she had…I'm just going to call it just sort of like not really music **[00:08:16 inaudible]**, it could just be sounds. And again, I didn't get to hear it, but just sounds. Could be **[makes chimp like sound],** it could be anything like that. And it really did help him better control his sensitivity to hearing, she swore that after this he should never wear headphones and never be listening to music through headphones or anything like that, 'cause it could mess it up. And so, he never has, which wasn't hard because he didn't like headphones anyway. But he actually went through this therapy and after that, one thing she said to me I thought was so odd, I just kind of dismissed it, like yeah. She said, *“you know, we've had people who've done this on the autism spectrum, and they tend to eat more, have a more varied diet after this.”* And I'm like, *“how could that possibly be?”* And he did, we got home and he began to eat a more varied diet. Was the sounds that were just in the world that were just upsetting him so that he just…I don't know. But anyway, it really did help, and his hearing has not been as sensitive. It still is sensitive, but he used to cover his ears *all* the time and now he very rarely will cover his ears. And **[00:09:34 inaudible]** a long time ago.

**Interviewer:** Oh yeah. You said 2006?

**Interviewee:** Yeah, 2006 I think, yeah.

**Interviewer:** Got you. And when he was more sensitive, you mentioned machines outside, like a leaf blower, lawn mower and those things, would people's voices also upset him or be upsetting?

**Interviewee:** Yeah. And actually, even to this day he is very sensitive to the tone of people's voices. So, if you use a harsh tone or something, he actually is very sensitive to that, and will react more harshly than you'd really would want him to. He’ll overreact to something like that. He might get very angry and upset that you didn't really mean it that harshly, but to him, for someone who has a hard time reading emotions and whatnot, for sound, he is much more sensitive to that. I mean, reading someone's face or whatever, obviously no. But as I said in my questions and everything, sound I would say he's hypersensitive to.

**Interviewer:** Got you, thank you. And touch, you mentioned touch.

**Interviewee:** Touch, yes. Actually, for calming him down if he had gotten real upset – and I'm thinking specifically about 2007. I was actually… lived alone with him for about six months when his dad and brother went overseas, and so I was having to control him and manage him myself. And one of the things that one of the therapists recommended that really worked was just to hit him with like feather pillows. If he got *real upset,* if I could just hit him with the feather pillows, you know, obviously nothing was going to hurt him, but that just hitting him with it just really did help sort of comfort and calm him. Also just massaging his feet, he would really like that. In fact, sometimes he would just stick his foot up in my face, you know, and like, *“what do you need, George?”* and he’d just stick his foot up in my face. And [he] always goes barefoot, he’s very much **[00:11:41 inaudible]**. Getting him to wear shoes was really an issue. He is much better about that now, but start…when he first went to school it was like, *“no, he has to keep his shoes on,”* and it's like he won't keep his shoes on, you know? So, I would say those are kind of touch issues, that not wanting shoes on or wanting to be able to run barefoot off something that you and I might find uncomfortable but wouldn't faze him at all.

**Interviewer:** Were there other textures or other articles of clothing that he preferred or had trouble with or has or had?

**Interviewee:** Yes, but I would also say touch, if I could equate that also to foods, he's very much…like if you gave him…he loves ice, for example. He likes crunchy foods, he likes crunch, he wants…like crackers and anything crunchy. Honestly, if you gave him ice-cream, he would just go **[makes puking noise]**. I mean, that whole mushiness in the mouth, he still just can't stand it, whatever. If it's ice cream or yogurt or anything like that, he just…it doesn't matter, it is just like it would be for you or me if we were running your fingernails over the chalkboard or something that would just make you go **[makes puking noise]**, you know, that was very much texture. So that to me is also touch – in the mouth, but for someone who's very oral, that kind of stuff, no.

**Interviewer:** Yeah. And you mentioned his diet, how it used to be limited and then he had that auditory integration therapy, now it's less limited. Could you talk a little bit about that too?

**Interviewee:** He has over the years become more and more. So it used to be all sort of monochromatic foods and, again, crunchy, so that ends up being a lot of carbs. Still not a vegetable kind of person but would love to eat…although recent[ly], I don't know why he's having some dietary issues now we're not sure about, but he used to eat like 3 apples *a day*. I mean he would *love* apples and pears. Again, and you don't slice them up, he wants to just *bite* into it. If you slice it up, I'd come pick him up and someone would say, *“he didn't eat his apple,”* and I'm like, *“that's impossible! He loves apples.”* And they'd cut it up and I'm like, *“no, no, no, just let him bite into the apple, he wants to bite it.”*

**Interviewer: [00:14:29]** He likes that input, it sounds like?

**Interviewee:** Yes. He really wants to be able to bite into it and take a big chunk out of it and then eat it. He'll eat it all the way down to the core. So again, crunchy kind of foods. But he would eat grapes, so we got him to…he would eat grapes. There were some other foods that weren't as crunchy, obviously, but celery…he loves celery and all that kind of stuff, but again, crunchy foods like that was what he would really like. And then also, I suppose crunchy but also healthy and safe were herbs. So, for a long time I had an herb garden and he would just…I'd literally just send him to school with a bag of parsley and cilantro, and he would eat that the same way someone else would eat a salad, but he would want all of those kinds of smells and aromas. Lettuce – has no interest in lettuce, but certainly cilantro and parsley were just huge, he would eat a whole bag of that – which is very healthy.

**Interviewer:** Oh yeah, for sure. And so is he sensitive to smells as well?

**Interviewee:** I think so because he…in terms of what he likes, not so much a revulsion to anything, but he does like smells. There are certain smells that he likes, and that goes back to plants and whatnot. And then herbs, just knowing that that's OK, those are plants that we obviously know are edible. He does initially would go around sniffing and smelling things, and I don't really remember him ever being like “*ugh*,” put off by something that smelled badly, but I do think the attraction of certain smells, you know, he would, we would, pre-pandemic, we would go to…well, first of all, when he would go horseback riding, he does **[00:16:37 inaudible]** equestrian therapy, having – even to this day, making sure that he just has stuff in his hands to be doing constantly. So, rosemary or basil or… **[to Tim]** Tim I'm forgetting the name of the big plant out there, what’s… **[to Rachel]** bay leaves! Couldn't think of it all of a sudden. But anything like that, so it's in his hands and he's riding the horse and he's doing his hands and smelling it and everything, he really likes that. So anyway, that kind of thing.

**Interviewer:** Yeah. And does he have any visual sensitivities? Does he like to look at certain objects?

**Interviewee:** Well, again, we never were able to get his vision tested or anything. But I can tell you that when he was a child – and if you can imagine sort of at the windowsill level, it’s nice if you’re a little boy and you can stand up at the window and the windowsill’s just is right at eye length. And he loved and still loves *“Thomas the Tank Engine.”* So, he would run it, he would keep his head face and he would run it across in front of his eyes and then back across again. So, I think visually he liked it coming into his view and then out of his view. He also would watch movies – and *still* does this – in fast forward, and just *love* watching them in fast forward or backwards and watching it go backward, watching it go forward. I mean, these are movies he's watched 10 million times anyway, but he really enjoys that sort of thing. And he will even look – and people have noticed this when we've gone places, but particularly we would take him to special needs church service thing. And there might be a doorknob, and a doorknob you and I wouldn't pay any attention to, but there could be a slight reflection in a warp of what you are and George will run across the room and then you can see that he's looking at himself in that doorknob, he's looking at himself in that doorknob. And people who have been around him for a long time go, *“there he goes, looking himself in the doorknob.”* You and I would never think to look at ourselves in the doorknob. But he'll even do that in the car in the backseat, he might get real excited and I can see him sort of looking at that little silver handle, and he's seeing himself there or something, and he's kind of going in and out of that door handle. And I know he's looking at his reflection in that door handle.

**Interviewer: [00:19:15]** Got you, thank you. And you touched upon this a little bit already, but how have his sensitivities changed overtime?

**Interviewee:** He's much less sensitive obviously than he was, even as an infant. Still very sensitive even as a child, but I would say that certainly…well in ABA, they certainly had worked – not anymore, but for a long time they did have to work very hard on making sure that he did not put inanimate objects in his mouth and that sort of thing. And I think that habit – did I say inanimate? *Inedible, non-edible*. Why did I say inanimate? **[chuckles]** I just caught myself and said*, ‘why did I just say inanimate?’*

**Interviewer: [chuckles]** I know what you meant.

**Interviewee:** Thank you. Oh my gosh! So anyway, things that were not edible in his mouth. And so he really doesn't do that anymore, and he doesn't necessarily put as many things in his mouth anyway, even the plants and whatnot, he will rub them a lot. And he will put – this is what I was gonna tell you – when we would walk up to the church, which is about 3/4 of a mile away, and his dad would walk up there as a way to help him get some exercise. And I would drive up and make sure everything was OK. It was also a good way to teach him to cross streets and all those sorts of things. But he would get a wad of just plants and everything, and Tim would have to learn which neighbors were tolerant of George pulling up their plants, and which neighbors were not, so they would have to cross the street as they're walking through the neighborhood.

But when George would get to church and he'd walk in, by this time he's got a wad of plants under his arm, so he can have like his…going in his hands, he's grabbing stuff and then he can put it into this wad that he keeps under his arm. But he would walk in and everybody’d go, **“[makes sniffing noise]** *Ahhh, that smells so wonderful!”* And at the zoo, we would take him to the zoo every week, and the same thing, it was just like this potpourri of smells. And you would find plants that you and I just never paid attention to **[00:21:31 inaudible]**, they might have even been a weed. But the smells were really, really interesting, and he would always have found those, and he would know which plants to get and which not to get.

**Interviewer:** Awesome, thank you.

**Interviewee:** And a lot of times he would only pull up the weeds **[chuckles]** and so people really did like that, *“oh yeah, he can come in my yard and pull my weeds anytime.”* I don't know that he was pulling him because they were weeds, he was pulling them because they had a certain smell that he had decided that he really liked, so he’d look for those weeds.

**Interviewer:** And does he still do that as often as he did when he was younger? Yeah?

**Interviewee:** Yes, yes. I mean, up until the pandemic when we quit, obviously had to quit going places. He was, yes, so up until earlier this year, yes, he was still doing that.

**Interviewer:** And I'm assuming you suspect he would still do it if he had the opportunities to do it?

**Interviewee:** Yeah, and clearly he does it when I go, we do go horseback riding still, and he and he is doing it there.

**Interviewer:** Got you. And then this kind of overall decrease in sensitivity you just described, do you think that's related to any independence that he's gained overtime?

**Interviewee:** I don't think so.

**Interviewer:** OK, that's totally fine.

**Interviewee:** I don't think so. I think it's…no, I don't. I never thought about it, to be frank. To be quite honest, I never thought about that being a contributing factor, but my gut reaction is no.

**Interviewer:** Yeah, it may not be for him, and that's totally fine. And so, how does your son and how do you help him manage and cope with his sensitivities, or handle them?

**Interviewee:** I can tell you one other sensitivity – touch. Here he comes in – less so on smell. He can't *stand* to clean himself if he has a bowel movement. And so, that when you say ‘independence,’ is a real concern because he needs to be able to clean himself in order to be truly independent and to avoid any other horrible side effects, having people having to help you with that. So, he can actually tolerate having feces on him and tolerate the smell and tolerate the feeling of that versus having to touch it himself. And then he would – and it made me think about that, he just came down and he wants to take a shower. That's another thing, as a child, when he was younger – he doesn't do it anymore, but when he was younger, one of the ways he would self-regulate himself if he was having a bad day, is he would just take lots of showers. Showers were very soothing and he understood that they were soothing and relaxing and it would really help calm him down and he would just be…if we hear George in the shower again and he was safe getting in the shower there on his own, and he can regulate the water, hot and cold however he wants, it was really very soothing and he knew that that was sort of a therapy for him.

**Interviewer: [00:24:39]** That's great that he was able to do that for himself.

**Interviewee:** Yeah, but that's also…sometimes we would also when he would get in the shower, we'd say, *“oh, maybe George pooped,”* because he was getting in the shower to help cleanse himself. That was an easier way for him to do it than to actually wanna wipe and touch it himself. So that whole thing of touching poop, really, I think it's a texture thing.

**Interviewer:** That's fair, that's super fair. Thank you for sharing that, thanks for remembering. So in general, so you just talked about showers, which is a great segue, but how does he or how do you help him manage and cope and handle his sensitivities?

**Interviewee:** Well, like I said, just…I don't…well, when it comes to touch and like showers and…some of the things were very comforting to him and so we didn't try to discourage it. There was nothing unsafe about it. It was the hearing that was the sensitivity that we felt like gosh, this is really interfering with life. And even if he's just in the classroom or even therapy, whatever he's in, and you know, you’ve got the lawn maintenance people who show up and they may be across the street, it's really, really bothering him. And you're, you know, he's not getting any benefit out of this. So, you know, we've just…I think that's one reason we tackled that one sort of directly head on, and the putting things in his mouth obviously could be very unsafe, if not unsanitary. There's unbelievable amounts of plants out there I had to teach myself, just like, *“oh my gosh!*” We had our house, we were in Houston, Texas and our house was covered with *all these huge* azaleas. Well, they're poisonous!

**Interviewer:** Oh, I didn't know that.

**Interviewee:** Yes, azaleas are poisonous. The whole Rhododendron family and all these things that you have in your yard that everyone’s…sago palms, poisonous. All these different things that people typically have landscaping in their yard are poisonous. So, we had to rip *all* that. We have no shrubbery around our house. But Hibiscus is not poisonous, so you could have hibiscus. I mean, I've had to sort of learn, learn what you could have and what you couldn't have because it just wasn't safe to let him be outside and then run over and grab azaleas. Antenna is – especially the little green berries, are *very* poisonous. And they may not be poisonous per say, but they make you just really sick to your stomach. So, in any event, I actually took a foraging class to see sort of…’cause in the forging class they would tell you what you could eat and, *“oh, by the way, you should really stay away from this plant, 'cause it is very poisonous.”*

**Interviewer:** No, that makes total sense.

**Interviewee:** So that's kind of what we tried to do, is to…I think in terms of managing it, is just making sure that if we can control the environment, that we are trying to control what he has access to. If it's water, I mean, he loves showers, he also loves swimming. And so, we would take him swimming, Tim used to pick him up in the summer, we don't have a pool, but he would take him to the public pool every day on the way home, and he just *loved* it when the public pool was open. Of-course it was closed this summer, but he would *love* the water, and that was just a really great treat at the end of the day, just to get into the water. And fortunately, at the Y and at the public pool too, they…even though you have turnover of staff, they got to know George. And so, they would know that when he jumped into the deep end, it was perfectly safe, that he can't swim the way you're supposed to swim, you know, which is arm over arm. But he could float, which you could see George just floating in the water, as hyperactive as he was, he would just get in the water and eventually just float, which was very nice. He also taught himself at the Y in *really* cold water at the deep end, and it was like 10 feet deep, that’s very deep. And he figured out that he could lower himself on the ladder to the bottom of the pool and then let go and then just float up. Very peaceful. But if he just jumped in on his own, they knew that he was going to be OK, 'cause he could…he's very strong, he's very coordinated, and he could tread water and could swim. He would swim through the water…I always tell people George can swim, but he swims like a dolphin, which is how little kids…I don't know if you have children, but little kids if you see them in the water, when they first are playing in the water, they kind of dive down and come back up and dive down and come back up. That’s why he still does it, and he's strong enough. If he could swim, he would definitely be able to do the butterfly, because that takes a lot of strength…

**Interviewer: [00:29:42]** Yeah, that’s a hard one.

**Interviewee:** …just up and down, out of the water. He could swim the length of the swimming pool, which was a good 100 yards long, you know, this was like a competitive swimming pool. And he could do that without swimming the way you and I do, and be just driving up and down the whole time, like a dolphin. That would be very hard, and he could be doing that when he was like 9 10 11 years old. So, not now as an adult, but as a young kid. And so, we knew he was…he always was very attracted to water, so I was very keen. Drowning is like the number one cause of death for people on the autism spectrum.

**Interviewer:** Hm, I didn’t know that.

**Interviewee:** I've read that from several different sources over the years. There is a high attraction to water, and so I really did teach him to jump into the water to me, even as a little teeny kid, and then just motor his way back to the side so that he could always get back to the side. I was just intent, I was just obsessed. So, he did and then he just learned the water and he loved it. So that's kind of some of the ways, it’s just understanding what works for him and what doesn't, and then trying to, as best we can, accommodate that in his in his life.

**Interviewer:** Yeah, for sure. Thank you. And you've touched upon some of the therapies that he's received, you talked about OT, you talked about the Auditory Integration Therapy, you talked about ABA. Were there other therapies or services that he received to help him with his sensitivities?

**Interviewee:** The occupational therapy focused very much I think on that, along with some other skills of trying to build block towers and all those kinds of things. But not, I mean, it's just sort of the basic speech, PT, OT, equestrian therapy. He loves being outdoors. And even though it wasn't swimming therapy, but we would take him swimming a lot. No, I mean…we would take…he loved being outside. For years and years we had neighbors who wondered why we even had a house because we spent so much time outdoors with him. And then he kind of just stopped one day as he got older, but he's just spent lots and lots of time outside in our yard. And always bare foot and never, *never* – this is a sensitivity he doesn't have, he's impervious to the weather. So, it doesn't matter to him if it's 90 95 100 degrees, it doesn't matter to him if it's 25 30 35 degrees – which we don't get here very often, but what we do get. So he doesn't really care what the weather is.

**Interviewer: [00:32:43]** Is it that he doesn't care or that he doesn't notice those temperature?

**Interviewee:** He doesn't notice, he's impervious to it, it doesn't faze him in the least. So, there's no for him to say, *“oh, it's cold, I should put on a jacket,”* or anything*.* I mean, it's me just saying, *“no, George, you need to wear a jacket or something.”* But we actually have a family picture that was taken – well at this point, it's been probably six years ago.So, he was about 15, I guess, 14 15. And we had scheduled to go get a picture taken outdoors because again, taking him into a studio just wouldn’t work. But anyway, it's always better just to do anything with him outdoors. We went to the Arboretum and the professional photographer came. It just so happened it was in January, just so happened that it was like an unusually cold day. It literally was like 30 degrees here, and we went out to see him at like 8:00 o'clock in the morning and get our pictures made, and we're like all bundled up and we're just freezing cold. And George is barefoot, I mean, I had him in a jacket, so we're all color coordinating and everything, but he's barefoot. And so, if you look at the picture really closely, he's barefoot and we're all bundled up and he's not at all, and it's very **[00:34:01 inaudible]**. It didn't bother him at all.

**Interviewer:** Are there other bodily senses that don't really register with him? Like if he gets a brute, like bonking into something, will that hurt him? Will he know if he's in pain or something?

**Interviewee:** No, because with his self-injurious behaviors is, he will bite himself really badly on his forearm and just, I mean, it's never bleeding really badly, but it could definitely cut the skin with some bleeding and really be just hard and swollen and bruised. But he will definitely – and this is just something that just has gotten worse and worse, and fortunately, we're in a good phase right now. When he was young, he would hit his head when he was frustrated on the floor or something. He’d really stopped for a long time, and then in the last few years he started doing it again, and I mean it would look just *really* bad, I mean to the point that it was just…there are dents in my car frame where he hits his head – and I have a Volvo – hits his head in the car frame around the doorknob ’cause he didn't want to get in the car. He’s slamming his head into the car, and you're just like, *“you gotta stop, you're gonna kill yourself, this is…you've got to stop,”* when it was really bad. And I'm going to see, I don't know if you can see this, but this was a fairly recent picture. I don't know if you can see that, can you see that at all?

**Interviewer: [00:35:36]** I see some blood, yeah, I do.

**Interviewee:** Yeah, that's him in my backseat. We got to school, and I said, *“this is the morning he's having.”* That’s how hard he kept hitting his head on the doors, on the wall and everything to get him out of the house. Clearly that hurts. You’ve hit your head so many times on blunt surfaces. He didn't hit his head on anything that would have cut it, that's just the slamming it and slamming it. So, that's very bad.

**Interviewer:** Yeah, must be very scary.

**Interviewee:** Heartbreaking. It’s heartbreaking. You just know he's hurting himself, that's causing serious, serious trouble. So anyway, that's…fortunately he's in a good place on that right now. We're not sure why, but that picture is from just probably two months ago. So it's…you can see, does he not feel it? Does he not get the same sense of pain that we get? Does he not under…I mean, clearly, it's a way he shows and expresses his intense frustration and anger, which is better than attacking me or whoever else is there, which is also known to happen. So, it was good to sort of have him deflect from attacking other people, but if you're doing that to yourself, I mean, that is no better. It's just…it's horrible. That, can I explain that? Does that mean that he's getting any satisfaction? Does he not really have a sensitivity, he could actually hurt himself that badly and not feel it? He’s clearly feeling something, and it's not just…because some people, therapists have said, *“well, he's just getting a reaction out of you and you just have to not react.”* So, I'm trying to be very calm as I try to stop him from doing it, but even if I don't react at all, he just keeps doing it.

**Interviewer:** Got you. Well, thank you for sharing that. That must be really challenging and hard to go through.

**Interviewee:** Right, it is. It is.

**Interviewer:** Yeah. Thinking about the therapies he has received, like the OT, the auditory integration therapy, do you think those things helped him with his sensitivities?

**Interviewee:** Yeah, yeah. Yes, definitely. And if we could get him into any other kind of therapies that would help him with his sensitivities, that would be great.

**Interviewer:** And do you attribute those therapies to his decreased sensitivities?

**Interviewee:** Mh-hm, I would, I would.

**Interviewer:** Got you. And then, when your son is in a scenario that has sensory experiences that are aversive to him for whatever reason, does that cause or increase anxiety for him?

**Interviewee:** Oh yes, yes, absolutely. So, he might get very upset, agitated. You could be somewhere and suddenly something like that happens and we're just immediately like, *“abort! We gotta get out of here, like right now. We’ve got to get out of here* right away*, because he is not going to be able to deal with this.”* So, you know, it's…when we go places with him, even when he was young, we had to have a plan and a backup plan. You go somewhere, you gotta have a plan for how you're going to get out of there safely if something does set him off in a bad way.

**Interviewer: [00:39:23]** So, they've always caused anxiety, like negative sensory experiences?

**Interviewee:** Hm-hmm.

**Interviewer:** Got you. And then, thinking more broadly, look more globally, what goals or hopes do you have for your son in terms of his sensory sensitivities?

**Interviewee:** Well, being able to control them, to be able to recognize what is going to cause a problem for him, 'cause we can't always be there to manage these things or prevent them from ever happening. So, if he's ever going to go into a group home or go into any sort of setting where they…it would…for him to be independent and you know, at some point he will have to live without us. Then he's gonna have to be able to self-regulate and understand how to control his own reactions to things, anticipate when something might cause a problem, being able to communicate that to someone that, *“this is really bothering me. I need to leave,”* or something that would help caregivers care for him in a positive way, 'cause you can't always control your environment.

But at one place that he's been on the waitlist of since he was like 5 years old, one of the things we liked about it was that – and it's here and not too far outside of Houston. It's very hard to find places, even day programs that George would be able to tolerate and would be – not just tolerate, would be a positive experience for him. But in these group home settings, there at least it's not just a matter of throwing a bunch of people into the same house all of the same sex, you know, they can have males and females in the same house. But trying to get personality wise, so George would not do well in a house…my easiest example is, if he was put into a house with a bunch of guys who are really rowdy and liked watching sports all the time and are jumping up and down, screaming and yelling and goading would be horrible for George. He would not like that at all, he wouldn't like…he wouldn't be able to read their emotions and their anger and their joy, he wouldn't like all that noise. He would be much better off – even though he's not a musical [person], he'd be much better off in a house of people who are just quiet, by themselves, maybe listen to their own music, but we can’t let it be rock music. I mean, he really likes classical music, I’ve been getting him to listen to opera. So you know, it's just going to have to be the right kind of mix like that.

So, it's not just who you could be friends with, ‘cause George isn't really going to develop friendships with people. He definitely has developed bonds with people, absolutely, and he can be very sweet and affectionate, both to us family members and to caregivers or therapists. But you know, it's a different way of saying that you have to get along with people, people just have…there was actually, when he was horseback riding, there was one woman who he was in a class with her and she just would *screech,* like the whole time, just **[makes screeching noise]** just all the time, and…and my cat just looked at me like **[Rachel laughs]**. And we just said, *“George can't be in this class.”* And so, we actually ended up…he also doesn't like…he's very impatient, he doesn't like stopping and waiting, which when you're taking in a group class, you're taking turns doing things, he hates that. Once the horse stops, he just wants to get off. It's like, it's over! And so, he's been doing private lessons for years now. But part of it was also triggered by this woman in his class who was just…I even found it very difficult to be there, and we’re outside, OK? And I just, you know, it was *really* difficult for me to even bear. So, I was really glad when it was like an excuse to say we just can't be in this class.

And then we just got him in a private class and we just go really early in the morning when no one else is, before they even start their regular group lessons. But that kind of someone in your house that just has a very annoying voice or just one of those screaming constantly or just high-pitched voices, that was just her stimulation and what she did all the time and George will go **[makes screeching noise].** So, he likes that high pitch sound, but it's his own high pitch sound and it's kind of a squeaky…hers was really harsh, just couldn't stand it.

**Interviewer:** Yeah, that's fair, [I] could imagine that being very irritating to hear that a lot.

**Interviewee:** Yes. Oh, just nonstop too…it was just once I…I felt so sorry for her parents.

**Interviewer:** Yeah, probably got used to it, unfortunately.

**Interviewee:** And they are, the same way we are used to some things that I'm sure they shake their head and go, *“oh God, I can't believe…”* you know. She wasn't attacking them the way George might physically attack us. So, we all have bite marks and scars on us from George’s attacks. But that's part of the…that's again, that's what we deal with versus what they're dealing with.

**Interviewer: [00:44:55]** Yeah, every family has their own things.

**Interviewee:** Yes. I will say this, when George always got his therapies, speech, OT, PT, *always* got them at the hospitals, and people would be like, *“well, why don't you just go to clinic? There are lots of good clinics that do this.”* I always prefer – especially here in Houston. At first it was at Memorial Hermann and then it was at Texas Children's, the vast majority of the time was at Texas Children. And I just said I always felt like at a teaching hospital, you're going to be getting people who really are at the top. They're hiring like – my assumption – they’re hiring like the best and the people who were very…I'll call it leading edge, just in touch with whatever’s going on. But also, as a parent, I found it – and when George was young, I was taking him like four days a week to Texas Children's. And either first thing in the morning, like their 8:00 AM therapy so that I could then take him to school, or when he was real little, he was in like 3 and 4, I was taking him. He'd go to just the school in the morning and I'd pick him up at like lunchtime, after he had lunch, and then I'd take him. It was before the 3 o'clock hour when everybody wanted to get their after-school appointments. It was a way of getting him on the schedule. And I found, as a parent, it was very…I could always see other families who had it so much worse, I could see other children who had it worse, and so it was easy…it would help me in dealing with what we were dealing with to see so many other people whose kids had feeding tubes and breathing tubes and wheelchairs, and all of these different things. And George was perfectly healthy, perfectly healthy. And so, I could always see them and realize that it was…we were lucky. And if you go to a clinic you didn't really get that perspective, but the hospital you definitely did.

**Interviewer:** That makes sense, absolutely.

**Interviewee:** We're seeing just some of the sickest kids who were coming there for therapy, week after week. So, that to me, psychologically, really helped.

**Interviewer: [00:47:18]** Yeah, I'm sure. Thank you for sharing that. Shifting gears a little bit, thinking about community, as George has grown up and aged a bit, how has his and your community reacted to his sensory sensitivities?

**Interviewee:** Well, for the…at the YMCA, for example, they knew that he was very sensitive on his hearing and that it could…and it was a…the pool we would go to at the Y was an indoor pool, which helps me 'cause I'm very fair skinned and I didn't want to have to deal with the sun…

**Interviewer:** I understand **[chuckles]**

**Interviewee:** …But it was a wonderful Y that had like these *big* industrial garage doors that would go up that are glass, so you could get a sense that you're outdoors on beautiful days which you have a lot of in Houston. People would say, *“Houston, why are you going to a YMCA that has an indoor pool?”* And it's like well, but one whole side…2 sides of the building or 1 1/2 sides of the building can open up on pretty days and the breeze is blowing in, and you’re swimming laps and you're looking at the sky, it's over there but you can see it. But, even when those doors were open, you know, pools indoors are just loud. And so, then you have the lifeguards who have their music blaring, right. They can’t have headphones on, but they have the music blaring. And my husband was…Tim is a science teacher, so he took like a measuring device in there and reported how this was really unhealthy, high volume for anyone. But for my son, this is really bad, **[chuckles]** it got him in trouble. But they would even see us coming down the hallway, they would lower the volume, not only because Tim got him in trouble, but they also knew it really upset George, and that it was not good for him and he was gonna get agitated, and then we were going to have a real problem on our hands. And we were bringing him there for the water and the therapy, which was so calming for him, and they could crank it back up as soon as we walked back out again. So, I think that's one place that they didn't understand, and most people had no idea, you know, or whatever. So, I think that's just was educational for them and for the staff at the Y to know that this sound level really is too high and it's not safe for anyone's ears. But for our son who had a sensory issue, they became very respectful of that. They literally would see us coming, soon as George would come through the door, they would just turn the volume down.

**Interviewer: [00:50:13]** That's great, they were so accommodating. That's wonderful.

**Interviewee:** Yeah. I think also just neighbors, like I mentioned earlier about letting George you know, who will let him pull their plants up by the roots or rip, tear a branch off or whatever. You have some neighbors who are very tolerant of that sort of thing, and others who aren't, but OK, we don't know all of our neighbors. We've lived here his whole life, but neighbors come and go, and some neighbors are just like, *“no, don't mess with my perfect yard.”* So, I think that's true. And then also, well again, this is pre pandemic, but we have two churches we would go to, both Episcopalian, we started some special needs programs. One is a special needs program, it’s basically like a Sunday School for George so he can go to a safe place while we worship in church, because we just couldn't bring him into church, and we couldn't just…didn't want to just leave him home with the sitter or whatever, and so the church provides this. And it's basically just a safe place for George, and he gets to go in there and watch Thomas and the Magic Railroad and they even got these big like pillowy…it's called like a cloud. It was this big, pillowy thing with foam in it and everything that George could just lie on.

They would have blankets and wrap him up in it, and at one point when he was really little, they got – it was a cool idea and until we got like weevils or something there, but they would buy like these big bags of corn, dried corn and different feeds and things. You get them at feed stores. Dried corn is fed to deer. I don't know if you know much about deer and hunting and all that, so. Not hunting, but dried corn is what they would put out for deer, for example. And you get a big bag of it, I mean it’s *huge!* And they put it in a tub, and George will just get in this tub filled with…you could do beans as well, maybe that's easier to envision. You could do dried beans, right? Could be black beans, it could be brown, any kind of beans, but dried. And he would get in there and just roll all around and just *love* the sensory of rolling around in these…it could have been marbles, but this was a lot cheaper. And so just I think them having the…loving coming up with ideas for what he would enjoy and what might be soothing for him and making it a comforting environment. Always had very low lights, they knew to keep the lights low and the sounds low and that sort of thing, just very accommodating.

And then we also set up…started a program then, it's an offshoot of that, was to have a worship service that families of special needs children and adults could come and worship together. So also again, a very anything goes, take your shoes off, run around barefoot and circle time sitting on the floor. George had a hard time sometimes being in this big room with all these people, so we had piles of blankets and things that he could have his little safe corner. It was not expected that he would come sit in circle time 'cause he just wasn't going to do that, and we weren't trying to teach him to do those things. This was again just a place where if he's in the room he's hearing the story, he’s hearing the music, and if he's comfortable, he'll run around the room. And you could be running all around the room during the story time or whatever, so who cares? You know, this is your place. So, all the kids could be doing that. So, George was not alone in that sense. So anyway, both of those, the service that was the family worship service was the one that we would walk up to. So, we would go to that together, and it was called Rhythms of Grace. So anyway, I think those are examples of how the community has been accommodating, a few are examples of that. As he gets older, I think it became somewhat easier in a sense that people know that he's just not…it's very easy to tell that there's something obviously really wrong here, this is not just a kid who's acting out and having a bad day and a spoiled brat. This is a kid who can't talk and is having emotional issues or sensory issues or whatever.

**Interviewer: [00:55:09]** So, was the community less accepting when he was younger because it was harder to immediately understand?

**Interviewee:** Yeah. I mean there were certainly…yeah, because I think they would judge, they were very judgmental. I mean, we were someplace, we were at Thomas and the Magical Day Out – Day Out with Thomas. And you go in this…they have this big fake train, looks like Thomas the Tank Engine attached to a regular engine. So it's the size of a little engine, but the real engine is like at the back of the train and it's pushing it along, so you can actually ride with Thomas and get in these old railcars and you'd ride.

**Interviewer:** Oh, that's awesome.

**Interviewee:** We did that several years. And more than once, probably three times, in particular, it makes me think of that. You'd have some parent come up and say, *“I bet you regret having him vaccinated, don't you?”* Just a total stranger, you know. *“Are you proud of yourself that you got him vaccinated and now look what happened to him!”* I mean just, you're just dumbfounded that someone could come up and say that to you. And we do believe, we do believe in vaccinations.

**Interviewer:** As do I.

**Interviewee:** You know, that kind of thing. A lot of times though, at the playground in the neighborhood where George is, kids might be really cute and go up to him and say, *“hey, you wanna play? We're playing ball over here.”* And of-course George is like oblivious to what they're trying to do and everything, and so we would just kind of explain to him and, you know, sometimes if the kids just wouldn't understand, we might talk to the parents and let them understand that they could talk to their kid about it. Sometimes kids would come back with something that was really ugly, but generally speaking, no. I mean, generally speaking, I think people would realize there was something wrong here, that he wasn't playing with them and he wasn't responding to them when they come up and say, *“well, don't you want to play with the ball? I'll throw you the ball,”* and he's just like oblivious, and the little kid is having kind of a hard time with that. But I think, you know, you can always just talk to the parents and explain to them, and they’re always really good, and sometimes very apologetic, like, *“oh my gosh!”* You know. One little girl, one day – I’ll never forget, she put her hands on her hips and said, *“well, he's got a mouth, why can't he talk?”* The mother was horrified.And I said, *“well, it's not his mouth, he has a mouth, but there's something wrong with his brain, it's his brain that's keeping him from being able to talk. And you can't see that, but he does have a mouth.”* And so, the parents were just horrified. But that was the only time I can really think of a kid saying something, but she was a little bossy, bossy little girl, so.

**Interviewer: [00:58:12]** I mean at least she wanted to include him, like that's a nice intention.

**Interviewee:** Yeah, right. I was like, *“he can't talk…”* whatever, whatever she wanted to play required talking, but he wasn't gonna participate anyway, you know.

**Interviewer:** Yeah. And then thinking again more broadly and more globally, what hopes or even worries do you have about how his community will continue to react in the future regarding his sensory needs?

**Interviewee:** Well, I mean, it's…as you can imagine you know, restaurants, for example, are always just for whatever reason, they've always decided the louder the restaurant, the better, right? Open pizza kitchens and everything else. So, I mean, *we* would always just go out…we learned when our boys were young, we just had to take them out before the dinner hour, if we wanted to go out to eat – back when we would go out to eat, I mean at pre-pandemic, we had quit going out to eat. But for years we haven't gone out to eat with George. But again, you have to go to a place that's going to understand that it's not loud, people aren't being loud, there aren't too many people talking, all those kinds of things you have to take into consideration. You can’t expect everybody to just…like the YMCA, where they just turn off the music when you come in. I mean, everybody else is there enjoying that, right? So, the places are really loud and that's…sound really is an issue.

We even quit doing the autism walks, Autism Speaks walks, because they always but had these big loud bands and everything playing. And I'm like, *“why are you doing this? Our son is going absolutely nuts!”* We had to leave before the walk began. Why? This is for all people with autism, they tend to have high sensitivities, especially of hearing. So, that kind of thing is just baffling to me, is why does Autism Speaks, my gosh! Don't they understand this? So, we had to quit doing that. I will say though, Tim just reminded me this, we did take George to the theater twice. The theater has been…even the ballet has done this as well – so these sensory sensitive programming, so he didn't really like the ballet, the Houston Ballet, he really wasn't interested in that, but they've had those programs. But even the theater, so I took him to The Lion King, they had The Lion King that was sensory friendly, they had…so that meant the sounds were lower, that meant the lights weren't as bright, that meant they had people…they had a safe area out in the lobby setup where you could have bean bag chairs and different things so that you could go to a safe place, but they still had the sound being piped in and they had it on TV monitors so you could watch it if you were out there with your child, or maybe your kid was more comfortable watching it on the screen or whatever.

So, we were able to do The Lion King with George and we were able to do the Rockettes with George and he really enjoyed those experiences. And then if he was not able to deal with whatever was going on or just needed a break, then we could go out into the lobby and we were able to go through…both those times we went with other families and we were able to stay the whole time with him, so that was really wonderful. And so that's really nice. And when he was when he was really little, I had tickets for the kids programs at the Houston Symphony, and he loved going to those and had…there wasn’t anything sensory related, but you know, it's classical music and it tended not to be like huge Beethoven or anything like that. But in any event, he was always great; as soon as the music would start, he would sit back up in his seat and sit there and listen to it, it was fine. And then when – unfortunately, or fortunately, the kids’ programs they tend to turn and want to talk to the audience and have the kids answer questions and raise their hands. And as far as George was concerned, when the music stopped, it was kind of like the horse, once the music stops or the horse stops walking, I'm done. So, he would be ready to leave, and then the music would start back up again I could bring him back in, but he didn't want to be in there when it was all that talking stuff. But that's a different situation.

But, you know, at least on the sensory issues of people at least trying to realize that there needs to be…the children's museums, the zoo, they're all trying to at least incorporate at least one event or one performance, you know, here and there, not all the time, but here and there that might be better for families with kids with sensitivities to light and sound. They can't really help you too much on the crowds, but they can have more attendants, they can have more ushers and what not to help you out. **[01:03:43]** Oh, and one time they did the same thing at the Astros game, they had sensory nights at the Astros, Houston Astros. And they had a special place for us to be able to go and get a safe room to be in. So, his brother *loves* baseball! So, we were able to do that as a family and Matthew could be out sitting, watching the game and all that. And then George had no interest. But, we could at least be there and could come in and out and they would have things. And then one day he was having a *really* difficult time, it was really loud. And they went out of their way, I mean ushering us with their security guards to get us to the elevator and up the elevator and everything. So, there have been times people really have gone out of their way. But again, it gets harder as George gets older and he's an adult now, and you don't want…you don’t know what could set him off. But anyway, it's all those kinds of things you just kind of worry about in your mind, something could set him off and then they wouldn't know that he's really sensitive, and what he's upset about has nothing to do with what you think it is.

**Interviewer:** Absolutely. Do you wish there were more programming like that for kids like your son, or young adults like your son?

**Interviewee:** Yeah, I mean obviously. And just more awareness of what those issues are and what those sensitivities can then trigger in terms of challenging behaviors, which could be injurious to him or to some or to me or to a total stranger. Yeah. And as he has gotten older and he's bigger than me or Tim, so you know, and he's strong, even…he's just a healthy 21-year-old man. And if he gets out of control, it's harder to prevent there from being something that's a really serious injury. Or just there not being an injury, just spoiling the event for everybody, you know? We don't want to be the one that spoiled the event for some other family, either.

**Interviewer: [01:06:09]** For sure, thank you for sharing that. We're going to our next chunk of questions, if that's OK. Thinking about like the transition to adulthood, where do you see your son in that?

**Interviewee:** Well, I mean he's…I guess, I mean he's making progress. I guess I’d feel a whole lot better if we could find…I'll put it this way – he’s not going to be able to go to an ABA program 30 hours a week for the rest of his life. I mean, there's going to have to be at some point where he ideally can get into some sort of a day program that works for him, and then that location, that facility has a residential component so that he could eventually then begin to live there, and he sort of has grown into that place. That's ideally what you'd like to be able to see, so that one day – as one mother explained to me, she said it was like, *“it was like I went to pick my daughter up and she didn't want to leave, she didn't want to go home, she wanted to stay with her friends,”* and she said*, “I knew then that it was time, we could start that transitioning of having her stay there and live there.”* And we just don't have anything like that, so that's a transition to adulthood that we just don't have. And even though yeah, he's on the waitlist for a place, I don't know that there…people with autism are very different from people with Down Syndrome, they're very different from people with other intellectual disabilities.

Wandering is just a really huge issue, a safety issue, and changes in routine. I mean, a lot of day programs though, one of the big attractions is they do all these day trips and they go to all these different places. That would be absolutely maddening to George. And yet it's just like every day is Christmas Day if you're other people with disabilities. But for George, that change in routine of not knowing everyday where you're going to be going and getting on buses and bands and going places and going to the mall, that would just be horrible for him. So, finding programs that may have worked very, very well for most people with disabilities up to this point, it just [doesn't] work for people on the autism spectrum necessarily. And so, finding those places and then obviously getting him as a spot there is a whole other issue, but even identifying those places, identifying day programs, Tim and I spent almost an entire summer, you know, we were always taking all these trips going to these different programs and trying to scout them out, and we'd come away, go, *“wow, what a really wonderful program! Oh, that's just great, too bad it's not good for George.”*

**Interviewer: [01:09:33]** So, that fit’s what it's sounding like?

**Interviewee:** Yeah, just would be awful for him, you know. So, he just wouldn't like it at all, and so you know. So anyway, there are a lot of good programs out there, but not for George and not for a lot of people on the spectrum. So, that to me is sort of the…when you ask me where he is on that transitioning to adulthood, to me, transitioning to adulthood is really being able to find another place where he could live and have caregivers and whatnot, who are sensitive, understanding what his special needs are and everything. We just haven't found them.

**Interviewer:** And then thinking kind of like at this stage of independence that he's at, are there things he can do independently? And what are some things he needs more support with?

**Interviewee:** Some things he's actually regressed on, and I'm not really sure why, but even something as simple as just getting a drink of water. I mean, he used to be able to just, even when he was young, he would get a cup out of the cabinet and go to the refrigerator door and get ice and water – and all he drinks his water, he won't drink anything else. So, now he just tells me that he wants to drink and I go get it for him. So, I don't know why he is regressed on that, I really don't. So, there are things he could do for himself. We were actually…at the prior clinic he was at for ABA, they were working on some life skills, like doing some simple cooking. **[Speaking to someone else]** Do you wanna get me a glass of water? I'm really parched. Thank you. **[Back to Rachel]** I'm getting like a dry voice from talking so much.

**Interviewer:** Do you wanna pause for a minute to get water?

**Interviewee:** No, he's gonna get me a glass of water, my husband. Snap to it **[Rachel chuckles]** Yeah, you're good at that. **[To Rachel]** So anyway, we were getting him some things like…you could get like a little cup of macaroni and cheese that's like already made. You just basically are sticking it in the microwave, maybe with some water. There's rice you could cook that way, he *loves* rice, so you could just…one of those monochromatic foods that he would be able to cook in a microwave and that kind of thing. But they don't do anything like that where he is now, which is fine. So, there's some things like that that he could do, but I mean, even if he had…I just can't imagine, maybe eventually. He's better off just being able to open the refrigerator door or the pantry door and just get out whatever he needs to eat and it's already cooked or whatever. I mean, to expect him to be able to even cook even something simple by himself without any supervision is just…it's hard to imagine that would really happen.

**Interviewer: [01:12:39]** For sure. Is he able…so you talked about like cleaning up after a bowel movement is hard for him. How is he with other hygiene habits?

**Interviewee:** Not very thorough. I mean, teaching him to brush his teeth has been…he will let you do it, and he knows the steps of putting the toothpaste on the toothbrush and putting it in his mouth. But it's just sort of like brush brush brush done. Really washing himself, no. I mean, if you put the shampoo in his hand and you say, *“wash George,”* and he'll go like that, but it's not going to be all over his hair. It's going to be just like right here. You say, *“wash your body,”* and he'll rub on his chest, and that's kind of it. You know, you really have to say, *“no no, get your back, get your arms.”* You're having to prompt him, he just really doesn't have much interest in doing it. I mean, he'll let you help, but again, that independence would be so much better if he would take a real…I mean, he loves the water and he loves to shower, but he's not nearly getting clean.

**Interviewer:** Got you, that makes sense. And then, do you think he'll be able to achieve more independence in the future?

**Interviewee:** Well, I sure hope so. I mean, he'll never live independently, but…he’ll never live independently, but I do think he can get become more independent at things, at daily living tasks. You know, he will do certain things like carrying the garbage out. He can sweep a little bit, he'll clean up after himself, but again, you have to prompt him. He doesn't really necessarily care, you know, because we say, *“no no, George, you have to clean up,”* then he will do that. Now, he is fastidious about some things. So, in his routines and all, he'll come down here and if there is scissors, he's not…well, I guess we taught him too well when he was young that scissors are dangerous. So, scissors, if there's scissors out, he always puts them in the drawer, and knives always go back in the drawer. So, there's some things like that that he…and he's picking up like, right now, dish towels and putting them in the dirty clothes even though they're not really dirty. They could be…it could be a fresh one you just hung out and he's putting it in the dirty clothes, and you know. He brought down his plate the other day and he had finished eating, so he put it back in the cabinet. So, you might get something out of the cabinet and it's dirty, but you know how it got there, right. So at least he was trying to be helpful, he finished eating and he put his plate back. I mean, he kind of gets it, but he gets it at the wrong things or the wrong time or it doesn't really matter. We do have…are you familiar with those sheathes that you can have on your knives to keep them safe?

**Interviewer: [01:15:52]** Yeah.

**Interviewee:** Yeah, so we have knives. So, our knives are locked up like that. So, you know you're…he's not gonna be able to, he wouldn't be able to open that up, so I don't think so. Anyway, we have our knives. But if he sees that there's a knife lying on the counter, he will put it in the sink or he’ll put it back in the drawer because he knows it shouldn't be out, that knives are not safe, so he’ll put it away. I mean, he does get that that's unsafe, that's nice for to know that he understands that's unsafe.

**Interviewer:** That's really helpful.

**Interviewee:** He also doesn't break things, so that's really nice. I know lots people in this…of all kinds of disabilities who, when they act out and get angry, they are breaking things in the house, breaking other people’s and families’ things. George isn’t one to break things, so that's actually really good. He doesn't go around trying to destroy property. He will put dents in my car by banging his head on it, but he's not…he may put dents in the sheetrock by banging his head on it, but he's not trying to, that's not his goal. The goal is not to destroy objects or…and he's always been very good with our cats. He's never hurt the cats, he's never bothered the cats at all. So, in that sense, that's actually all very good, 'cause that would help him in not…in being able to live and get along with others or being around other people. But you do have to watch that he may throw something away. He will throw something away and it may not really need to be thrown away. I mean, he's thrown my wallet away before, he's thrown away eyeglasses. I mean, he doesn't quite understand what really should be thrown away or not thrown away. If your phone is missing, chances are it's in…check the garbage can because it's probably in there. We keep our garbage can outside, in fact, for that reason.

**Interviewer: [01:17:50]** That makes sense. In any of his programming, have they worked on money skills, like does he understand what money is? No?

**Interviewee:** No. And he really can't count. I mean, we count for him up to 10 or something. But no, he wouldn't understand money at all.

**Interviewer:** Got you. And then thinking about kind of growing into some independence, what do you think will help him move into adulthood – whatever that may look like for him?

**Interviewee:** Well, I mean, I think being able to get out and, you know, post-pandemic being able to get out into the community, to be able to go places. But it's gonna be a *challenge* to get him to go back to places again, it really will be, to get him to go back to church, to get him to go to the zoo, to get him to go to the **[01:18:41 inaudible]**, these places that we haven't been to. I mean, when we first got into lockdown here, he wouldn't even leave his room. I mean, he was…and just kind of picked up that something was unsafe. Just to get him out of the house when we started taking him back to the programs, it was a challenge, he was very afraid to go out. It was like he wasn't sure what was going on out there, but he knew it wasn't safe. It's going to take a while to get him back to where we'll be able to go back to any of these things. And he became very depressed, we've never seen George depressed before. But he wouldn't eat and he would just lie in bed almost all day. And we ended up getting blood work done like twice, and as it turns out, he was having a bad reaction to one of his meds. But the first time we got his blood work done, it was perfectly healthy and everything was fine, even his cholesterol was good, but something was really wrong. And we just said, *“well, I think this is George depressed.”* We’d never seen him depressed before, and he couldn't tell us how he was feeling, but he was just…he put himself in solitary confinement in his room and wouldn't even really eat and just wanted to stay in bed and sleep.

**Interviewer:** Well, I mean, it's fair, it was and still is very scary time, it’s all so unknown.

**Interviewee:** Right, right.

**Interviewer: [01:20:17]** Thanks for sharing that. And now putting these two things together, his transition to adulthood and his sensory sensitivities, how do they intersect for George?

**Interviewee:** Well, that's just going to be with a community understanding his sensitivities and being accommodating of his sensitivities and helping him deal with those sensitivities, you know, keeping noise levels down and not expecting him to eat foods that have textures that are really repulsive to him or allowing him to run around barefoot or whatever it is. Those kinds of things that…all those, they’re just, they don't sound serious, but if you don't address them and you aren't aware of them, it could create a very bad, maybe even dangerous situation where he would just get very very very upset.

**Interviewer:** For sure. And when you say community here are you talking about like future group home or like a residential program, or just like holistic community?

**Interviewee:** Yeah, right. Or even a day program that he's going to or whatever. I mean, we can't expect that he's going to be in a situation forever where it's ABA, where people are used to dealing with people on the autism spectrum all day. There should be a mixture of people just like, you know, and of all kinds of disabilities, and their being as accommodating of him as they are of someone who's in a wheelchair for different reasons. You know, everybody's disabilities are different. But it's easier with those you can see, maybe, I don't know if that's a fair statement. But if you could see that someone is blind, if you could see that someone can't walk, if you see [or] can tell that someone is deaf, maybe you would be more accommodating. With George you just don't see what his – necessarily, what his disabilities and needs are, it's more abstract. And I think, therefore, it's harder. It’s harder for people who are even very sensitive and wanting to be accommodating to even know what they should be accommodating, right?

**Interviewer:** Absolutely. And then, would you say his sensitivities are an obstacle, a vehicle, a bit of both, or neither towards his independence?

**Interviewee:** I would say it's an obstacle.

**Interviewer:** How so?

**Interviewee:** Because it would limit the places that he could go and the environments where he could live or even be in day programs or the people he could even be around, and not just the physical setting but the people he could be around, like the girl at the horseback riding, you know, equestrian therapy who was just so incredibly loud. You know, there's things like that that could make it prohibitive.

**Interviewer: [01:23:22]** For sure. And then, relatedly, what do you anticipate as being challenging for George as he does gain some independence in relation to his sensory sensitivities?

**Interviewee:** The challenges he will face?

**Interviewer:** Yes.

**Interviewee:** Well, he's very impatient. So, I mean, I think he's gonna have to become more tolerant and patient himself, and that everything isn't…I mean, he's in one-on-one ABA therapy, he's basically one-on-one with us here. Anytime he's going to be in an environment where he's having to share time and space and attention, it's not that he's going to be demanding, but it is what he's accustomed to because of his needs being so intense. And now that he has epilepsy, which he did not have until just a couple of years ago, he’d never had a seizure before and then he had **[01:24:28 inaudible]** seizures. So, that's all new, which makes this whole thing even more complicated, sensory aside. Now he's no longer just a healthy person with autism, he's now an otherwise healthy person, but with tonic-clonic seizures that make his care that much more complicated. And even if he felt odd or felt like a seizure was coming on, he couldn't really at this point tell you how or tell you that something's going on, could give you a heads up. I don't know, I've never had seizures to know what that's like, but for some people they can kind of tell maybe something's going on. Almost – I mean it's not a fair analogy, but you know, if you felt like you were gonna faint, you might know that you needed to sit down or get someplace safe. Maybe you might have something like that sensation coming over you before you actually had the seizure onset.

**Interviewer:** Yeah, I think that happens to a lot of folks.

**Interviewee:** Yeah. So, you knew that you needed to at least alert someone or whatever, or at least sit down and be in a safe place. So, all of this just made it that much more complicated, but back to just sort of being patient, I mean, he's gonna have to learn to be more patient and tolerant of kind of what's going on and not just getting what he wants when he needs it – and it's not that we give [him] everything he wants like right away, you know, he just has never been very patient. Even at stoplights, he doesn't like stop lights and stop signs, he just doesn't like traffic.

**Interviewer: [01:26:24]** And this impatience, is that related? Is it kind of like him as an individual, or is that related also to his sensory needs as well?

**Interviewee:** I think it's more of him as individually, to be quite honest. But it may be somehow related to some sensitivities. I don't think so as much, I think that's more his personality, that's something he's going to have to somehow deal with.

**Interviewer:** Totally. And then what do you think might help your son at this intersection of sensory things in this transition?

**Interviewee:** Well, I think some additional therapies to deal with some of these lingering sensitivity problems would be very helpful. And that could be very helpful for him and, yeah, just being able to be out and about and tolerant. To be tolerant, you need to be able to endure things and maybe you need to have some desensitized sensitivities, so that you can tolerate things better, whether it’s sounds or lights or touching or activity levels and…anyway.

**Interviewer:** You said therapy. Is there a particular therapy that you think could be most helpful for him?

**Interviewee:** I think music therapy might be helpful for George, and he actually had gotten approved for that, but that gets us back to having a real difficulty taking him to a new location. And at the time he got approved for that, he was going through a very difficult sort of self-injurious and aggressive behavior phase and it was like, we just we can't put those two together right now, it's not going to work. So, there's always a fear that…and I mean, even with the equestrian therapy which he's been doing for years and years and years at the same place with the same instructor, there have been bad experiences there which she has tolerated very well. But there’ll be days we’ll drive all the way out there, and he's all excited about going. And then we'll get there, and then he won't want to get out of the car. There's some anxiety, and he doesn't want to get out of the car, and I have no idea what the anxiety is and why he won't get out of the car.

And yet he was very excited, got dressed, there are only certain clothes that he wears when he goes horseback riding, so he knows that when he puts those on, he's going horseback riding. No confusing, right? Certain shoes, pants, shirt. And if he gets me those shoes and he wants to go, I'm like, *“nope, we're not going horseback riding, no riding today.”* And so, he's all excited about it and then he gets there and he won't even get out of the car. So, I can't explain why that happens sometimes. Whatever it is that was bothering him or made him change his mind, if he could just sort of…I mean like last time he didn't wanna get out of the car, and finally he did get out of the car, and he had a really good class. So, being able to say, *“OK, this is kind of bothering me a little bit maybe, but I'll give it a try,”* would be a whole lot better, if he would be willing to just give it a try.

**[01:29:56]** 'Cause you know, if he wants to go…I mean, what we've always had to learn is he is nonverbal, like it or not, if he does tell you that he wants to leave or he wants something to stop, you need to listen to that, because you want him to know that when he communicates, it gets him what he wants, because he does have a problem with even understanding the power of communicating, right? So, if he wants to leave, then we'll, then we'll leave. So, when he has indicated on the horse that he's all done, ‘I'm all done, I wanna go,’ then we'll just cut the class short and we’ll be OK. ‘Thanks for telling me George, I appreciate your telling me that. That's really important that you tell us when you are done and you want to go.’

**Interviewer:** Absolutely, absolutely. Do you feel like there are gaps in the available services or interventions for individuals like your son?

**Interviewee:** Oh yeah, oh yeah. Just the fact that there aren't these kinds of therapies and they aren't readily available, or that there aren't day programs for people like George and there aren't…we don't always want to just be doing different field trips to different malls and bowling and movies and…oh my gosh! Things that just wouldn't work. And even residential facilities, there's just not for…and then also just on a medical front, I mean…excuse me.

**Interviewer:** No, it's OK.

**Interviewee:** Moving into the adult world for medical care is like falling off a cliff. When you go to Pediatrics, there are people…for anyone with special needs, not just autism, anyone with any kind of disability. There are more pediatricians who are focused on certain things and interventions and treatments, therapies, surgeries, whatever. But once you age out of that world, it's like you just dropped, you just landed on a new planet. There just aren't resources, there aren't medical facilities, you know. We've been very fortunate that George is at the Baylor Transition Medicine Clinic, and through that we've been able to access some other specialists like their sleep clinic and whatnot. But again, that's called transition medicine because it's supposed to be transitioning you from Pediatric specialized care to adult medical care. And you really just have to find that very special doctor who's willing to spend a little extra time with you and takes special care and you know, willing to spend more time and effort with you and your special needs when they are trying to run through as many patients as they can every day. If the medical community can't even adequately, I mean, there's nowhere close to adequately, just, it's abysmal! If the medical community can't address the needs of people with disabilities and special needs, then it's pretty hard to imagine the rest of society will. It's a sad statement, but I mean, those are the people that we…and here we are in Houston, TX, one of the biggest medical centers, if not the biggest in the world? One of the best! We're not in some podunk town in Texas, or we're not in Iowa or not in Nebraska, or North Dakota, you know, we're not out in some whatever. We're in Houston, TX!

**Interviewer: [01:34:07]** Yeah, you’re in a place with access and it's still hard.

**Interviewee:** And they just don't exist. You know, it's very very…and George was actually first denied the Transition Medicine Clinic when we tried to get him in, he was denied because he didn't have the complicating medical needs. It wasn't until he had his **[01:34:30 inaudible]** seizures that I re-applied and he got in. His epilepsy ended up getting him in there, but had he just been a healthy, severely disabled kid like he had grown up being, he wouldn't have ever gotten in.

**Interviewer:** Interesting. Well, I'm sorry you…

**Interviewee:** I went back and I said, *“this is my son’s situation now,”* and the guy said, *“oh maybe we can get you in now.”*

**Interviewer:** I'm sorry he has seizures, but I'm glad he's able to get this help now **[both laughing].**

**Interviewee:** There was something…there's a silver lining to that, but I mean, you know, that's just really sad. But that's just the world, that's just the reality.

**Interviewer:** Absolutely, thank you for sharing that. We're almost at the end, sorry this is going on a little bit longer. Thinking again broadly, how have your son’s sensory sensitivities, how have they impacted your goals, hopes and expectations for him as he is navigating adulthood?

**Interviewee:** Well, I just think it has really shaped what kind of environments we can find for him that would be appropriate for him and where he would be happy and you know, in his…where he would be happy. He would feel comfortable, he would be happy, he would know that he's accepted, and it's put real limitations on those kinds of places that are open and that are appropriate for him. I mean, *they* are happy when [they] meet us and whatnot, just not **[01:36:24 inaudible]**. But we know that it's just not going to work for him, which also tells us that they don't know that much about autism if they don't know that that's not going to work. So, right program, again, a great program for someone with Down Syndrome or someone with Cerebral Palsy, but not necessarily someone like George.

**Interviewer:** Yeah, someone with different needs.

**Interviewee:** Someone with totally different needs. And those are the people whose needs have been the focus of providing those services, and thank God. But, you know, now you've got a different group. And in the state of Texas, just to be honest, I mean, the state of Texas doesn't do anything for the citizens, it's pitiful. I mean, I put George on the waitlist when he was 5 years old for services and they're just coming through.

**Interviewer: [01:37:22]** Good thing you did it when he was 5 though.

**Interviewee:** Yeah. When he got his autism diagnosis at Texas Children's Hospital and we'd already gotten it through the school district, 'cause he started in the preschool for PPCD program, the Pre-school Program for Children with Disabilities here, at age 3, and that was the first step, going through Texas Children. Once I had those documents, I then went to Harris County and had him evaluated there and they determined that he had autism and intellectual disabilities, and they put him on a waitlist. And I said, *“how long will it be for services?”* And they said, *“oh at least 12 years.”*

**Interviewer:** Whoa, that’s a long time.

**Interviewee:** We actually have a meeting tomorrow. He has now just been approved for home and community services and we're having our first meeting tomorrow, phone call with the Harris Center, which is Harris County's program for people with mental health and intellectual disabilities, to go over what those program options are. He's 21!

**Interviewer:** Wow, and you did it when he was 5. Well, it is good that you are that forward thinking then to figure out he's gonna need these things.

**Interviewee:** I mean, worst case, we don't want to rely on anything related to the government, you know. But, on the other hand, you gotta have options, right? So, you always…you gotta have a plan, have a backup plan. And when you have a special needs child, you always…as a parent, you have a plan and then you should really have a backup plan. But when you have special needs children, have a backup plan for the backup plan. And so, this is the backup plan for the backup plan. So, you know, we're not going to put him in some state group home, but in any event, it's just really sad that there's just not any awareness by the government here, that anything needs to be done, you know.

**Interviewer:** Yeah, it's hard. I'm sorry. We’re gonna move on to our last chunk of questions. We're almost done, sorry this is taking longer. You’ve sort of answered this already. So, finally, as a caregiver, as a parent, as a mom of someone with autism and also some sensory sensitivities, what does transitioning to adulthood mean to you specifically?

**Interviewee:** Well, I think just being as independent as possible. Being able to care for himself, especially in terms of grooming and dressing, it doesn't have to be meal preparation, but grooming and dressing and where his physical body is taken care of. And being able…and being happy, you know, around people and in a program that is supportive and accepting of him for who he is.

**Interviewer: [01:40:24]** Absolutely. And has this perspective changed overtime?

**Interviewee:** Has his perspective changed?

**Interviewer:** Has your perspective.

**Interviewee:** I don’t really think so, no. When George was really little, probably 5 years old, I think, we decided we were never gonna retire, we were gonna continue working to bring in money to support him. And that long term care insurance for ourselves, so we could try to stretch what we have and you know, began just totally planning differently. We just knew we were…we didn't know what was ahead, but we knew it was going to be a long road. And you know, when you tell people that we have to care for our son for the rest of *his* life, he's 21. I can't even…we're not worth $10,000,000. So, you know, **[responding to Tim]** not yet. **[To Rachel]** You know, unless you're worth $10,000,000, literally $10,000,000, it could cost $100,000 a year, I don't know what it's gonna cost. What's it gonna cost? I don't know. And we don't want that to be a burden on…the one reason for the long-term care insurance was because his older brother, who's like 2 1/2 years older, we figured OK, so you've got a younger brother who is disabled going into adulthood, your parents are now elderly. I was 43 when I had George, so I'm 64, Tim’s 65. So, when Matthew gets to be in his 40s and he's getting into his peak of his career and he's got a family, children, now he's got two elderly parents and a disabled brother. How do we lessen his burden? Those are the hard conversations that we had. So, I don't think in that sense our expectations or goals have really changed. I think we've been pretty brutally honest with ourselves. I wish I had $10,000,000, that would make it easier, but – I’d even take 5!

**Interviewer: [Laughing]** Well, I hope you win the lottery.

**Interviewee:** Thank you. I’ve gotta buy a ticket, I've never bought a lottery ticket, but.

**Interviewer:** It could be an early Christmas present.

**Interviewee:** You never know. And so, I don't think our expectations or anything have really changed. I think we've been pretty brutally honest for a long time.

**Interviewer:** That makes sense. It probably helps with planning, to be honest though. What do you see in your son's future?

**Interviewee:** Well, we have to remain optimistic. We have to remain optimistic that his seizures will get under control and it will be…he'll go years without ever having seizures again. We have to be optimistic that with the growing awareness of autism and what that means. They're not all brilliant people on the…who are like…they're not all Bill Gates or you know, if Bill Gates really is even autistic, I have no idea, but you know, that's what people would like to think, *“oh well, you're autistic, then you're a genius!”* So maybe you are, maybe that's Georgia's whole thing. But you know, the world is becoming more aware of autism and what their special needs are, and programs are being available, whether it's through the theater or the ballet or the Houston Astros or whatever. So, I mean, as all that awareness keeps growing and growing, that helps, that's all very encouraging. I don't think we as a society will regress from that, we’ve still got a long ways to go. And then hopefully the medical community will also be able to move forward and make progress for dealing with adults as well as children with disabilities.

**Interviewer: [01:44:29]** And do you see him being in a group home eventually?

**Interviewee:** Yeah, although I feel…yeah, all of these tiny houses are appealing, so you know, you never know. But that would have to be, again, that has to be where his brother…what's gonna work really best for his brother who doesn't even live here, he lives in Pennsylvania. So, where does he end up and what's going to be the best situation? Even if he was in a tiny house, I mean, he would still have to have some kind of supervision, but you know, with cameras and devices and everything else. And now, I've got a device that he sleeps with that he wears on his wrist to alert if he was having a seizure in his sleep, which is a new device that I really didn't think he would wear. He actually is very good about wearing it.

**Interviewer:** That's wonderful. That must reduce some stress.

**Interviewee:** It does, it does. And it would send off an alarm on my phone. Any caregiver would know, and having a ring camera, we have a ring camera in his room. So, although I'm not doing it now, I could have been watching him in his room, which is where he is. I could've been watching to make sure he's OK and he's safe. So, all that technology really really will help in terms of his being able to be watched and monitored without having to have someone sit in the room with him, which he really hates. He likes to be by himself. He'd rather just be in his room by himself, and he doesn't want somebody sitting there with him. But you could be watching him on a monitor. He used to be able to tolerate that, but as he's gotten older, maybe that's an adult thing. He doesn't want people in the room, he just wants to be alone.

**Interviewer:** I like to be alone. I think that's pretty typical; you know.

**Interviewee:** And that's what his brother would sometimes say, *“well, Mom, what do you expect?”* I mean, either he's a teenager or, *“mom, what do you expect? I mean, he's like 21. You want somebody else sitting in your room with you when you're 21? I don't want anybody sitting here watching me.”* And even if you’re just sitting there reading a book, he doesn't really necessarily want it, I wanna be alone.

**Interviewer:** Absolutely.And then last formal final question. You just…this perspective you’ve articulated in terms of like what does it mean for your son to transition, how have his sensory sensitivities impacted that perspective?

**Interviewee:** Well, I would say very very dramatically, because you can't expect those sensitivities to just go away. They can certainly be better managed, they can certainly become lessened, less severe, but there has to be an attention to that in order for him to be able to be happy and being in an environment where he feels like he is respected and can be happy.

**Interviewer:** Yeah, absolutely, thank you. This has been wonderful. Would you like to add anything? That was my last formal question.

**Interviewee:** Oh gosh, I think I've talked so much. You’ve probably never had a conversation go on this long. But anyway, I apologize if I just rambled on.

**Interviewer: [01:47:39]** No, no, this was *amazing*. This was so valuable, so helpful. I've learned so much, don't apologize. Thank you for keeping on talking for so long.

**Interviewee:** Well, you know, I went through those questionnaires. It was like, oh my gosh, some of this **[01:47:51 inaudible]** stuff up or whatever. But anyway, it just makes you…and I'm gonna have to look up that auditory integration training and send you something on it, that was actually very good.

**Interviewer:** I would love to learn about that, sounds amazing. I'm so glad it was helpful for your family.

**Interviewee:** Yeah, it really was. So, you know, you just, and again, you just sort of try some things. I mean once when I was up in Connecticut doing that and a client of mine called and I told him where I was and I said, look, you know, *“I'm not down in Mexico having my son injected with like* **[01:48:26 inaudible]** *and stuff like that.”* You know, it's like, there are people doing all kinds of things that they think are gonna cure autism and I said, “*I'm up here, my son is wearing headphones and he's listening to some music*.” Worst case, we wasted our money and our time being up here for two weeks, but.

**Interviewer:** If that's the worst thing you wasted, that's…

**Interviewee:** That’s the worst. I'm not having him injected with whatever, you know. So, we will never do something like that. But anyway, the only thing he's injected with are his vaccinations.

**Interviewer:** As he should be, as we all should be. Do you know anyone else who might want to participate? We're still looking for some families. It's OK if you don't, I ask everyone.

**Interviewee:** Wow. **[Talking to Tim]** You know, an interesting family, Tim, would be the families with the triplets. She asked if there are any other families that might want to participate with this, like with disabilities and sensory. **[To Rachel]** Yeah, there's a family here that we know through this church service, this family service. Of-course we haven't seen them now since February, but they're both professors at the University of Houston, and they have triplets with special needs of varying degree, two boys and a girl. One boy has been mainstreamed, but definitely has some issues. I mean, **[01:49:58 inaudible]**, jumping up and down and whatnot. And then they can…they're all verbal, although the one who's the most severe is less so. But I mean he wraps up in blankets and his massage. There are a lot of sensory issues for all three of them. They’re ones that come to mind, and I think the parents would be very…they’re…**[to Tim]** Where are they from, Chile? Ecuador? **[To Rachel]** Ecuador, they’re from South America. I mean they've lived here in United States for quite some time anyway. But anyway, they’re South American, they speak with this little bit more thick [accent], it's relatively thick, but in any event, they’re **[01:50:53 inaudible]** professors, so.

**Interviewer:** Would it be OK if I contacted them? Do you think would you be able to send my information? Like what would be the best way to like at least…?

**Interviewee:** I could just reach out to them and tell him I've done this and see if they would have any interest in doing it. And if so, I would be happy to share their information with you, or would they prefer that you reach out to them and then I could just reconnect with you?

**Interviewer:** Yeah, that would be wonderful.

**Interviewee:** Yeah, I would be happy to do that. They're the ones who come to my mind from this. You know, the problem now is that there are other parents that I know from the clinic George goes to, but to be honest you just kind of wave and you say hello, but we never get out of our cars anymore and I don't even see some of the parents anymore. So, you know, I never really exchanged email information with them, whereas this other church group, we do have exchanged info. So, they’re the only ones I can think of I think that would be the best.

**Interviewer:** That would be wonderful. Would you like me to send you our flyer? Would that be helpful for you?

**Interviewee:** Yeah, that would be helpful. I could just send that to them and see if they have any interest and tell them what I did and it's…yeah.

**Interviewer:** And there's no pressure. If they say they don't have time, they don't want to, it's super OK, doesn't matter.

**Interviewee:** Yeah.

**Interviewer:** So, thank you so much, this has been wonderful. As soon as this audio renders, I will send you a final thank you email, it will include a gift card as compensation for all of your time. Small question for you, you said you have that meeting tomorrow. Would you like copies of the reports that you completed? Would that be helpful for the meeting tomorrow?

**Interviewee:** No, I don't think so. They’re just gonna be telling us what the programs are that are available, so it's gonna be for us to get educated on what's out there and then we can just sit down and decide what is available. But for example, we did just also get approved in November for the first time for respite. Respite, 16 years waiting for respite. But we finally got that and it's like a *freaking pandemic*, I don't want anybody come into my house, you know? So, we found someone through care.com, and she's coming here, and we really like her a lot. But we're having her come just…and we were approved for 24 hours a month, but they said you have to use at least one hour a month not to lose it. So, it's like fine. So she just comes to our house and she washes her hands, she wears a mask and she sits here and we're just letting her go into George's room, him get to know her, she leaves. And I just said we'll just use this as a time to sort of build a little bit of a relationship so he can become comfortable with her. And then you know, we’ll worry about where this goes from here, but at least we finally have gotten some respite. But I didn't want to turn it down, even though we literally don't have anyone coming into our home, we don't even have anyone coming to clean or anything, we don't want anybody coming in our home.

**Interviewer:** Yeah, no one is in our home either.

**Interviewee:** So, you know, it's like OK, we got respite, great. Now when we can't go out, we get respite. But that's OK. So, that's how we're sort of using that. So, there may be something here where we have to take advantage of it so we don't lose it, or else we'll go back on the waitlist, which will now be 20 years. So, you know, I don’t want George to be 40 years old when he finally gets some services. So, we have to find a way to use the services, I just don't even know what they really are, so.

**Interviewer:** Well, I hope it's a helpful meeting for you.

**Interviewee:** I hope so, I hope so. Anyway, so I don't think what we have done would be helpful because it's really for us to learn about the services that are available.

**Interviewer:** Understood. I figured I'd offer, if it could help you, I’d want to try.

**Interviewee:** It’s a good idea. **[Crosstalk]** I mean, just the final report just to know how the study has gone and if you got any…when you eventually do wrap this up if there's…I think I checked the box. I'd like to see the results.

**Interviewer:** Yes, we’ll definitely do that.

**Interviewee:** Just to see, learning something, you know, you never know.

**Interviewer:** Yeah, absolutely. I submitted an abstract to a conference with some preliminary data, so if that gets accepted, I will send the poster around to you as well, and then later down the line when we do have a formal report, you will also receive that, eventually, whenever it happens.

**Interviewee:** OK.

**Interviewer:** Do you have any final questions for me? Anything I can do for you?

**Interviewee:** No, that's all **[chuckles]**. It’s been good, I've enjoyed it, thank you very much.

**Interviewer:** Oh, thank you. I've enjoyed it too, I appreciate you making time during a busy time of year and just this has been great. Thank you.

**Interviewee:** OK, thank you very much and you take care and have a happy holiday.

**Interviewer:** You too, happy holidays. Talk to you soon.

**Interviewee:** Bye.

**Interviewer:** Bye.

**[END OF TRANSCRIPT]**