**[Start of transcript]**

**Interviewer:** We’re recording. And I will be asking you questions about your perspective about your child's transition in regard to her sensory sensitivities and interests, in relation to her transition to adulthood. And I’ll be doing something called a semi-structured interview, which means I have my planned questions, but I'll also be adopting my questions to follow our conversation based upon what you say, so it actually makes sense for you.

**Interviewee:** Sure

**Interviewer:** Do you have any questions before **[crosstalk]?**

**Interviewee:** No.

**Interviewer:** Okay, yeah. And if there are any questions you don't want to answer or they make you uncomfortable, that's okay, you don't have to do that.

**Interviewee:** I'm not shy, I'll tell you.

**Interviewer:** Okay, cool. Just…you know, you want to make sure that no one gets uncomfortable, that's not the point of this. So could you please start off by telling me about your child's sensory sensitivities and interests?

**Interviewee:** So, her sensory – she used to be actually really severe, but she used to have a…like auditory, loud noises, vacuum cleaners and things like that. We did do a…auditory therapy, which really helped a lot.

**Interviewer:** Yeah.

**Interviewee:** But every once in a while, she still blocks the ears, but it's…now with therapy, it's gotten to the point where it's not really aversive. And then, **s**he does have some physical touch sensory issues. So sometimes she doesn't like if you touch her back. She has some eczema on her and some of it is right at the base of her neck. If I get in there really good with the psoriasis shampoo, she kind of cringes a little bit, so she doesn't like that. But her sensory issues have never really been, I would say, you know, one of her biggest challenges or one of her biggest issues.

**Interviewer:** In regards to her sensitivity to touch, is that like light touch? Is that deep touch?

**Interviewee:** It's both. I mean, she doesn't even like if I just, you know.

**Interviewer:** Yeah, absolutely!

**Interviewee:** Just touch her back. So yeah, I mean she doesn't like the light touch, so she definitely is not going to like the deep touch.

**Interviewer:** And then **[02:22 crosstalk].**

**Interviewee:** I think it's just the upper body, because she does have some motor planning issues, even physically motor. And I used to take her to a craniosacral therapist who also did massage and we tried to work that hip area and she’d manipulate her and she loved it!

**Interviewer:** Oh! Okay.

**Interviewee:** **[02:46 inaudible]** from the waist down though. So, you know, I think it's the back and the neck and the head is…that’s, you know, sensitive for her. I mean we all haveour own sensitive areas, but **[trails off]**

**Interviewer:** Totally!

**Interviewee:** And then her interests, she is definitely a mama's girl, ‘cause she loves music. So that's her biggest interest, it is music. Really just listening to it, and she kind of likes to bebop to it. I wouldn't call it dancing but close, you know, as close as she can.

**Interviewer:** Yeah.

**Interviewee:** And she loves reading, she's actually self-taught read since she was **[03:20 inaudible].**

**Interviewer:** Mm, that’s great.

**Interviewee:** And she loves doing puzzles, and she loves taking walks out in nature. So, I would say those are her most **[03:34 inaudible].**

**Interviewer:** And then, thinking about her auditory sensitivities, so you said they were more severe when she was younger. What did they look like when she was younger and what do they look like now?

**Interviewee:** So when they were younger…when she was younger, it was a full-fledged, you know, hands like cringing kind of thing. And now she'll just do one…sometimes she'll just put one finger in one side. She would never get really like upset or frustrated and run away. She would just block it, as opposed to having, you know, a reaction to run away, or have a meltdown afterwards or something like that.

**Interviewer:** And what about her sensitivity to touch, has that always been present for her?

**Interviewee:** I think the older that she is, the worse it's gotten. I don't remember her being like that when she was younger. It's almost like it's…I think it started when, you know, the period started and the whole hormones, so it could have something to do with that.

**Interviewer:** Yeah, and then music, what type of music does she like?

**Interviewee:** Well so, you know, I mean she's so…she really has a lot of different areas…I mean, you know musicians that she likes. I mean, she's 17, but she still listens to The Wiggles and the Doodlebops. And she loves Signing Time because, you know, they had that huge series of DVDs where they teach you signing. And…but it's all songs, so she loves those songs. But she listens to modern music. Her three favorites are Celine Dion, Prince and Fleetwood Mac. So she's definitely mama’s girl **[Both laughing].** But you know, she's so funny because one minute she's listening to Prince and the next minute she's like, you know, listening to Twinkle-Twinkle Little Star or The Wheels on the Bus, so. I don't think she cares, I think she just…she really loves that Rhythm. But she gets down my little girl, she does!

**Interviewer:** And does she use music to help block out sounds that she dislikes?

**Interviewee:** No.

**Interviewer:** **[05:49]** No? Mm-hmm. And then in terms of other ways that she manages and copes with it. How does how does she manage and cope with her sensitivities?

**Interviewee:** Well again, I mean I think, for a loud thing, it's really just putting that finger in the ear. As far as the touch, you know, she doesn't really have the…I would say unfortunately doesn't have the cognitive ability yet to say, you know, “*Mama don't touch!”*, you know, “*that hurts!”* Or something like that, you know. And we're working on those kinds of things but you know, her having reactions coupled with her language processing is you know, I mean I…we’re trying everything that we possibly…I literally am looking at a stack of books on the floor, I just got to… **[06:35 inaudible].**

**Interviewer:** Yeah.

**Interviewee:** …that's language processing books. They came in and I'm getting ready to go through them, so yeah. So, I mean we're working on that, but she really just kind of, you know, shrugs a little bit like*, “okay don't do that!”*

**Interviewer:** Absolutely. And then you touched upon a therapy that she received to help her. Can you talk a little bit more about the therapies and interventions that she's received? In regard to her sensory sensitivity **[07:00 crosstalk].**

**Interviewee:** For the auditory or **[07:01 Crosstalk].**

**Interviewer:** Yes, auditory and touch.

**Interviewee:** So, there's a program in Beverly Mass called Project Child. And it’s kind of a listening program, auditory therapy, and we did it for three to...somewhere between three and four months, and it was like four days a week, and you went in for like two hours. And you had these headphones on, and the OT worked with you, and you did all of these movements, real, you know, real big gross motor kind of movements while you had these headphones on. And you know, sometimes therapy works, sometimes it doesn't and, you know…as Buddha is my witness.

**Interviewer:** Yeah, it helped her?

**Interviewee:** I'm telling you she walked out of that program in four months, and she…I took her to the beach, and she was standing at the ocean, hands down everything.

**Interviewer:** That’s awesome!

**Interviewee:** Before she would walk to the ocean like this, and she would stay like that the whole time. And she went and it didn't…it was gone, it was literally gone overnight, it was gone overnight!

**Interviewer:** That’s awesome!

**Interviewee:** Yeah, so **[trails off]**

**Interviewer:** That’s really great. And when was this?

**Interviewee:** Five years now.

**Interviewer:** Okay. So, like 12-ish?

**Interviewee:** Yeah.

**Interviewer:** Mm-hmm. And kind of thinking a bit about independence that she's gained as she has become a little bit older. Do you think any of that independence has caused changes in her sensitivities, or is related to any sensitivity changes?

**Interviewee:** I mean, I think everything is relative. I think, you know, when you have progress in one area, you're going to have it in something else. And you know, I mean independence, perfect example **[09:00],** who wants to bake and cook and use a mixer if you have to go like this the whole time, right? So now, you know, she can work the…she can make herself a smoothie, she can, you know. So yeah, I mean, I would say that they are, you know, directly related.

**Interviewer:** Yeah, absolutely! It’s pretty cool that she can do that now. And then, do her sensitivities cause or increase anxiety for her?

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

**Interviewer:** No? Why not?

**Interviewee:** She's not an anxious…I think if she gets anxious about anything, it's language.

**Interviewer:** Mm, okay.

**Interviewee:** You know, because she just doesn't have any kinds of ways to, you know, really get across what she's feeling, and that might be frustrating to her. Or we might say something to her that she doesn't understand, so that might be frustrating.

**Interviewer:** Mm-hmm.

**Interviewee:** As far as her sensory issues now, I mean, they really don't affect her that much anymore these days, you know.

**Interviewer:** But they did affect her more when she was younger?

**Interviewee:** Yeah, definitely.

**Interviewer:** Can you provide an example of how they really did affect her before, but less so now?

**Interviewee:** Well, I mean again, if you're in a house, if you're anywhere, and you're in the middle of doing something…when she was going to school, anytime that there was a bell, she could be outside in the playground having a good old time, and that bell…recess bell rang, and then that was it. And she sometimes would…not go paralyzed, but I mean, she froze because, you know. So, then you know, what happens if you're climbing up a ladder to go down a slide and all of a sudden you have that and now you let go. I mean, you know.

**Interviewer:** Mm-hmm.

**Interviewee:** She’s had…she had several incidences like that where, you know, an unexpected noise or even a truck going down the street, and you just stop what you're doing, and you know. If a child is swinging and you were getting ready to run in front, but then you stopped because you had to do this, you know, you're going to get hit. So it's those kinds of things.

**Interviewer:** And, so it was mostly loud noises that would really bother her?

**Interviewee:** Yeah, definitely.

**Interviewer:** **[11:29]** And so you mentioned that she doesn't have a lot of anxiety in regard to this. Was…is that constant? Has she never had anxiety related to sensory sensitivities?

**Interviewee:** No, I don't think she ever has. Again, I think her…any kind of anxiety or frustration that she has, has to do with language.

**Interviewer:** Yeah, absolutely. No that makes sense for sure. And so, what are your goals or hopes for her in regard to her sensory sensitivities at this point in time?

**Interviewee:** Well, I would like her to be able to articulate to us, you know, what she's actually feeling. And so the goal, I would say, would probably be more body awareness and being…to be able to express and articulate exactly what's going on when she's feeling something. Of course, you know, the other half of that argument is, has she always had these things, and really feels like it’s just part of her? I mean, if you’ve always had numbness in this hand since you were born…

**Interviewer:** Yeah, how do you know?

**Interviewee:** …how do you know that that's not what you're supposed to feel like? So…and of course, when you don't have the language, I mean, how do you teach a child what hurts and what doesn’t? I mean in order to say, “*oh yeah, this hurts!*” you have to hurt her. Who's going to do that? You know what I mean? So, there are a lot of challenges to this, you know. How do you describe what numbness feels like? How do…you know, you might be able to…like sometimes she has an itch on her back and she'll come over and say, *“mama scratch my itch.”* Okay, so she gets what that feels like, but what does it feel like to her? Does it feel like what it feels like to you? You know what I mean? So it's very difficult when you don't have the cognitive ability to be able to articulate exactly what's going on in your body.

**Interviewer:** Mm-hmm, absolutely.

**Interviewee:** And I think that's the biggest challenge really, is to get her to really acknowledge and to articulate what she's feeling.

**Interviewer:** And does she have trouble, like communicating in some way that she's hurting internally or something?

**Interviewee:** Absolutely! She could be…I know this is going to sound horrible, but I mean she could be in bleeding internally, she could be having horrible stomach pains. Unless she actually physically shows me, you know, like I can see it on her face, I would have no idea.

**Interviewer:** Got you.

**Interviewee:** I know, it's been our biggest challenge.

**Interviewer:** Yeah, I'm sure, absolutely! And then shifting gears slightly onto to our next set of questions. As she's grown up a bit and aged, how has your community reacted to her sensory sensitivities?

**Interviewee:** She doesn't go out in the community, really at all.

**Interviewer:** Has it always been the case?

**Interviewee:** Except when she was in school. I mean we go out, but I wouldn't say that…I mean she doesn't have friends. And I would say in most cases when we are out in the community, in the sense of going to the grocery store, and you know, if she does this once…I mean you can get…when you look at her, you can tell that she has challenges; people stare at her or they kind of look at her with wide eyes, like*, “God! I can't talk to her she…”* you know **[15:16 inaudible]** very bad reaction. So, I…we don't go out much.

**Interviewer:** Yeah.

**Interviewee:** No, well, it's not, I'm not the only one. I think a lot of people that have children with a disability…I mean, *I* don't care, people don't bother me, I never let anyone bother me, I could care less. I mean, if they knew her like I know her, they wouldn't feel that way. But a lot of people are intimidated, and they let you know that.

**Interviewer:** Intimated, how so?

**Interviewee:** Well, you and I are having a very nice conversation, you're a very lovely person, you're very easy to talk to.

**Interviewer:** Thank you.

**Interviewee:** When that's not…you're welcome. When that's not the case, how do you talk to someone who can't talk? Or can't have a conversation? Some people don't have enough confidence in themselves and their reactions are… **[16:08 crosstalk]**

**Interviewer:** Got you!

**Interviewee:** …you know, *“I feel intimidated.”* I have a brother who is 17 years older than me, so he's you know, 70. He used to be a principal for our junior high school, and he told me he was intimidated when he's around her. So I mean, you know. It's hard. It's…some people just don't deal very well with disability. Other people will come up to her and go, *“hey, what's up?”* And if she doesn't say anything they’ll go, “*cool, how's it going today?”* And if she doesn't, you know respond they’re like, “*whatever*,” you know, so some people get it. I have to say, I tend to hang around with…in fact I'm going down to The Cape this weekend, and to my best friend who has a son same age with autism. So, you know, I think we kind of tend to stay with people that are in the same situation, so they understand, you know.

**Interviewer:** Absolutely! And was the community more or less accepting when she was younger?

**Interviewee:** No. Again, we didn't…we didn't really go out very much. I mean, you know, what are we going to do? Take her outside walking down Main Street with all the cars and all the…you know what I mean? So unfortunately, because of her set of circumstances, she…you know, it was hard to bring her out in the community.

**Interviewer:** Yeah, and this seems like it's different across different spaces and places in the community too?

**Interviewee:** Exactly! Yeah.

**Interviewer:** **[17:48]** Got you! And then what are your hopes or worries for her in regard to how the community will react to her in the future?

**Interviewee:** I think my biggest fear is probably that, you know, if she ever gets into a situation where she is alone, we're looking at, you know, day programs and things like that now – that, because she has cognitive challenges and because she has the language processing, that someone will take advantage of her, [that’s] my biggest fear.

**Interviewer:** Yeah, absolutely. Thank you for sharing that. We're going to shift gears a little bit to our next chunk of questions. In the transition to adulthood, where do you see her?

**[Silence]**

**Interviewee:** So, you know, it's funny she's actually going to have her neuro-psych done in a couple of weeks, and just kind of preparing for guardianship and all that stuff. And you know, I think because of my worries about her being taken advantage of, that…I hope that we can cometo a situation where she can…her and I can work together, so that I can still keep an eye on her.

**Interviewer:** Absolutely.

**Interviewee:** You know, I would like to see her in a day program. I mean she can she can stay with me for the rest of my life, and I think there's a huge stigma with a lot of people that work in this field that, you know, “*oh, you've got to get them independent, you've got to get them a job, they’ve got to work, they've got to be around other people*, *they have to be*…” Why do they have to? You know, I mean, I think I have a very different view on that and I'm sure that people would challenge me on that. But I want her to be happy.

**Interviewer:** Yeah, sure.

**Interviewee:** And I'm very, very willing to open her up too many different scenarios, and if one fits for her and she likes it then go for it. But if she's not happy and she's not comfortable, I'm not going to do that to her.

**Interviewer:** Absolutely. So, you said that people might challenge your beliefs, so why don't you think that's necessary, necessarily?

**Interviewee:** Because I think what matters in life is that you're happy. And if you're happy listening to music and just being in nature, and going for a walk and you know…I don't want her to be in a situation where because it's difficult for her, she gets stressed out and we all know that stress is the leading cause of every disease on this planet. So, she already has enough challenges. Why stress her out being in a situation that she doesn't want to be in? I'm not going to force her to…I mean if her happiness is her being with me, then I'm going to make that happen. Even if we have to live in a cardboard box under a bridge, I don't care. I mean, she's already suffered enough and she has enough challenges. Right now, what we're doing at home, she's happy. She learns at her own pace, she's not forced to be in situations that she doesn't want to be in, and she’s happy. If you could see her right now, she's bopping away in her room because she's out, she's…I was making lunch, so she's on her downtime now and happy as a clam.

**Interviewer:** That's great! Happiness is really important.

**Interviewee:** Well, of course it is! And working at a grocery store bagging groceries and standing there being miserable while everybody stares at you, it’s not what it's all about. I mean we have, you know, I think we have these ideals in our head that everybody has to work and you know, and there are some organizations out there that are…I call them the inclusion Nazis. They just feel like, *“you have to treat my child the same way, they have to have every opportunity that your child has.”* I don't believe that, I mean that's what make the world go around, is being different. If we were all the same, how boring would that be? I mean…so, I think that we all need to do what's best for ourselves and she lets me know on a daily basis what she enjoys, and what she likes and what she doesn't like. And that's my job as her mother and advocate to make sure that she's happy, and if it means not bagging groceries, that’s fine. If she goes to a day program and they start teaching her to do some assembly work, I mean, you know, let’s face it, she's not going to be a scientist, or a teacher, or a lawyer or anything like that. But if they start teaching her some things and she loves it, *go for it!*

**Interviewer:** Yeah.

**Interviewee:** *Go for it!* Let her do it all the time, I don't care. But she has to really be happy at it. It has to be genuine.

**Interviewer:** Yeah, absolutely.

**Interviewee:** Oh, you know.

**Interviewer:** That makes total sense. And then thinking about the skills that she does have right now, at what stage of independence is she? Like, you talked about how she can make a smoothie, like can she fix her own meals? Things like that.

**Interviewee:** She's not…she can’t cook a meal, she can cook with me.

**Interviewer:** Yeah.

**Interviewee:** So like, I have her cut up the vegetables and, you know. But as far as cooking on the stove, she doesn't do a lot of that, but she makes her…she always like…if we’re having just a salad, she's my salad girl, she can cut up veggies and everything. She makes her own bed, cleans up her own room, gets dressed. She can…I mean, she could, you know, when she gets home from her dad's house on the weekend she puts her clothes in the laundry, she puts all her stuff away, you know, without being told. So, she does a lot of things independently. You know, showers and bathes, and does her hair, and brushes her teeth. She does all those hygiene-y kinds of things.

**Interviewer:** Yeah.

**Interviewee:** There's sometimes when it's two days into her period that I realize that she actually has it, because she just knows what to do when she gets it.

**Interviewer:** Yeah, absolutely.

**Interviewee:** So, she's good with those kinds of things.

**Interviewer:** Mm-hmm. That's fantastic!

**Interviewee:** **[24:42 inaudible]** the house…like obviously she couldn't go grocery shopping by herself, but when we do go grocery…well, when we used to be able to go together to **[24:50 audio cuts].**

**Interviewer:** You know **[chuckles]**

**Interviewee:** …we don't do that anymore now. But you know, I would say, you know, we make a list and I say, “*okay, we're in the produce department, what's in the produce?”* and she'd go, *“apples*.” “*Okay, how many apples do we need?” “Four*.” “*Okay, go ahead.”* And she’d go and get her own, you know, so she can do those kinds of things.

**Interviewer:** Yeah, it's great. And thinking about her like, achieving more independence, what do you think she will be able to achieve?

**Interviewee:** That's hard. That's kind of a hard one.

**Interviewer:** Sorry!

**Interviewee:** What do I think she *can* achieve, or what would I like her to achieve?

**Interviewer:** Both? Or will be able to

**Interviewee:** I have no anticipation that she's going to ever drive a car or live alone. But, I think my goals for her are all language-based. I mean, I would like her to be able to advocate for herself, I'd like her to be able to tell people how she's feeling, things that she likes, why she likes them. To me, I would like for her to have more language.

**Interviewer:** Absolutely. **[26:11 crosstalk]** I'm sorry, I cut you off.

**Interviewee:** I said…no, I said, so she can be more relatable, so she can have, you know, relationships with people. That's more important to me than her living independently or driving a car or getting a job.

**Interviewer:** Totally, absolutely! And do you think there are other…there are particular things that could help move her into adulthood, whatever that might mean for her? **[Silence]** Like services, interventions?

**Interviewee:** Sure. I mean, if I had a full-time aid or, **[silence]** maybe not full time, maybe like 30 hours a week or something like that, and they could work with her independently and take her out places, but focus on speech.If I could do more speech during the week, if there was a specific program that worked with teenagers and just focused on communication and social skills. Yeah, I think if there was a particular program that focused on those things, I’d be happier than a clam. But, you know, it’s either school or you wait till she's an adult and then they stick you in some kind of program.

**Interviewer:** Yeah. And then putting these two things together – sensory sensitivities and transitioning to adulthood – how do they intersect for her?

**Interviewee:** Well, I mean again, I think if she has…if she has more language, she can then articulate and communicate her sensory issues and then advocate for things that might remedy those situations, or you know, be able to say, “*okay Mom, I need to get to see Desiree and have a massage, and get some brain work done*,” you know. She could say that for herself, so she could advocate, you know for her own health.

**Interviewer:** Yeah! No, totally. I know you talked about how her sensory sensitivities aren't kind of like a driving factor. But would you say they’re an obstacle, a vehicle, or a bit of both in terms of her gaining some more independence?

**Interviewee:** I mean, I know…I don't think that they're anything, they're not at a level that they affect her daily…just her daily living. I mean, it’s not something that's a hindrance or you know, something that's going to, you know, be a factor of you know, it's not like, *“she has these sensory issues, so she's never going to* *blah, blah blah,”* you know. I don’t think that's her problem.

**Interviewer:** Yes, no absolutely.

**Interviewee:** Language. Now, if you ask me that same question about language, I would have a completely different answer. But I don't think her sensory issues have anything to do with her, you know, I think she's gotten to that point where they're just there.

**Interviewer:** Yeah, absolutely.

**Interviewee:** They're not a problem, they're not help. They're just there.

**Interviewer:** **[29:47]** Absolutely. Kind of just neutral, it seems like.

**Interviewee**: Well, no, I mean think about it, how many times do people do this? But I mean you probably saw me I'm doing…I just got out, you know, my hair is still wet, so I'm trying to get my curls, so I'm doing this the whole time**.** So, it's like a natural…we have a natural…people put their hair behind their ears, people take a, you know, tapping a pencil. I mean, everybody has a quirk, if you will, you know

**Interviewer:** Totally.

**Interviewee:** Hers are, you know…and there are some people who don't have autism, who don't you know, who just don't like to be touched.

**Interviewer:** Absolutely, they're quite universal and it's very heterogeneous for every **[30:23 crosstalk].**

**Interviewee:** I think that's where it's gotten to. It's just gotten to a like, *“okay, this is Grace.”*

**Interviewer:** Absolutely **[30:29 crosstalk]**. And so, this question then might not be super relevant for her, but I do have to ask it anyway. What do you anticipate as being challenging for her as she does gain more independence in regard to her sensitivities?

**Interviewee:** I mean, I think again, it all has to do with being able to identify, you know, that body awareness, and then being able to articulate. I think that's going to…and how it relates to her adulthood. I mean, I think the older that she gets…the older we all get, we all have you know, our needs change. And you know, will she even have those higher-level needs when she gets older, you know? I don't know. Yeah, that's kind of a hard one to answer.

**Interviewer:** No, that's totally fine.

**Interviewee:** That's a hard one to answer.

**Interviewer:** And what do you think will help her in this domain?

**Interviewee:** I mean, you know, if she had access to all different kinds of therapies, like…I mean, you know, my biggest qualm with the health industry is that, you know, they'll go to bat for you if you want a new drug, but when they have a therapy that is not mainstream, but actually helps, you got to be Rockefeller if you want that therapy because, you know…and for Grace, what really helps her is massage therapy and craniosacral therapy, but insurance doesn't cover that. So unfortunately, you have to get a part-time job or, you know what I mean? And it's just pathetic. So, what would help is if we had more access to…or if they broaden the term ‘healthcare’, because today's healthcare is not healthcare, it’s ‘sick care’.

**Interviewer:** Yeah, it’s unfortunately very true.

**Interviewee:** Yeah. And so, some people define being sick as, you know, having a heart disease and needing to take meds or, what's the difference with having autism and sensory issues and needing massage therapy and craniosacral therapy?

**Interviewer:** **[33:11]** Absolutely. You actually just gave me the best segue to my next question, you like read my mind.

**Interviewee:** Of course I did! You can throw me my extra money later.

**Interviewer:** Oh, yeah, absolutely **[chuckles]**. Do you feel like there are gaps in the available services and interventions?

**Interviewee:** Oh absolutely! It’s no question. I mean, and the reason why I say this because I…you know, I come from a holistic background. So you can't…I mean, if you really want to provide…you know, my biggest thing when she was in school was, I used to say, they forget what the I in IEP stands for, and the I in IEP stands for individual. But they put them in the same classroom, with the same teacher, doing the same stuff. That's not an I, you know, and if they really…if people really want to kind of step back, look at the big picture, then we will have a little bit more to work with. And I mean, I think…I have always thought that we need to start looking outside the box, you know, with like these different kinds of therapies, even music therapy. I know some children who…I've seen them be completely nonverbal and then have music therapy and *boom!* Like, they're talking! So, do we have music therapy in our schools? Not a lot of them.

**Interviewer:** Mm-hmm.

**Interviewee:** And then you know, and then don't even get me on the medical piece, because we could be here for hours. But you know, I mean there's just, there's a lot to it. Like, we’re just doing Grace’s genetics reports and you know, she's got some you know, she…or had some major gut issues and you know. “*Oh, well*, *you know,* *so we'll give her some meds*,” and it's like, do you understand the gut-brain connection? You know what I mean? It’s like, where did you go to medical school? Did you not know that the gut is your second brain? So, if something's going on in the gut, this ain't going be working, you know, like they don't approach it, they just…and then you find someone who's like a DO or functional medicine or something like that. And oh no, we can't go see those people! They're crazy freaks, you know, they don't shave their armpits and you know, they all smoke weed and you know, they're lighting incense and all. I mean, you know, there’s such a horrible look on what people would call alternative, you know, I call it actual medicine.

**Interviewer:** Mm-hmm.

**Interviewee:** But if it's not mainstream then, you know…and the sad thing is the people that I have a relationship with, that also have children with autism, I've seen more gains doing natural things like, you know, craniosacral or music therapy or supplementation, or you know, hyperbaric oxygen therapy. I've seen more children have more gains with those approaches, than anything any regular medical doctor has ever done.

**Interviewer:** Yeah. And so what types of interventions do you wish existed or were available to Grace or to kids like Grace?

**Interviewee:** Yeah, so I would love to see you know, like we talked about earlier, like maybe some kind of a school that focuses more on relationships and communication as opposed to sticking them in a regular classroom doing ABA. Sorry.

**Interviewer:** It’s okay.

**Interviewee:** Hate it!

**Interviewer:** It's okay.

**Interviewee:** And let me just tell you that the community is starting to wake up to the fact that ABA is just creating little robots. You know, I'm a Sunrise mom. Have you ever heard the Sunrise program?

**Interviewer:** I looked it up after reading your demographic form, but I didn't know about it previously.

**Interviewee:** Yeah, so the Sunrise program, the, you know, Floor Time, those approaches need to be readily available in our schools through our insurance. It's just not working, the whole, you know…so I would say alternative things like the craniosacral therapy, you know, children who have to go to OT or PT for any kind of muscular, or gross motor skill, why can we not also provide a therapeutic massage? I mean I'll be honest, so I have fibromyalgia and I just went to my massage therapist last night; I couldn't sit in my car and drive without my sciatic nerve, I mean just like pain going through my…to the point where I would have to put the cruise control on, and stick my leg up, you know what I mean? So, one treatment from my massage therapist and I am completely fine!

**Interviewer:** Great! I'm glad to hear that. I’m sorry that was so painful.

**Interviewee:** So, these people, you know, and I mean even **[39:00]** energy medicine, whether you believe it or not. I mean, I've had people have lifetime troubles that have gone away instantaneously with doing Reiki, or you know. So I mean, just kind of looking at the whole…and even nutrition therapy, **[silence]** I mean, just letting children have access to fresh vegetables and fruits and…I mean that was part of the reason why I took her out of school, is because they just fed them *crap all the time*! I mean besides the school meals, which she never had, but I mean in the school, you know, having birthday parties and all that kind of stuff. I mean, I'm not saying I don't like that but I'm just saying that they, you know, they should have access to more nutritious **[40:05 crosstalk].**

**Interviewer:** Yeah. When did you pull her out of school?

**Interviewee:** When she was in third grade.

**Interviewer:** Okay, so it's been a while then.

**Interviewee:** Yeah, she's a senior this year, technically.

**Interviewer:** Yeah **[chuckles]**. And kind of a little bit more of a big picture. I guess you kind of already answered this in not so many words, but I have to ask it. How did Grace’s sensitivities impact your goals hopes and expectations for her, as she does navigate the adulthood?

**Interviewee:** I don't think they’re…except for not being able to articulate them, I don't think they affect her at all.

**Interviewer:** Yeah, absolutely. Okay. So we're going to go for our last chunk of questions, we’re almost there. You're doing great.

**Interviewee:** Because I'd like to go to Cape soon. I have two hours…I’ve got two more hours to get ready.

**Interviewer:** Oh, no, no. We're almost done. I have three, four more questions, so we're almost done **[laughing]**.

**Interviewee:** No problem, no problem. It's me I talk a lot.

**Interviewer:** Oh no, I book a lot of time for these because everyone talks a lot. You are not the only one **[laughing].**

**Interviewee:** Oh good! Thanks, they’re on to me.

**Interviewer:** As a caregiver, as a mom, as a parent of someone with ASD and some sensory sensitivity. What does transitioning to adulthood mean to you?

**Interviewee:** I mean again, I just go back to the same thing. I just want her to be happy and, you know. You know, some of us…our career is everything to us, you know, not me personally, but I'm just saying, you know, for some for some adults career is everything and, you know, I don't know if she'll ever have that feeling of you know, “*I have to go to work today, because being part of…you know, being a productive member of society is my…makes me happy*.” I don't know if she's ever going to feel that way. And my only goal for her is to know herself, and be able to tell you know, be an advocate for herself, be able to tell people what she wants and what she needs.

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

**Interviewee:** No.

**Interviewer:** No? And then… **[42:22 crosstalk]**

**Interviewee:** I’ve always felt that way about her.

**Interviewer:** And then thinking more specifically about her future, what do you see in her future?

**Interviewee:** I see her finding herself. I see her being able to articulate her wants and needs. And I just see her continuing to be happy and…I know the word, but I can't…uninhibited? I mean just…being the kind of, like a flower child kind of thing where, you know, she'll be in a park and she'll hear some music and she’ll just start dancing. I want her to feel *free* to be whoever she is, whoever that is. And she can be thing one on Monday and thing two on Tuesday, and it won't matter. You know, I just want her to be happy being herself and you know, being okay. And I never want her to feel like I'm trying to fix her, because she's not fixable.

**Interviewer:** Absolutely.

**Interviewee:** She’s not something to be fixed. You know, fixing and helping are two different things, so I hope that I can always continue to help her to be the best that she can be. But whatever that looks like, you know, I'll never stop. I mean, she'll be 50 years old, I'll be…oh god! Let's see, if she's 50, I'll be 83. I'll still be bringing her to speech therapy, you know what I mean? Like I mean, I feel like our brain will never stop, you know, we can never stop learning and whatever helps her I will continue to do it. And if someday she says, “*Mom, I don't want to go to speech therapy anymore*,” I'll be like, “*fine,* *then we’re not going.”*

**Interviewer:** Yeah, that's fair

**Interviewee:** But right now she loves it, you know, she's enjoying her time.

**Interviewer:** Good. That’s awesome.

**Interviewee:** So, I just want her to be her, whoever that is.

**Interviewer:** And then I think I know the answer this next question, but it's my last question. Did her sensory sensitivities impact this current perspective?

**Interviewee:** Never! No.

**Interviewer:** That's right.

**Interviewee:** I was just very fortunate that on the day she got diagnosed, my true Italian came out, and after getting past the fact that I wanted to **[45:00]** kill the doctor who gave you that diagnosis **[chuckles]**…well, because he had given us such a grim prognosis, and I…but because he did that, I just said, “*no way*!” you know, I remember telling to my…saying to my husband at the time, I said, “*they can clone a sheep, they can make a baby in a test tube, but they can't do anything for my kid that just got diagnosed with autism? Are you kidding me!* “And I was bound and determined to find and do anything that I could to help her, to make her life, you know, this time on this planet as wonderful as it can be. And you know, despite what anybody's or your beliefs are, you know, I just believe that that she chose me because she knew I was going to make a difference. So **[45:56 crosstalk].**

**Interviewer:** Yeah, I mean it sounds like you [do].

**Interviewee:** Thank you, I try. I mean, I feel like, you know, we're in such a wonderful time period because, you know, we have so much information accessible to us. And people who don't go out and learn and do whatever they can, I feel sorry for them because, you know, there's just so much that you can do. I mean like, I literally have five hundred dollars worth of books sitting on the floor there, and I can't wait to jump in and start even learning more, so.

**Interviewer:** It sounds like you do so much to support her, you do sound like you help her in way that **[46:38 crosstalk].**

**Interviewee:** Thank you. I feel like I do, and I hope that…so far she still likes me, so **[46:45 crosstalk].**

**Interviewer:** That’s an accomplishment too **[both laughing].**

**Interviewee:** So I must be doing something right **[laughs].** Because now she is probably saying “*where’s my dinner!” “where’s my lunch!”* **[46:54 inaudible]***.* So yeah, okay.

**Interviewer:** That's actually it for my formal questions. Is there something you’d like to add?

**Interviewee:** I do not think so. I think we pretty much **[47:06 crosstalk].**

**Interviewer:** Yeah, thank you. Your thoughts and your insights are so, so helpful.

**Interviewee:** Thank you.

**Interviewer:** We so appreciate you sharing it and being honest and vulnerable with us.

**Interviewee:** Well, you know, I do…like I said, you know, at the beginning of our time together, I just, you know, I feel like if Grace's challenges can help somebody else then, you know. So, we try to do studies whenever we can and…

**Interviewer:** Thank you.

**Interviewee:** …you know, I mean, I just feel like if we can help, our experience helps somebody else, what good it is going to be if I don't share it, you know? So.

**Interviewer:** Well it's definitely helping us. This is such a unique perspective and it's really wonderful to see how everyone is different in this perspective.

**Interviewee:** Yeah, yeah. Great.

**Interviewer:** Do you know anyone else who might to participate in the study?

**Interviewee:** So I put it out there, I did, I’m on a couple of groups. So I mean, I think right now to be honest with you, I think so many people are panicking and just not in the right place with this pandemic, so.

**Interviewer:** Totally.

**Interviewee:** You know.

**Interviewer:** Nope, understandable. It's rough.

**Interviewee:** And then not knowing when people are going to get to school and, you know. But I’ll just…I'll put it back out there, and just say, “*hey, they’re still looking*” and **[trails off].**

**Interviewer:** Yeah, that'd be awesome, thank you. Totally unrelated – is your friend doing okay? You mentioned that her dad or her husband passed, I think?

**Interviewee:** Yeah, thank you. Thank you. Yeah, I mean, I think it was hard because, you know, I mean obviously not many people came to the services and then you know, and there were some family issues around it, so. Just like when my mom passed away three years ago, I haven't talked to my siblings since, so. And now she's going through the same thing, I don't understand what's wrong with people. But yeah, you know, sometimes a tragedy can bring out the worst in you, and sometimes it can bring out the best.

**Interviewer:** Hope she's doing okay or continues to kind of **[48:58 crosstalk]**

**Interviewee:** That’s very nice. We’re actually going to lunch on Monday.

**Interviewer:** Good **[49:02 crosstalk].**

**Interviewee:** The three of us…The Three Stooges, we used to call ourselves. The Three Stooges, we're getting back together and going for a little lunch, so.

**Interviewer:** Awesome! I hope you enjoy it, I hope you enjoy your cake too.

**Interviewee:** *I'm so excited!*

**Interviewer:** It will be nice.

**Interviewee:** *…*it’s going to be in the best place ever!

**Interviewer:** Where, in The Cape?

**Interviewee:** Well, actually I call it The Cape but it’s actually the South Shore, so she lives in Cohasset.

**Interviewer:** That's still nice. It’s somewhere that’s not where you are now.

**Interviewee:** A quarter mile down her street, she has her own beach. So, yeah, it's fine. Surrounded by two and three million dollar houses. Yeah, it's fine.

**Interviewer:** **[Chuckles]** Absolutely!

**Interviewee:** It’s all good.

**Interviewer:** Well, thank you so much for making time for us.

**Interviewee:** You’re welcome. You’re very welcome. If you need anything else, just shoot me an e-mail or whatever.

**Interviewer:** Thank you. Likewise too, and I put an order in for your gift card, so as soon as it comes in I’ll send it your way.

**Interviewee:** Don’t worry about that.

**Interviewer:** You'll see it soon.

**Interviewee:** That’s the least of my worries.

**Interviewer:** Awesome. Well, enjoy getting ready, have a good trip.

**Interviewee:** *Thank you!* Okay, we’ll talk to you again. Thank you. Bye-Bye!

**Interviewer:** Bye!

**[End of transcript]**