**[Start of transcript]**

Interviewer: ---works and we’re recording.

Interviewee: Uh-huh.

Interviewer: And I’ll be asking you about your perspective about your child’s transition to adulthood in relation to his sensory sensitivities and interests.

Interviewee: Okay.

Interviewer: And we’ll be doing something called a semi-structured interview. So, I have my planned questions here but then I’ll be adopting my questions to follow our conversation to actually make sure it fits for what we’re talking about.

Interviewee: Okay.

Interviewer: And that’s it. Do you have any questions before we begin?

Interviewee: No. None.

Interviewer: Okay, awesome. And if there are any questions that you don’t want to answer or make you uncomfortable, that’s totally fine. You don’t have to answer anything if you don’t want to.

Interviewee: Okay, thank you.

Interviewer: Of course! Could you start off by telling me about your child’s sensory sensitivities and interests?

Interviewee: Yeah. My child has…is both seeking and also aversive. At the same time, which I think is fairly typical for a lot of kids with sensory issues. So, I would say he is seeking a lot of the time. And he’s seeking attention. [Laughs.] He’s seeking deep tissue pressure. That’s what---he really likes that. He is averse to smells. Sure. Sometimes averse to loud sirens, lights. But those are his main things. This has gotten a lot better since he was younger. When he was younger, he was very averse to many things. Especially, you know, tags on clothes. I only bought certain kinds of socks that I learned worked for us. Certain kinds of clothing. Averse to buttons. Averse to texture.

Interviewer: Gotcha.

Interviewee: I even made him a special little chew toy. This is before chewies.

Interviewer: Yeah.

Interviewee: I used aquarium tubing.

Interviewer: Oh! Cool!

Interviewee: And drilled a hole and wire in tubing and gave him a chewie so that he would no longer chew his coat apart. So, I’m the only one in the history of the aquarium tubing company to call them and ask them if their aquarium tubing was non-toxic. [Laughs.]

Interviewer: [Laughs.] Well, it’s good to know.

Interviewee: That was a very long hold period for me, while they looked that up. But you know, necessity is the mother of invention.

Interviewer: Absolutely. Can you talk a little bit more about things he’s averse to? You talked about smells, what type of smells, things like that.

Interviewee: I would say strong smells. He has difficulty feeding the cats and that’s not wet food, it’s dry food.

Interviewer: Okay.

Interviewee: So, that’s not necessarily a strong smell to you and I, perhaps. Like, I’m sure if I opened tuna fish, he would not like the smell. He tends to smell his food before he eats it, definitely has a smelling thing. I’m trying to think, he’s also, ask me again, I’m out of my train of thought here.

Interviewer: Oh, no, it’s totally fine. So, you talked about how he doesn’t like some lights, what type of lights are aversive to him? Strobe light? Bright lights?

[00:03:01]

Interviewee: Sometimes bright lights. We did end up getting him sunglasses, which, you know, we’re not the family who usually buys a child prescription sunglasses. We usually feel like, “suck it up,” but we did get him prescription sunglasses, because he does seem to be averse to bright lights. At the beach he’s all into the waves, all into that input, but only to a certain point, and then then he wants, like in a tent with it, like closed, with a towel over his head, he’s done.

Interviewer: Gotcha. And you said he also seeks out deep pressure. What does that look like for him?

Interviewee: He wants backrubs, he likes to have the squeeze, he likes it if we basically hold hands and basically disco dance. So, if my hip will push really hard into his hip, like we’re sideways, we’ll do that back and forth a little bit. He is 6’6” so I can only do that a few times because he’s so big. He really wants that deep tissue pressure, for sure.

Interviewer: Absolutely. How does he cope with these sensory sensitivities and also interests?

Interviewee: I think he’s learned to ask for things. He’ll come over and say, “*Rub my back*,” and then normally I’ll rub his back. If I rub his back on the outside, “*No, under the shirt*,” and he doesn’t want me to use fingers, he wants the deep tissue pressure, he’s learned to do things like that, to ask for what he needs. And that’s obviously improved as his communication has improved, as he’s gotten older.

Interviewer: Yeah, absolutely. And does he ask to not have things, so like, does he ask to avoid the smells he dislikes? Or does he ask to avoid the bright lights or the sounds?

Interviewee: He will, or he’ll turn around and say, like, “*Ugh*” and waft it away, or “*that smells really bad*,” or “*I don’t like that*,” that’s pretty much...

Interviewer: Yeah, totally. And does he do for sounds? Does he use like headphones, or does he cover his ears?

Interviewee: He would cover his ears for startles, that’s normally what he’d do, like if we’re at a parade, long ago, when we could attend parades [laughter]...

Interviewer: Yes, pre-COVID...

Interviewee: ... I’d try to give him a head up, like if I see the fire engines coming, and he’ll kind of shudder and go, “*Ugh*,” with his hands over his ears and say it’s too loud.

Interviewer: Okay, gotcha. And then on the form you talked about some therapies that he has received for sensory sensitivities, can you talk about that?

Interviewee: Yeah, in the past when he was younger, when he was in preschool, we did the brushing and deep tissue pressure, and that has been very helpful, and I feel that that’s kind of helped me with that kind of disco move that we do, where our hips touch. I know that’s what he’s seeking, and probably even the rubs on the back. We did a lot of different therapies, trying to put his hands in paints, just trying to get him used to things like that, shaving cream, things like that. He’s still averse to that, but if I ask him to do it, he would do it, he’s not going to flat out refuse to do anything.

[00:06:23]

Interviewer: Mm-hmm, and is that change, like when he was younger, he would refuse?

Interviewee: Oh, absolutely, yes, absolutely. When he was younger, he was a challenge, for sure.

Interviewer: Gotcha.

Interviewee: That’s why I’m being rewarded now. [laughter]

Interviewer: Absolutely. So you’d say these therapies helped him over time?

Interviewee: I would say the therapies definitely have helped him. Someone else I know said you can’t put a price on maturity. It’s true, as time goes on, they have more experiences, they learn different things.

Interviewer: Yeah, absolutely. I was going to say, you’re giving me great segues.

Interviewee: I was going to say, even if you think of today with the mask, okay, that’s been a big topic amongst many of us with kids with autism, dealing with the mask, how long can they wear the mask, we learned quickly to use phrases like this is a choice, this is not a choice. For him, this is not a choice, you’re going to wear the mask, because it isn’t a choice. If you would like to have input in what we’re having for dinner, that’s a choice.

Interviewer: Mm-hmm, and is he doing okay with wearing the mask out in public when he has to?

Interviewee: He is. He’s nervous about being too close to people, but who isn’t? So, yeah, when he became too nervous, then we started to force him to go with us places, like he was getting too, like, “I can’t go anywhere,” and we said no, we’ve got to nip this in the bud, because we thought from the beginning, as everyone did, why do two people have to go? Just one of you go. Now we don’t try to overexpose him but we’ll say, like, we’re going to Target, or I’m going to Panera to pick up something curbside, why don’t you come with me.

Interviewer: Mm-hmm, just kind of get used to it?

Interviewee: That’s helps him, yeah, and the masks, like he likes wrestling, so we order a wrestling mask, he likes the Flyers, so we’ll get him a Flyers mask, we’re trying to get him the things he likes.

Interviewer: Yeah, absolutely, that makes sense, totally. And then you mentioned how he was averse to more things when he was younger, so in general, how have his sensitivities whether it’s seeking or avers to things, how has that changed over time?

Interviewee: I think I’m surprised when I filled out the survey to think about how much he is still seeking. It was helpful to do that survey with him.

Interviewer: Good.

Interviewee: Yeah, it was very helpful, because some of the things I didn’t even think of, I never thought about him smelling a flower or not smelling a flower, and I said to him, would you smell a flower if you picked it, and he said no, and I would have said maybe. So it’s interesting, you don’t think of those things. But definitely I think through the therapies, through his school program, things have definitely, for us, gotten better. He is a lot less rigid than he was before.

[00:09:21]

Interviewer: Can you give an example of how he’s less rigid now? What does that look like for him?

Interviewee: The prime example of that is he had such a limited palate when he was younger. We ate waffles, french-fries, pasta, cold vegetables, don’t even get me started, like out of a can, don’t get me started on that. We worked to hot dogs and we went on a cruise I guess now three years ago, and he ate frog’s legs. So, that is what that looks like.

Interviewer: Gotcha.

Interviewee: It was just offered to him, and he ate them. So, not something he picked. But he is now an adventurous eater, whereas before, he really was very averse texture-wise. Like, he could eat chicken nuggets, but he couldn’t eat fish sticks, because you think of the texture differences, that was a big one for him.

Interviewer: Totally.

Interviewee: So, he really has learned that there can be some good things on the ends of some textures he might not like.

Interviewer: Mm-hmm, and what about clothing? You talked about that.

Interviewee: He’s definitely better. I make accommodations, too. Now, of course there are things that are tagless, so the underwear I buy is tagless, shirts, for a while I was looking for tagless, now I just look for tall. But like today, right before I got on the call with you, he turned a tag on the side of his shirt and said can I get rid of this, and I said yes. And it wasn’t a new shirt, but it was rubbing against him or whatever. So, things like that have gotten better, for sure. And like I said, before he wouldn’t wear anything with buttons when he was younger. We did Cub Scouts, wearing the uniform was hell, he didn’t like the buttons. I think he likes the security of a zipper, because when I used to wear a sweater or something with a zipper, he would zip me all the way up. I like that, so you must like that, mom. He didn’t say it, but I knew that’s what he meant.

Interviewer: Is he more okay with buttons now, if he had to be?

Interviewee: Yes, yes. We then did ROTC for two years in high school and he was a little more comfortable with the buttons at that point.

Interviewer: Gotcha. And then you kind of alluded to this with your maturity comment, but do you think these changes are related to any independence that he’s gained over time?

Interviewee: Absolutely, absolutely. We try everything we can to build up his self- confidence, like I said, the school has been wonderful, I think that’s one of the reasons he eats so many different things, is that we started with school lunches. You know, when you get a school lunch, especially when you’re in elementary school, you kind of get what they give you. So he would come home and say, I tried a salad. And I’m like, you what? You know what I mean? Or I tried soup, or I tried something like that, and then they started making more foods at school, well, it’s peer pressure.

[00:12:27]

Interviewer: Absolutely. Are there other examples of where you think independence kind of prompted some of these changes over time?

Interviewee: I think he likes to be able to choose what he wants to wear. He has man shorts, he has swishy shorts, and then we have man shorts which more like a khaki kind of thing. He knows that we’ll compliment him if he wears those, so he likes to wear the man shorts. He wants to know what everyone is thinking of him, he wants to be socially appropriate.

Interviewer: Mm-hmm, absolutely. And then thinking more specifically to his sensory sensitivities, does it cause anxiety for him, or increased anxiety if he has to engage with something that is averse to him?

Interviewee: Yes, absolutely, especially if we’re going somewhere where he doesn’t know if he’s going to know somebody, especially with a peer group. We’ve had issues where there has been a special needs dance and it’s in a different high school. I had one a few years ago, I took him to one and I got a phone call half an hour later that I had to come get him. My girlfriend and her daughter stayed with him and he was having stomach upset, GI issues, because he was so anxious, because he didn’t know the lay of the land, he didn’t know who else would be there, it was dark, and so that anxiety, definitely.

Interviewer: Mm-hmm, do you think that anxiety was related to the new situation or to being afraid...

Interviewee: I think it was the new situation, but again, like I said, it was darker, he didn’t know where everything was, he likes to know what the plan is. Like, if we go out on vacation, he’ll do a lot of planning with us. He wants to know, I always joke that he not only wants to know the room we’re going to stay in, he wants to know the color of the drapes, he really wants to know the plan. [laughter] The internet is a wonderful thing for that, because you really can look at pictures of everything.

Interviewer: Yeah.

Interviewee: We’re going to Key West in two years to celebrate his 21st birthday.

Interviewer: That will be nice.

Interviewee: Every day we talk about what we’re going to pack, he looks at houses, where are we going to fly to, what are going to do, every day. I just know that’s exciting for him, that’s something he wants to discuss, so it’s all good.

[00:15:06]

Interviewer: Yeah, absolutely. If he has a smell that he doesn’t like, that does cause anxiety for him?

Interviewee: It can, he will want to get away from it. He’ll talk about something, like we were at church and he’ll say, “*Dad, dad, that woman, I didn’t like the smell*,” and he knows enough to be shushed then, but he’ll talk about it over and over again when we get back, and he wants to leave.

Interviewer: How does he manage that anxiety?

Interviewee: There’s a lot of questions, he’s a big chatter, he’ll say, “*I’m anxious*,” or he says, “*I’m worried*.” Right now the anxiety, of course, is about what’s going to happen with school.

Interviewer: Fair, super fair.

Interviewee: Super fair, we’re all anxious about that. So there are a lot of questions, a lot of perseveration about things. He has a lot of anxiety about what other people are doing, that’s pretty much how that manifests. Sometimes he will have GI issues if he’s nervous about something, but that’s mostly how it manifests, is the talking.

Interviewer: Gotcha. And has he used intervention therapies or like medication to help with that anxiety?

Interviewee: In the past when he was younger we tried the whole host of different things. We had tried Focalin, we used Focalin for a while, we had used Adderall, we had used that, we had used, um, well, I’m trying to think, what’s the big one, we tried some different medications, and it came to where I would offer it to him on the weekends and say do you want to take this or not, because I felt like he didn’t need to focus, and so we began kind of coming off those. So, those are mostly ADHD medications. We weren’t going to go on something that was more for anxiety, and I can’t remember what it was, but one of the side effects was seizures, and at that point he had just had an unexplained seizure, so we decided that we were not going to go onto that.

Interviewer: Yeah, for sure, that makes sense. And has his anxiety changed over time in relation to the sensory sensitivities?

Interviewee: I would say because he’s more vocal about things, he’s able to tell us when something is bothering him, where before more the behaviors would come out when there was a sensory issue. I think his anxiety and the sensory are all tied together. When he was younger, he would turn his shirts, like the hem of the shirt, and start working on that thread, and then pull the whole hem out. So I learned quickly how to zigzag on my sewing machine, and we would zigzag his shirts so that he could not do that. So, I definitely see he definitely gets more with the anxiety, more fidgety, more picking at things, he definitely is a nail biter. I never cut his fingernails, because he takes care of those himself. Luckily or unluckily, I still do the toenails, but he definitely has that anxiety where he adjusts. A lot of times his fingers are in his mouth for different things, not always appropriate, I mean, he’s not like a thumb sucker, but he will, like if he touches a piece of food, then he’s put his fingers in his mouth, and then not go to a napkin.

[00:18:55]

Interviewer: And has that been consistent over time, as well?

Interviewee: Yes, that definitely has been.

Interviewer: And then thinking kind of about the future, what are your goals and hopes for him in regards to his sensory sensitivities and interests?

Interviewee: We’re hoping obviously that he can find some kind of combination of work and volunteerism that will take up his time and make him happy. So, I do worry about being somewhere with the loud sounds. His goal in life is to work at the Philadelphia airport, so I believe he wants to be a skycap, so that would be someone who takes your luggage, or the big dream would be to drive that little cart, truck thing through the airport. But if you think about, there are a lot of noises at the airport, there’s the beep-beep, or startling, some of those things are going to be a challenge or him, for sure, and let’s talk about smells, there are going to be passengers with all different kinds of smells, things like that. His strengths are heavy lifting, anything with wheels, he likes that sensory input. One of his favorite things ever is anything with wheels that he can pull. So, we’ve graduated obviously from the wagon, but now we do pulling suitcases. He always wants to have a suitcase that has wheels, because he’s looking for the input. He likes to feel the bump, he wants to feel that, so we’ve actually incorporated some of his sensory seeking into what he wants to do.

Interviewer: Mm-hmm, it makes sense.

Interviewee: Yeah, absolutely, I mean, I think that’s important, you have to find your child’s strengths and also their needs and try to incorporate into profession, for sure.

Interviewer: Do you think he would be able to learn some coping mechanism where he could be at the airport pulling these things and having a job he likes, but still being able to overcome the noise and the sounds?

[00:20:54]

Interviewee: I think absolutely, because he wants it so badly. I think that’s really, he’s able to overcome anything. He also plays ice hockey. Now, if you think of ice hockey, and it’s all special needs kids, so if you think of that, it’s amazing that the kids can play ice hockey. You have the buzzers, it’s cold, you’ve got a lot of padding on, you have a lot of restrictive padding on, you have a helmet on, there’s all these different things, but he loves hockey so much that he will be bound and determined to do anything, he doesn’t care, and I see it with many of the kids, some of them with Down syndrome, a lot of them with autism, really, are able to just cope with that because they really want to play hockey.

Interviewer: Mm-hmm, absolutely, thank you. We’re going to shift gears a little bit, but again, you’re giving me a nice segue, so this will be a good transition. So, thinking about him as he has grown up and aged a bit, how has his and your community reactive to his sensory sensitivities?

Interviewee: I think on a whole it’s been good. You know I have a nonprofit and I do autism awareness assemblies, so we talk about sensory issues a lot, and I’ve been doing that for 12 years. So we see a lot of people in the community and I know a lot of people. I’m seeing more and more people, as I’m sure you are, with bigger ones, could be noise counseling or different activities, I’m seeing more and more kids with special needs out and about in the community. Not right now... [laughter]

Interviewer: No one is out...

Interviewee: Yes, so I think that has been good. I think people are relatively accommodating, the firemen not so much when they hit the sirens, but I think people are now more sensitive and see that people are having anxiety or different things with sensory issues, and are more willing to make accommodations.

Interviewer: Mm-hmm, absolutely. And then thinking back to when he was younger, was the community more or less accepting and accommodating of him?

Interviewee: The community was definitely less accepting.

Interviewer: Less accepting, how so?

Interviewee: I think there was a lot less knowledge about autism, sensory issues, et cetera. I was also younger and more inexperienced, but it definitely was a challenge, for sure. With sensory issues, I remember he took a ball at Target out of the ball corral and tipped over into the next section, so we just left the store, you know what I mean. So I think as more people become aware and obviously as the numbers are increasing, unfortunately, for autism, pretty much everyone knows someone with autism and/or sensory issues. So, hopefully more people are being more aware and sensitive to it.

[00:24:05]

Interviewer: Mm-hmm, absolutely. And then thinking back to your community, past or present, were there specific spaces or places that were more or less accommodating or accepting?

Interviewee: I think in our community we have a playground called Jake’s Place, which is a place for handicapped accessible and I think once that was built, people had more of an understanding and it was obviously built as a memorial playground by my grandparents. It was more of an understanding that that’s where a lot of people with special needs, physical and/or developmental would converge, along with other kids in the neighborhood. So, I think that was a good thing, for sure. I think some of the children’s museums in the area, they started doing an autism sensory night after they closed on a Sunday night, so we did that a lot of when he was younger, and that was a great thing. I think more places are just more aware, like I know even the movie theater offers a sensory program where the lights are not as dark, et cetera, so I think you do have businesses and areas that are being more accommodating.

Interviewer: Mm-hmm, absolutely, thank you. And then our last question for this section of questions, do you have hopes or worries about how his community will react in the future?

Interviewee: Sure, obviously, that’s everyone’s biggest fear, to see how things will play out, for sure. I obviously worry about him being taken advantage of, this is the part where I cry, Rachel. [laughter]

Interviewer: Oh, I’m sorry.

Interviewee: No, it’s fine, let me get a tissue.

Interviewer: Oh, okay, you don’t have to answer if you don’t want to, also. You’re also not the first person who has cried, so there is strength in numbers.

Interviewee: No, no, no, I mean, I think everyone just worries about their child. I think you try to set things up as much as you can for their security, and that’s what we do.

Interviewer: Absolutely.

Interviewee: I know we’ve applied for and received SSI, we’re his legal guardians, and we actually bought the house next door and have a home for him in the future that can be supported. So, I feel like we really put everything we can into place.

Interviewer: It sounds like you’re being supportive and you’re doing the best.

Interviewee: Well, again, we want to look to the future and make sure that he is for sure taken care of.

[00:27:01]

Interviewer: Mm-hmm, absolutely, thank you for sharing that.

Interviewee: Oh, you’re welcome.

Interviewer: We’re going to shift again. In the transition to adulthood, where do you see him?

Interviewee: Hmm, that’s a very broad question.

Interviewer: It is, I have some smaller questions if it will help prompt you.

Interviewee: I think we’ve kind of just firmly established that he is firmly in puberty physically, now that he’s 6’6” and is like a Sasquatch, things are good. [laughter] I think we have two more years of high school, so I think once he’s 21 and we’ve aged out of the program, then we start a job search. I guess that’s his push to adulthood. He says, “*When I’m 20 I’m going to watch Family Guy*,” that’s his kind of gauge, and he constantly says, “*I’m an adult*.” Yes, you’re legally an adult, but there are many things we have to help you with.

Interviewer: So, what do you help him with, in terms of adult things?

Interviewee: Well, because we’re his legal guardians, we manage his finances, we manage his medical, we manage his schooling. Just before this, I had to make a grilled cheese sandwich. It’s trying to teach him things. I will provide activities for him, we provide transportation, we really do manage everything. The hardest thing is stepping back and having him try to learn to do more and more by himself.

Interviewer: Mm-hmm, absolutely. And so the next of chunk of questions, what stage of independence is he at? What can he do by himself?

Interviewee: He can navigate I would say socially pretty much by himself. He’s on the computer, he has a phone, he knows he has to check with us before he accepts a friend request, so that’s like a safety measure built in. He can stay home alone, and I’m comfortable that he would hopefully know the right things to do if there was an emergency. He helps, we have a riding mower which is something he wanted, so he helps mow the grass. The riding mower is a car substitute, because he will not drive. So, those kinds of things, he helps with yardwork, he can do some schooling by himself, some of the online work by himself.

Interviewer: On the form you talked about he has a job 10 hours a week, right?

Interviewee: Ten hours a week through school. So normal, and again, normal times, right, they normally attend classes in the morning and then around 10:30 they would have lunch, which he says is way too early for lunch, and I agree. And then our Access Link Paratransit would pick him up around 11:00 and then he would work for the rest of the afternoon and get home around 2:30. So, there are different job locations there, one is Habitat For Humanity, one is a restaurant, one is a catering hall, another was a senior center where they did people work.

[00:30:25]

Interviewer: Gotcha, and can he cook things by himself? You just mentioned you helped him with the grilled cheese.

Interviewee: I would say no, I would not like him to use the stove by himself.

Interviewer: Gotcha. What about cleaning himself, taking care of his body?

Interviewee: Yes, it’s interesting because once they turn 21 in New Jersey, you would fill out the NJCAT which is done by the Department of Developmental Disabilities and you figure out all the things that they can do by themselves, and they’re given a scale. So, they say to fill this out you need to imagine your child alone in an apartment. So, yes, he can totally provide all selfcare, except for bathrooms, I provide wipes. He tells me when he’s running low on wipes, but then I have to empty the trash, then we’re back to the smells and icky things, things like that. It can be a few days when the body wash is empty and I don’t know. So, he does all this independently, yet I need to still supervise those kinds of, purchasing, making sure that he has the things that he needs for selfcare.

Interviewer: Yeah, absolutely. You talked about how you take care of him financially, does he have some type of concept of money and some type of concept of money management?

Interviewee: Not really, I would say no. We’re still in the stages where we’re counting money, and that’s not always accurate. That’s one of the questions that the lawyer for guardianship asked him about buying an X-Box, how much would that cost, and he had no concept. When it comes to gifts, people say well can I give him a gift card, or I can give him cash, yes you can, but he has no real concept necessarily of what that is going to do. He doesn’t seem to know that $20 will buy you and your girlfriend a meal at McDonald’s, you know.

Interviewer: Do you think he wants to live on his own? Is he excited about the house you purchased next door?

Interviewee: He is, he definitely is. He talks about living down the road from us in a little town in an apartment, and that may be a step we do in between, who knows what happens. It depends on where we are with the family. He would like to live alone, it’s going to have to be in something not necessarily supervised all the time but very supportive. COVID has been interesting because it has taught us many things, like he can’t open soup, he can’t even do the pop top with the soup.

[00:33:05]

Interviewer: Like he doesn’t know how to open it?

Interviewee: He doesn’t, and his hands are so big, too, so we’re trying to teach him with a spoon, and the whole process, it’s not intuitive. It’s like push forward, and it’s unknown to push up and back.

Interviewer: It’s kind of funky if you don’t what you’re doing, I guess.

Interviewee: It is, to open bread, he doesn’t understand the twist tie. So it’s interesting, in the future do we have to open all bread and then put a different kind of tie on it? I’m not sure. So, with different skills we have to decide whether we’re going to teach them to him or move out of our way to buy bread that doesn’t have a twist tie that has the other little clipping thing. These are all these things that you have to start to think about as he’s getting older and trying to teach him skills.

Interviewer: Yeah, absolutely. And then do you think he will be able to achieve more independence in the future?

Interviewee: Yes, I do, I think he’s learning all the time. And he is a good listener, so I think definitely through repetition, I think showing him how to do things, he will continue to learn. I would have never said when he was younger that I could have left him alone, so like the grocery store, anything like that, that would have never crossed my mind.

Interviewer: Yeah, but now you do that.

Interviewee: But now I do that.

Interviewer: What do you think will him move into adulthood?

Interviewee: I think just having more and more positive experiences, really, to just continue to build his self-esteem. He likes praise, that’s the biggest thing for him. He likes the ‘atta boy’ he really likes that, and I think that will just continue. And he’s so proud when he can accomplish a new skill. So I think just continue to work on those kinds of things.

Interviewer: Do you think there are particular services of the interventions that you think would help him move into adulthood, also?

Interviewee: I think definite, I mean, obviously in New Jersey it’s a DVR so it’s more of a vocational program that we will use that is supposed to help him look for a job. I haven’t heard the best things, but you know, because all of us parents talk. But as you can probably tell, we’re very strong advocates for the child, so we will push any connection we can to find things that are going to work for him, for sure. I think we’ve already started with, we’ve now transitioned to Special Olympics, so he will be doing the same sports since he was 4, same hockey, same soccer. And now I’m not sure we’re going to play soccer in the Fall, we’re not even sure if it’s going to happen, but I see us now, last year we hooked up with Special Olympics, and that’s wonderful, because that can go on until, you know, forever.

[00:36:07]

Interviewer: Yeah, absolutely.

Interviewee: I think things like that are really helping him feel like masses or effusions an adult as he’s around more people that are older and doing more things, et cetera, and we have several friends on the team who definitely have disabilities but are working at a convenience store. So he sees things like that, his friends that are working.

Interviewer: So, they’re kind of like models for him.

Interviewee: Yes, I believe so, I think that’s important.

Interviewer: Absolutely. And now putting these two things together, sensory sensitivities and transition to adulthood, how do they intersect for him?

Interviewee: Like I said, looking for a job that kind of meets his needs, like working with luggage, where he has something that he enjoys, it kind of meets his needs, the heavy lifting is good for him, he likes the rolling of the suitcases, he likes to travel, so it’s just trying to intersect all of the things that he really likes. I mean, obviously we would not get him a job at a cat food factory [laughter] so you have to look at things that aren’t going to bother him. I used to joke about the best job for him when he was little, the best job I thought for him would be UPS driver. Because it’s quick transactions with people, then all the input, from the door being open, you know what I mean, he likes directions, that’s a big thing that he’s very good at, he likes heavy lifting, and everyone looks good in brown.

Interviewer: Absolutely, and you have the wheels, you talked about that.

Interviewee: Right, and making people happy when you bring them something, so that was always my big thing, but he just started having a big interest in travel and said I want to work at the airport.

Interviewer: Being personally motivated, it’s such a huge thing, so that’s important.

Interviewee: Absolutely, and we’ve a train to the airport to see how that would work for him, and he really enjoyed that. So we’re on our way to try to find things that will work for him.

Interviewer: Yeah, absolutely. And then would you say his sensitivities and interests are an obstacle, a vehicle, or both for him, in terms of his independence?

Interviewee: I think for us it’s a vehicle. Like I said, we’re trying to find a job that meets the things that he is really good at and interested in.

Interviewer: Absolutely. And then, what do you anticipate as being challenging for him as he does gain more independence in regards to his sensory sensitivities?

Interviewee: I think advocating for himself is going to definitely be a challenge for him. When he doesn’t like something, he has enough social awareness not to say something, but sometimes you need to say something. Like, you know, you have a co-worker who wears perfume every day and you can’t take the smell of it, then eventually you need to say something of figure something out, and those are going to be things that are definitely going to challenge him a lot.

[00:39:22]

Interviewer: Does he struggle to know that he can something or struggle to know how to say it?

Interviewee: Really, both. He would say something to us at home, like, I don’t like the smell of that lady, or whatever, but he wouldn’t know that he could say something, and he knows it’s not appropriate to say something, you know, it’s that fine line, it’s a social skill that we struggle with. So he wouldn’t know, you and I would go to HR and be like, listen, I can’t take this lady she wears perfume all the time, is there any chance we can establish a fragrance-free zone or something like that, try to problem solve. He would have no way to figure any of that out.

Interviewer: Gotcha, that makes sense. Do you think he could learn the skills, talk to HR when you don’t know how to talk to your co-worker? Do you think that would be a skill he would be able to learn over time?

Interviewee: I think it would be something we would have to help him out with. I foresee, like people talk about empty nest, there will never be an empty nest here, it is going to be us telling him, and I play this game with the teachers of anything, trying to help him navigate. If he comes and tells me something, we joke, it’s a who’s on first routine. We don’t know, he’s not a reliable witness so what he says is either how he’s interpreted something or you have to then go and try to figure out what is actually happening. So then it’s trying to navigate with the teachers, well, Eric is saying this, I’m not sure if this happened or how this happened, can you help me figure this out?

Interviewer: Yeah, absolutely. And then what do you think will help him in this intersection of sensory sensitivities and transitioning to adulthood?

Interviewee: I think again it’s more exposure. The more he’s getting used to things and more exposed to stuff, you just tend to get more used to things. He is relatively accommodating on many things. Again, this is a choice, this is not a choice. So, if you want to work at the airport then this is something that happens at the airport. So you will have to decide. It’s back to A-B-A, if you want B, you must do A, or if you want A, you must do B.

Interviewer: Yeah, absolutely. And we talked about vocational programs earlier, but do you think there are particular services or interventions that will help him perhaps by gaining exposure?

[00:42:10]

Interviewee: Yes, I think so, for sure. There is a program we’re hoping to do is through Facebook, called Project SEARCH. I think it’s a national program, but in our area it would be at one of the hospitals, or at TD Bank. You interview for the program, if you get accepted then they place you in free internships within their employment. So in the hospital, think about it, you could have food service, patient transportation, records, janitorial, anything from that. TD Bank I think it’s like setting up meetings, but TD Bank is not high on my list, I’d rather go with the hospital, but of course, we’ll have to see where we are with COVID. But if we did something like Project SEARCH, that’s great, that gives him even more exposure. I like the vocational at school too, because this was his first year working, he could have done it the year before, but we chose to keep him with the academics. With this he’s at Habitat For Humanity, he’s vacuuming carpet, so it’s dirty work, he doesn’t love that, but he does it, you know what I mean? It’s cleaning at a restaurant, a small little mom and pop, he doesn’t love it, but he does it. So, you know, those kinds of things, the more exposed to it, the more you see other people doing those things and it not bothering them or them doing it, the more helpful I think it will be to him.

Interviewer: Yeah, and it’s also important to learn how to do things you don’t like to do.

Interviewee: Absolutely.

Interviewer: Because that’s life.

Interviewee: And, again, that goes back to us using “this is not a choice.”I always sounded like the bitch at Target, “*This is a choice, this is not a choice*.”But that is true, you have to be, especially with people with autism, you have to give them concrete choices. They’re not very good at gray, they’re good at black and white. You have to set your parameters appropriately.

Interviewer: Do you feel like there are gaps in the available services to him in this intersection?

Interviewee: I don’t know, we all worry about the cliff, when he turns 21. I guess we’re going to have to see what’s out there. I talked to girlfriend yesterday whose son is unfortunately 25 and they’re just kind of getting him set up with services, she’s the stepmother, so I’m going to give her that, but she said, you know, I talked to DDD, which is Department of Developmental Disabilities here in New Jersey, and they asked what services do I want? And she said, well, is there like an index of services? And they said no, you just have to tell us what you want. She she’s, I have no idea what I want. So that’s when you have to start talking and networking, talk to other parents, going to every conference you can, going through The Arc, I know The Arc of New Jersey has wonderful resource programs to kind of tell you what else is out there, because sometimes you don’t know.

[00:45:16]

Interviewer: Mm-hmm, absolutely. And I’m thinking kind of ahead, or more globally, rather, how did his sensitivities and interests impact your goals, hopes, and expectations of him in terms of transitioning to adulthood.

Interviewee: I guess again, we look at where he’s at and we know what his strengths are and where his deficits are, and we try to tailor his future to that. Will he be able to live without us, because of the some of the sensitivities. Will he be able to share a bathroom with smells and textures of things, toothpaste in the sink kind of things, that’s something we just continue to work at. So, I think it shapes everything that we do. We look at him as a total individual, quirks, what do they call that, I don’t know, spots and all, you have to look at the whole person and decide what’s going to work for them. And we do the same thing for our typical daughter, we look for schools for her, anything we did, any decisions that we made when she was younger, you have to look at things that work for her. We kind of joke, like she wanted to study abroad or go somewhere, and we’re like, well, you can’t a ride a bike, so you can’t go to Amsterdam.

Interviewer: I can’t ride a bike, either. [laughter]

Interviewee: But it’s the same thing, like, you can go to Amsterdam, but you can’t spend a whole semester in Amsterdam if you can’t ride a bike. [laughter]

Interviewer: True, I did not go there either.

Interviewee: It’s kind of an odd example...

Interviewer: A good example.

Interviewee: You know, you might be able to learn enough French, Spanish, or whatever, to study or be somewhere else, but if there is a skill that you have not been able to master, nor showed willingness to master, then that’s probably not the place for you.

Interviewer: Absolutely, it’s all about fit.

Interviewee: Yeah, it is all fit.

Interviewer: Mm-hmm, and so now we’re going to go into our last chunk of questions, so we’re almost there. As a caregiver, as a mom, as a parent of someone has ASD and also sensory sensitivities, what does transitioning to adulthood mean to you?

Interviewee: I guess it means it’s kind of the push to get them as independent as possible. Like I said, I’ll never really have an empty nest, I know that we’ll always have to continue to support him emotionally and physically in his quest to do things, and like I said, we put the financial piece in as much as we can, applying for SSI, and guardianship that gives the tools we need to be able to manage everything.

[00:48:06]

Interviewer: Mm-hmm, yeah, and has this changed over time? This perspective?

Interviewee: I think so. As he has changed, he is definitely not the same child he was at 5, thank goodness, we would be looking at a totally different picture. If he was the same child as he was at 5 then he would not be living independently, we would both be medicated, him and I both [laughter] in order to cope with things. It would definitely be a much bigger challenge. We would probably be looking more like a sheltered workshop versus some independent work.

Interviewer: So, is he more independent than you thought he was going to be?

Interviewee: Absolutely, absolutely. Yes, he really was challenged verbally, was really unable to make his needs known. There were a lot of GI issues, a lot of behavior issues. He was physically aggressive towards me. So he definitely is a much different child today, thank goodness, than he was.

Interviewer: And so what do you specifically in his future?

Interviewee: We see him being happy and healthy, that is the goal. And however that is going to be achieved, we’ll see. He has a girlfriend, the girlfriend would like to get married and talks about the honeymoon almost every day, more so not what happens on the honeymoon, but where they’re going. He has verbalized to us that he doesn’t want to have children, which is good, because that is not a part of our plan, as well, we don’t want him to have children. But we see him being able to work at least part time, and then also doing some volunteer work. We want him to continue with sports, he enjoys that, and we’ll do everything we can to make all that happen.

Interviewer: Yeah, I’m sure you will. And then the last question, how did his sensory sensitivities impact this current perspective that you have?

Interviewee: I guess especially when he was younger there were so many different things, so many different things to learn, and it’s really adapting. It’s learning if Plan A, B, and C don’t work, go to D. I think we just continuously looked for ways to try to increase the goals, try to introduce new fields, to try different things. You know, I know you don’t like this shirt with buttons. But let’s try this for 5 minutes. Or even adapting my own things, I look at pictures from when he was little and I had him in a little shirt and a little tie, and he was miserable. So, I learned that the next time we do pictures, we do a t-shirt with as sweater vest, and that way we don’t have the tantrum of the ...

[00:51:17]

Interviewer: Of the tie...

Interviewee: ... the buttons, right, and so it’s learning to manage my expectations, our expectations with what he can and will be able to tolerate.

Interviewer: Absolutely. That’s actually it for all my formal questions. Is there anything else that you would like to add?

Interviewee: No, I don’t think so, I think for us a lot with his sensitivity issues for us, especially with a communication disorder, a lot of it was trying to establish whether it was, is he choosing not to do something, or is he unable to do something, and that was really the big one for us. Are you choosing not to do this, or are you really, your sensitivities are that you cannot do this.

Interviewer: Gotcha.

Interviewee: And then you have communication impairment, which is what autism is, that is very much a challenge to try to figure out.

Interviewer: Yeah, absolutely. And how were you able to make that distinction? Or you still working on making that distinction?

Interviewee: We’re still working on it. We go back to the Abbot and Costello, Who’s on First? It’s just trying to figure what you physically can’t do and what you say I don’t really want to do this. Obviously, things for us have gotten a lot better. We have a friend, my business partner with the nonprofit, her son is 25, has autism, and he cannot make a phone call, his anxiety is high. He has a college degree, he has worked, drives, functions at the level you and I do, but his kryptonite paralyzed, cannot make a phone call, and always thought that he could make a phone call if push came to shove. His mother fell and broke her ankle, and he could not call 911. That is not a won’t...

Interviewer: Yeah, a can’t.

Interviewee: And I think that made it very crystal clear for him mom, that this is a major problem. She constantly is trying to get him to make small phone things, order a pizza, try to do things like that to try to increase his ability to feel positive about doing those things. But that’s a prime example of a ‘can’t’ versus a ‘wont.’

Interviewer: Yeah, absolutely, that’s an excellent one, for sure. Thank you so much, this is all I have. It was wonderful to hear your perspective and learn from you, so thank you.

Interviewee: Thank you, Rachel, it’s good to talk about it. That’s one of the reasons, besides wanting to be helpful, filling out the survey is very helpful for us to see things that I couldn’t verbalize. A lot of the survey said things, I’m like, wow, I never thought of it that way, or something that I can’t do or could do, I couldn’t have worded it that way.

[00:54:21]

Interviewer: I can send you the survey so you can see the responses if that would be helpful.

Interviewee: That would be wonderful, I think that would be very helpful to me, because I think it is, we’re still looking to try to make the transition as easy as possible.

Interviewer: Yeah, absolutely.

Interviewee: I try to do anything I can to learn about transition.

Interviewer: I have some other, my co-worker just last week, she took a law school class about Special Ed and the law, I’ll send you something she sent me about transitioning, too.

Interviewee: Oh good, that would be great. Yeah, it’s funny, because I’ve been going to conferences on transition for the last probably four years, but you know, as soon as, everything is going to change, you know, it’s a new governor, it’s a new president...

Interviewer: It’s a pandemic [laughter] ...

Interviewee: Yes, everything changes, so you go and just be as informed as you can about what’s currently happening and hoping it’s not going to change that much.

Interviewer: Yeah, absolutely. I’ll send you some stuff. Do you know what NSAR is?

Interviewee: I think I’ve heard of that before.

Interviewer: It’s like a national autism research conference, and they have like a summer institute every summer, and this summer was all about transitioning, so I’ll send you that stuff too.

Interviewee: Oh good, okay, that sounds great. I appreciate that, I can share some of that stuff with my cohort here.

Interviewer: Yeah, spread the word. So, I know you shared our Facebook post, thank you. Do you know anyone else individually who might want to participate or be eligible?

Interviewee: Let me think about it and see if I can come up with some other people who might be interested in it. I have a girlfriend whose daughter is nonverbal who has a lot of sensory issues. She was part of like the John Hopkins Feeding Clinic for a while when she was younger and she wears head cones when we go out...

Interviewer: ... Yeah, she’d be great, and we have no restrictions on language ability, all we ask is between 16 and 26, autism and sensory stuff.

Interviewee: And she is 19, and yeah.

Interviewer: Beautiful, if her mom wants to participate or dad, or whomever, we would love to have them.

Interviewee: I will ask and see if she wants to participate.

Interviewer: And if she doesn’t, it’s also super okay, we don’t want to pressure anyone.

Interviewee: No, that’s fine, that’s fine, the mom is actually like the original Snow White, she’s very soft-spoken, with black hair that curls under, she’s lovely.

Interviewer: Yeah, I’m sure. Well, thank you again, I will send you a gift card also as a thank you for your time.

Interviewee: Thank you very much, I’m very good to gift cards [laughter].

Interviewer: Excellent, use it well.

Interviewee: Alright, thank you, Rachel.

Interviewer: Yeah, it was nice to talk to you, again if you have any questions for me, let me know, I’m happy to help in whatever way I can.

Interviewee: I’m sure we’ll see each other in the future.

Interviewer: Hopefully, post-COVID, I’d love to see you in person.

Interviewee: Take care.

Interviewer: Bye.

[00:57:18]