**[Start of transcript]**

**Interviewer:** Okey-doke, we are recording. And I will be asking you questions about your perspective regarding your son’s transition to adulthood in relation to his sensory sensitivities. And I’ll be doing something called a ‘semi-structured interview,’ which means I have my planned questions and my script. But I’ll also be adapting them to fit our conversation so that actually makes sense for you and for your family. Do you have any questions?

**Interviewee:** No, I don’t.

**Interviewer:** Awesome. And if there are any questions you don’t want to answer for whatever reason, that is perfectly fine. “*I don’t know*” is perfectly fine as an answer as well. And if there’s anything you think of from earlier, feel free to bring it up whenever it comes to mind.

**Interviewee:** OK.

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

**Interviewee:** Current?

**Interviewer:** Sure, you can start there.

**Interviewee:** So he has strong smell feelings, like, if, you know, I’m eating something that he doesn’t like. He has very strong food preferences in terms of what he’ll eat and won’t eat related to the taste or the texture. He actually likes to put a lot of food in his mouth—not all the time, but pretty often. I think he likes the full feeling. He, you know … we haven’t asked him to wear anything out of, like, the sort of normal sweatshirt and shirt that he wears, but it wouldn’t surprise me if he still had, like, negative feelings about harder things on his body. He did, at least, when he was younger.

**Interviewer:** Did you say harder things?

**Interviewee:** Yeah, well, I’m just thinking of, like, chinos or button-down shirts, things that are less soft. And sound—so that was actually interesting filling out one of the forms because … the form about background noises. You know, we usually have, like, an air purifier in Nathan’s room because he spends so much time there. That does not seem to bother him, like, kind of like white noise. But if you had music playing near him, or a podcast, he would … if it wasn’t what he wanted to listen to, it would bother him. **[crosstalk at 2:31]**

**Interviewer:** Do you mind if I ask some follow-up questions?

**Interviewee:** Sure.

**Interviewer:** You mentioned smell first: could you talk a little bit more about that?

**Interviewee:** Like, if I’m having salad and salad dressing, he’ll be like, “*That smells gross*,” you know, really around food that he doesn’t like.

**Interviewer:** When you say they tend to be smells that you wouldn’t … that you yourself don’t notice?

**Interviewee:** Oh, well, I wouldn’t notice salad dressing because I like salad. And it is a pretty mild smell, you know. And—I’m trying to think if there’s anything else that’s, like, a good example of how that strong smell … the only thing I can think is it’s when it’s food when he doesn’t like it.

**Interviewer:** That’s fair. Thank you. And you did mention he had, like, has a lot of food preferences. Could you talk about that?

**Interviewee:** Well, he’s definitely, like, a white carbs guy. And—I think I mentioned last time we talked too—kind of a monogamous eater. You know, he won’t eat stews, if they have, you know, a lot of things together. I mean, there’s a lot of food he won’t eat period, but he really does not seem to like food to be mixed. And it’s not a visual thing, I don’t think. He won’t say, “*I don’t like those the way they look on the plate together*.” He did used to say that when he was younger, but it’s more like that I think it’s the **[4:00]** texture and the taste so, I think. Last night—my oldest my daughter’s here and cooked lentil soup and I was shocked because she actually got him to eat it and it had a little spinach in it. I was like, “*OK, let’s see how this goes*.” What … were you asking about the food preferences? So, you know, he likes cheese and bread. He will eat protein sometimes, like meat or chicken or fish, but it’s, you know, not consistent. He loves burritos. Likes burritos.

**Interviewer:** Even though they’re all mixed together like?

**Interviewee:** Yeah, yeah, yeah, yeah. Well, but he keeps them pretty simple. He has rice, cheese and **[inaudible at 4:52].** But yeah, yeah, yeah.

**Interviewer:** And, aside from keeping things separate, does he have other textural preferences when it comes to food?

**Interviewee:** I feel like he likes to stay in that continuum of not totally hard, but medium textured bread, cheeses. I mean, he’ll certainly have ice cream, you know. If he has a popsicle, he winds up chewing it, rather than licking it. He won’t say, “*I’m not going to eat that because it’s hard*.” So, to soften, he’ll say, “*I don’t really like the way that feels, you know*.”

**Interviewer:** That makes sense. Thank you. And you talked a little bit about clothes, like, liking more, like, comfortable clothing: does he have other textural or, like, touch preferences when it comes to, like, his body?

**Interviewee:** He’s always had a really hard time with keeping band aids on. He doesn’t like the way they feel. And, like I said, through his life, he’s gone through different periods where he’s, like, liked or not liked baths. He doesn’t … he will take showers, but he doesn’t like them. Lately, he’s back into baths again. So, you know, some of this stuff is not consistent. He doesn’t like it when his hair is long. He doesn’t … that’s actually the one thing … he’s not a kid who does not like to be touched, you know. He likes to cuddle. But he actually likes his feet massaged. He’ll will often ask, “*Rub my feet*.” But he will … Just a minute, wait. What was I saying?

**Interviewer:** I was asking you about touch.

**Interviewee:** Yeah, but I was talking about …

**Interviewer:** His hair.

**Interviewee:** Right. That’s what I was trying to say. So like, yes, he actually has luxurious hair, so like his hair so if his hair’s a little longer I might tend to, like, you know, go like that. And he doesn’t like it. He’s like, he’ll say like, “*Don’t do that*,” you know, “*time for me to cut my hair*. *Is my hair long? Is that why you’re doing it?*” And, yeah, I think that’s it on the texture piece. But again, that’s an example of … when he was younger, like, there would definitely be clothes that he would not like. In fact, he didn’t like to wear clothes that had more than **[8:00]** one color on it. He would want to wear solid-colored clothes, or he didn’t like T-shirts that had a print on it **[inaudible at 8:09]**. And it wasn’t even something that was, like, front and center for him visually, but you know … I mean—as an aside—that was really interesting for me in filling out these surveys, because obviously we’ve been filling them out for a while. I mean Nathan’s … so much of what I was answering was in the ‘sometimes’ category and that generally has been consistent because he’s, you know, he’s fairly high functioning but I … there were some answers that I was like, “*Oh, wow. That he’s … like, he’s progressed. He’s got it more together now than he used to*.”

**Interviewer:** Good. Awesome. I’m glad it could be reflective as well. For baths—you mentioned he’s gone on and off liking, disliking: when he does dislike it, what about baths does he dislike, do you know?

**Interviewee:** I think all he would say is “*I don’t like the way it feels*.” He wasn’t very specific.

**Interviewer:** That’s perfectly fine. Thanks. And you also talk about sounds and disliking sounds he doesn’t pick: is that all sounds; is it just, like, music versus, like, alarms or sirens?

**Interviewee:** Not sirens, but, like, all sounds in his immediate environment.

**Interviewer:** OK, awesome. Thank you. And does he have sensitivities to visual stimuli like lights or something?

**Interviewee:** Not that I … not that are noticeable. When he was very, very young, as a baby, yes. Like, when we were in the car and the light would change when we were driving that would bother him. But I don’t … that’s not something that rings a bell with me now.

**Interviewer:** Awesome. Thank you. And—you’ve alluded to this in your answers, but—how have his sensory sensitivities changed over time?

**Interviewee:** Well, some of them have mellowed, like … the clothes are the best example. However, I’ll tell you that, like, we haven’t … one of … Nathan has some motor planning and motor skills challenges. So, for example, getting dressed by himself, though he’s making progress, is still challenging. So and we’ve … he doesn’t really … this is actually probably a sensory thing. He’s never really liked pants like jeans or, you know, that needs to be buttoned and zipped. And I think part of that is him not liking the feeling. And part of it is that, because he has trouble with that kind of stuff, if he was off at school needing to use the bathroom, that would be difficult. So we never went in that direction. So I’m not sure he … and he also doesn’t … like, he wouldn’t … he would just be inclined to wear clothes that were more like joggers or sweats. And so I guess what I’m saying is: I’m not sure how much of that is avoidance on our part, so that he can be independent or his part because he doesn’t care, like, so much about fashion and what he looks like, or how much of it is sensitivity to the feel. But my instinct is that he doesn’t like the way the harder, more bound things feel.

**Interviewer:** Absolutely, thank you. And what about his food?

**Interviewee:** I would also say—and this is sensory, I think, in a dulled way—he doesn’t feel things around his middle the way that I would or that you probably **[12:00]** would, meaning, you know how if you put pants on backwards, they’re going to feel awkward. He also mostly doesn’t notice that. Or if pants were sort of, you know … if you didn’t do a good job straightening even sweats and they were sort of folded over or twisted—twisted is a good example. He doesn’t feel that. He won’t even notice that.

**Interviewer:** Yeah. Does he, like, notice if he’s, like, if he has a stomachache or something?

**Interviewee:** Yeah, yeah, he would.

**Interviewer:** Thank you. Have his food preferences changed over time or has that been pretty consistent?

**Interviewee:** Some of his food preferences have been quite consistent. And he’s never been, like, a diverse eater for sure. But are there things he used to eat that he doesn’t now?I think so. Like, he used to have cereal and milk a lot and now he doesn’t. But I’m not sure if that’s, like, a sensory change, or if that’s he gets bored of it, because he eats … whatever he likes, he eats a lot of.

**Interviewer:** What about smell: has that always been consistent as well?

**Interviewee:** Yes, yes. Yes. Yes. And on the food thing, one thing that has been consistent is this desire to have a lot in your mouth.

**Interviewer:** And that stayed the same?

**Interviewee:** Yeah.

**Interviewer:** Awesome. Thank you.

**Interviewee:** Again, he is very upset if you try to address it with him.

**Interviewer:** And what about his preferences towards sound: is that also consistent?

**Interviewee:** Yes. I actually think he’s mellowed on that one a little bit. But, like, car rides, major issue. We wanted to be listening to music with the family or listen to a book, it was impossible. Literally.

**Interviewer:** It was impossible and it’s no longer impossible?

**Interviewee:** We still definitely could not do that. We can negotiate with him a little bit, you know. Like, “*Well, can you …?*” and had us choose a song we would both like to listen to and he will engage with that process and do that. But he wouldn’t be like, “*OK, for 20 minutes somebody else gets to listen to their music and I’ll be OK with it*.”

**Interviewer:** Gotcha.

**Interviewee:** He also really does not like wearing earphones. That’s another sensory thing. Even earphones like you wear or earphones in your ear. He doesn’t like the way they feel and so that makes things very difficult and he also doesn’t like the way they sound. He says they sound different.

**Interviewer: [15:00]** OK, that makes sense. Thank you. So, you’ve talked a little bit about mellowing for some of his sensory sensitivities: do you think those changes are related to any independence that he’s gained over time?

**Interviewee:** Trying to think of the ones that he has changed on. The clothes, I wouldn’t imagine changed because of independence. Like, I don’t want to wear a print shirt, because why? I don’t see how that’s related. The sound, I would say more like just learning maturity and flexibility rather than independence.

**Interviewer:** That makes sense.

**Interviewee:** And what were some of the other ones I talked about?

**Interviewer: [inaudible at 15:53]** you said that mellowed.

**Interviewee:** Yeah.

**Interviewer:** Awesome. Thank you. And so how does your son manage or cope with his sensitivities or how do you help him manage or cope with them?

**Interviewee:** Oh, the other really interesting sensory one that I didn’t mention—and I don’t know where it fits in, like, the five senses—but, in the last year—longer, probably, a couple years maybe—he has taken to wanting to watch videos of the food that he’s eating. So, like, if he’s eating nachos, he’ll find a ridiculous, you know, video of someone doing a review of nachos and he doesn’t want other people to be at the table when it’s happening, that’s actually been a huge source of conflict, particularly with his siblings when they’re around. I think that I’m about to move. Let me just mute and …

**Interviewer:** I’ll see you soon. … **[18:00]** All right. Hello, again.

**Interviewee:** So yeah, he really likes to watch these videos and he really doesn’t like other people to be at the table when it’s happening. And I do think that that’s a sensory thing. Somehow it relates to his eating. It’s sort of multi-sensory. Anyhow, what were you asking before then?

**Interviewer:** Yeah, I was asking, **[crosstalk at 18:44]** no, no, please. I’m happy you shared that. I was asking how your son manages or copes with his sensory sensitivities, or how do you help him or your family?

**Interviewee:** All right, so that came up, because that’s a bit of a conflict in our house. So what we’ve done with that one is just said, “*OK, that’s fine*.” But then, you know, he’d be like, “*Well, then don’t cook something I like*,” because he doesn’t really get or … he’s not interested in this idea of, like, a family meal where people talk to each other. He will sometimes engage in that if he’s interested or in the moment, but he’s not like, “*This is something that, you know, should accompany eating*.” So he usually eats, you know, at other times, and then no one’s at the table. However, it is sometimes a conflict if someone’s sitting there and we just sort of negotiate and occasionally we can get him to move to an alternate flat space, sometimes we move. So, similarly with the sound, it is a negotiation and we always try to, like, push him a little bit, you know, perspective taking and all that. So it’s a combination of, “*OK, we’ll turn it off. Can you wait three minutes, blah, blah, blah?*” With some of these it’s just very difficult because it’s almost like, you can imagine in his brain it feels like screeching on a blackboard, which is hard for people to understand. Because it just seems, like, so normal, but, you know … So compromise and then, with certain things like a bath or a shower, you know, we’d be like, “*Well, you just have to do it, even if it’s for two minutes, because it’s a hygiene thing, and we know you care about yourself*.” And, you know, as a teenager, he’s gotten better at that. Like, he doesn’t like taking showers. Again, I don’t … I think it probably is sensory that, like, he doesn’t really like the feel of the water. But I also think … Oh, I have another one. I also think it’s just, like, multi-step process. It’s hard for him, the shower. But he really does not love the beach. He does not like to feel sand on his … and it’s hot, you know. So, I mean, that’s something that, like … one of my other kids doesn’t like the beach either. But it’s a little bit stronger with him.

**Interviewer:** Gotcha. And, for his smell preferences or just, like, do you, like, you or your family **[inaudible at 12:16]**?

**Interviewee:** So that’s sort of an easy one, because, like, “*OK, if you don’t like the way it smells,*

*just go somewhere else*.” And if we were both eating at the same time, and he was hungry, I would probably move.

**Interviewer:** Got you. And for touch and his clothing: does he just not wear the things he doesn’t like?

**Interviewee:** Right. I mean, you know, again, like, especially these days, things are pretty casual. But, like, if we needed to go to a formal party or something that was dressed up, he would manage it for the top. But he would wind up, like, probably taking it off as soon as possible.

**Interviewer:** Got you. Thank you. And has he ever received specific therapies or interventions for his sensory sensitivities?

**Interviewee:** I mean, the one that I think probably the **[22:00]** most is the touch because that has to do with OT, and he’s done, you know, some free OT stuff. I don’t know … there was so much going on that you could work on. I don’t know that anyone would have said, “*We’re* **[inaudible at 22:16]** *his sensory sensitivity*” at the time, but, like, the idea was all of these things that we’re doing are going to help his, you know, his systems.

**Interviewer:** Yeah, absolutely. Do you feel like the OT helped him in that capacity, in his sensory stuff?

**Interviewee:** I don’t really know. I mean, with a kid like Nathan, there was so much. I mean, thankfully, so many services being given, it’s hard to know whether it made a difference in the time he was receiving it or just over the years. He really didn’t like it, you know.

**Interviewer:** Got you.Thank you. And when your son is in an environment that has sensory experiences that are aversive to him, like, say, the smell or the sounds or touch, does that cause or increase anxiety for him?

**Interviewee:** Not in the way that I can imagine the most obvious example of that would be, like, if someone didn’t like thunder and it was a thunderstorm and they would get very anxious—not like that, but he would get very agitated. So, in that way, you know, sort of related.

**Interviewer:** Yeah. And, like, how does he handle his agitation or how do you help him or your family help him with that?

**Interviewee:** Well, I mean, the little example is, like, he … the feeling of a band aid. He would just wind up taking it off. In something like listening to music in the car, things could escalate pretty quickly, like, he would not be able to handle if you said, “*No, we’re going to have it on for 10 minutes*,” you know. And it would, like, not be worth it to have that argument in a moving car. He used to go to my family, my parents had a, like, cousins’ camp they would run with all their grandkids. And they used to have a music car and a quiet car and the quiet car was for Nathan, you know, where he wouldn’t have to listen to the music. So when else would he get agitated? You know, I can imagine if, like, in school, in a … this sounds sort of vaguely familiar to me, when he was younger if they were doing, like, an assembly of some kind, he didn’t like the noises or whatever, you know, his teacher would take him out.

**Interviewer:** Yeah. And you just kind of alluded to this with your example, but have these sensory experiences always caused agitation, has that changed?

**Interviewee:** Yeah, no, I think that’s probably … The things that Nathan gets super anxious about are, like, worries, they’re not physical sensations.

**Interviewer:** And, just to clarify, you were saying he … that agitation is pretty consistent.

**Interviewee:** Throughout his life, yeah. But he’s more, you know, mature about it. Like, when he was younger, maybe he would, you know, lose it.

**Interviewer:** Got you.So the management has changed, but not the **[26:00]** actual feeling.

**Interviewee:** Yeah.

**Interviewer:** Gotcha. Thank you. And now, thinking a little bit more broadly, what goals or hopes do you have for your son in regards to his sensory sensitivities?

**Interviewee:** Well, I think it depends on which ones. I think about the ones that could negatively impact his life generally. So, you know, one of them, like, the feeling that he likes of having a lot of food in his mouth, it’s kind of a turnoff for other people at the table. So I do hope that he’s able to modify that. He also, by the way, doesn’t … this is a combination, I think of, you know, you talk about sensory sensitivities, but that’s a spectrum. And on one side of the spectrum is not feeling things. And that’s going on with Nathan, so, like I said, not feeling how clothes are on properly or not, not feeling whether your hands are messy or your face is messy. That’s a big one. So he’s more, like, hyposensitive. And so I really, I hope that he’s able to get a little more awareness around that, so that he will be able to be in relationship—whether it’s, you know, deep or not—with lots of different kinds of people. And I certainly hope that he will continue to be able to, you know, wash himself and all that stuff in terms of water sensitivities and clothing. So those are the ones that I think about the most and a little bit the sound, I feel like that’s a little bit easier to manage, but …

**Interviewer:** Thank you, that makes sense. All right, we’ll move on to our next chunk of questions: so, as your son has grown up and aged a bit, how has his or your community reacted to his sensory sensitivities?

**Interviewee:** Yeah. So, I mean, I would say—by community, I mean school—he’s always been in with special ed services and we’ve had to work with the school at times about some of this stuff, but for the most part, you know, they’ve been open to being on a journey with us. So occasionally things will pop up that … especially when he was younger, like, well, he’s being stubborn or something like that, you know. But where I’d say it is noticeable is with our extended family, like my parents and his cousins, especially when he was younger. There was definitely a mismatch of expectations about, like, what Nathan should be able to handle and what he, you know, could handle. So, how have they handled it? What was the specific question again?

**Interviewer:** How has his or your community reacted to his sensory sensitivities?

**Interviewee:** Yeah, so, depending on the person, I want to say not well. I mean, like, the most obvious example being, like, my dad, who would, like, basically have the attitude that he should just manage his feelings and deal with it. And it caused definitely a lot of conflict. And it was … like, actually I was just thinking about this cousins’ camp. Nathan is one of four, with a twin brother, two older sisters and they, you know, had lived with him enough that they were able to be advocates for him, but it was stressful for them because they were young and they were having to, you know, have these conversations with their cousins and the grandparents and there was definitely, in some years, an attitude of like, “*Oh, well you …?*” that our family just, you know, **[30:00]** lets Nathan rule the world which, of course, was not how we saw it at all. And but it was just, like, conversation, education, that kind of thing. Yeah.

**Interviewer:** Thank you. I appreciate that. Would you say the community was more or less accepting when he was younger?

**Interviewee:** Less.

**Interviewer:** Why do you think less when he was younger?

**Interviewee:** Well, I think his reactions were stronger, right. And so they’re, you know, you had further to go if you were going to accept it. I also think, frankly, even in the last 10 years, Nathan’s 18 … even in the last 10 years has been increasing awareness and education around, you know, ASD. I, you know, I mean, we’ve been the beneficiaries of having Nathan when we did, because so many of the services and the laws that, you know … There have just been a lot of really positive changes in the last 10 to 20 years. So that’s part of it. I also think that, you know, they’re a little bit less noticeable now because Nathan’s able to manage them more. And, yeah, those two reasons probably.

**Interviewer:** Awesome. Thank you so much. What are other spaces or places: you just talked a lot about, like, school and family—were there other aspects of community that were more or less accepting of his sensory needs?

**Interviewee:** No, I mean, I think the only two other … I guess two or three other places that you could … that would be relevant. One is, like, stores and restaurants. And, you know, over the years, we’ve just taken Nathan fewer places that were problematic. He doesn’t like stores. OK, he doesn’t need to go to stores, he can order most things online. You know, restaurants are hard for him—actually really hard for him. It’s hard for him to sit for that long. He gets bored. And I think he probably gets, you know, overstimulated. It’s not like he’s saying, “*It’s too noisy in here*.” Sometimes he might, but it’s just … I really do think it’s sort of like the … so we would take him when he would want to go, because Nathan does like to be with people. But inevitably one of us would wind up, you know, leaving and going for a walk with him toward the end of the meal. So there’s that. And then there is our synagogue community, and we just would take him less and especially as he’s gotten older and he can be by himself, it’s fine, you know. So I can’t really think of, like, where else, you know, we’d be, thinking about it.

**Interviewer:** Has he ever had a job, like, a work community?

**Interviewee:** No, not beyond school, everything’s been through …

**Interviewer:** Thank you. So again, thinking broadly, what hopes or worries do you have for your son in terms of how his community will react to his sensory needs in the future?

**Interviewee:** Well, like I said, thinking about the one around food, like, negatively, like, “*I don’t want to be with him*,” so that would be a worry. Or that, like, around the sound, they would just think that he’s being stubborn, you know. In the worst-case scenario, you know, I can’t really imagine what it would be. But like, if he was in a place where his sensory stuff was getting in his way and he lost it, and someone thought he was being aggressive and he got in trouble with the **[34:00]** police, like, that would be a nightmare scenario.

**Interviewer:** Yeah, absolutely. Thank you. I appreciate you sharing that. We’re going to go on to our next chunk of questions now. So, in the transition to adulthood, quote unquote, where do you see your son?

**Interviewee:** In the transition to adulthood, like, in the next four years?

**Interviewer:** Like, do you think he is approaching independence? Do you think he’s still gaining skills? **[crosstalk at 34:28]** Do you think he’s, like, age appropriate or not, like, not age appropriate but, like, developmentally with on par with his peers?

**Interviewee:** OK, definitely not. I think he’s so much more independent and curious than he was, you know, like, let’s say four years ago. It’s hard to put a pin on it in terms of, like, where he developmentally because someone said … an OT we worked with years and years ago said this about, like, kids on the spectrum, “*They’re like Swiss cheese*,” you know, “*they’re … you can develop and they’ll be, they’ll be going along, but there’s still these huge holes*.” And that’s the case with Nathan. So I can’t really put, like, a pin in it. It’s not straight, it’s not linear. But, you know, there are some areas that he can really independent on. Like, last year—or two years ago even, at this point—he was really, really adamant that he wanted to go to a Celtics game by himself. And we were like, “*Well, that’s, like, kind of a big deal*. *I don’t know, bla bla bla.*” But we worked with him on it over a course of, like, four to six months, and he did it. So, you know, he can take the public transportation, he was there by himself, he met us there, you know, so there are pieces like that. But he also will not. He still needs scaffolding, support when he gets out of the bath to … like, we lay his clothes out for him. So, not there yet.

**Interviewer:** Gotcha. Thank you. Thinking a little bit more about, like, stages of independence: could you describe some areas where he still needs some support versus some areas where he is able to do things independent to a degree?

**Interviewee:** So where he’s really independent is with his computer and technology. Like, he’s very, very comfortable with a computer and, you know, finding information, getting at his classes. You know, if you wanted to find out when a Celtics game was, what day, what time, all that would be very … And he can … you know, if he has a question about a game that’s available or something, he can make a call by himself. He still gets nervous, and has to talk about it but he’s totally independent with that. I think he has emerging independence with some minimal food prep, like, he could never make himself a meal, but if he wanted to heat up a burrito or pasta with, you know, spaghetti sauce that was all in the fridge and already cooked, he could do that, you know, pour juice, all that kind of thing. And he can get dressed by himself. But he will often have his clothes on backwards. He doesn’t, you know, drive and isn’t interested. He’s said, “*I don’t know that I’ll ever want to drive*.” And it would be challenging for him, like, if he needed to get, like, five things together and put them in his backpack and get his coat on. And that’s the motor planning. And it’s also **[38:00]** focus, you know.

**Interviewer:** Absolutely. Thank you. How is he with daily hygiene and things like that?

**Interviewee:** We need to prod him. So, like, he won’t brush his teeth in the morning unless I remind him. And he does not have the attitude that he should, like, bathe himself every day. Except that right now he’s really into baths. So he will take … he will say, “*I want to take a bath*” and he’s pretty … he can … at this point he’s pretty independent about getting in by himself out by himself, all that kind of stuff if we lay his clothes out. But he will still, like, call and say, “*I’m ready to get out*.” And I’ll say “*OK, the towel’s right there*,” you know.

**Interviewer:** Yeah. And what about, like, household chores: is he able to, like, help load the dishwasher or take things out?

**Interviewee:** Able to or does he do it? That gets into who Nathan is, as a philosopher. He will tell you like, “*I don’t really want to grow up, like, I don’t, you know, I don’t want to have all these responsibilities*.” But anyway, he has a very negative attitude about helping out around the house. He doesn’t really feel like he should have to. And I could get into why he argues that. He has some very articulate, you know, points. He’s a smart debater. But could he? Yes, he could. He could take out the garbage. I think loading the dishwasher would be more challenging for him in terms of **[inaudible at 39:39]** and things. He has done laundry in the past.

**Interviewer:** Got you. Thank you, and—perhaps in a pre-Covid world—was he able to help you with shopping to, like, get things that he or you needed?

**Interviewee:** Well, he really doesn’t like being in stores, so we wouldn’t, you know, mostly wouldn’t bring him shopping unless you were going for a very specific thing that he was super interested in and you could sort of get him to go. I will say that Nathan’s one of these kids for whom the pandemic has actually been a real gift. Because he’s been able to be in his favorite place, which is home. And he’s engaging in school, he’s taking online, you know, drum lessons and voice lessons … but it has effectively taken away everything that’s super hard for him. Like getting dressed, getting organized to get out of the house, moving around in the world, you know, which is exhausting for all of us, and particularly exhausting for kids like Nathan. And so I … you were asking about **[inaudible at 40:46]**…

**Interviewer:** I asked about like, does he like helping with shopping and stuff.

**Interviewee:** You know, Nathan, being out in the world was really around, like, what he wanted to do. And school has always been a major issue. Like, he’s always hated school and he’s particularly hated going to school. So.

**Interviewer:** Got you.Thank you. And I think you mentioned he doesn’t really want to grow up, he doesn’t really want those responsibilities: does he ever express interest in wanting to live on his own, or is he happy in your home right now?

**Interviewee:** He’s happy in our home right now. We’ve definitely had conversations about how at some point he might want to live elsewhere and, you know, have a peer group that he’s living with or whatever. He will acknowledge that possibility, but he’s not that like, “*Oh yeah, that’s what’s going to happen*.”

**Interviewer:** Gotcha. And I believe you said that he hasn’t had a job: does he express interest in wanting one?

**Interviewee:** No. I mean, and he’s definitely very engaged with, like … we have, you know, case manager for mass rehab, and he’s got a lot of good transitional sports through the school. So they’re working with him on it. And he actually was—**[42:00]** actually I shouldn’t say that—he did act as a CIT, one summer, two summers ago. But very, very, like, supported, not sort of, like, your normal CIT expectations. But he was … Newton has a mayor’s internship program that he was going to participate in, and then it was Covid—and in the summer Covid, again, so I don’t … you know, that’s the negative. There have been a lot of positives for him about this. But those are negative. So how quickly it’ll happen … so but I mean, I think he will be able to have something definitely.

**Interviewer:** And is it because he wants something

**Interviewee:** I don’t know that he’s super motivated yet about that.

**Interviewer:** Fair. Super fair. And does he, like, understand money as, like, a concept?

**Interviewee:** Yeah, he does. He doesn’t necessarily understand the value of it. You know, like, he wanted a PS5. And they’re not … they’re impossible to find right now. So he found one online that was, like, $700. And I was like, “*No, you’re not doing that*.” And he’s like, “*Why not? I have it, you know, I have the money saved*.” But that’s bad use of money, so.

**Interviewer:** And does he have any friends? Has he, like, a social life that he manages to some extent?

**Interviewee:** He, you know … it’s funny, he’s a social guy. And he’s very well liked at school. And, for the most part, I think, through the years, like, some people would find him annoying, but he also always had kids who he would play with. But he does not have any … he will say no, he will say there are certain kids who are his friends, but when you compare it to what it means, like, in general, friends who go to each other’s houses, you know, go out with each other. No.

**Interviewer:** Thank you. And do you think your son will be able to achieve more independence in the future?

**Interviewee:** Yes.

**Interviewer:** In what capacities?

**Interviewee:** I mean, I really think in all capacities, like, there’s no area that I think, “*Oh, Nathan will never be able to do that*.” I do have a hard time imagining him living entirely independently, like, in a full-time job, with all the responsibilities that go along with paying your rent and getting to work on time and coming home and cooking. That is really hard for me to imagine. But I could easily imagine him living in a supported living environment, working, you know, part to full time job and not having everything to take care of, you know. We’ve been talking a lot about—this is way beyond sensory stuff, but—about, you know, supported decision making. And that’s really what we see happening, I think.

**Interviewer:** That makes sense. Thank you. And what do you think will help move him into adulthood and move him into this independence?

**Interviewee:** I mean, I think doing everything that we’re doing.

**Interviewer:** Yeah.

**Interviewee:** Getting him hooked up with various, you know, service providers plus ourselves. Continuing to have conversations with him about visioning. I mean, he’s a curious guy, he’s really interested in philosophy, we’re talking to him now about taking, like, a junior college class. With Nathan, historically, it’s always been best—and it’s true probably with everyone, but, like, on hyper for someone like Nathan—to follow his interests and allow things to develop around it. So, you know, he’s always been like, “*I hate school, I never want to*”in school, but he’s interested in philosophy. So we’re saying, “*You know, there are some really cool professors out there, go learn from them and speak to them*.”

**Interviewer:** Got you.Thank you. Besides kind of following his lead, like you just described, do you think there are particular services or interventions that could kind of **[46:00]** help facilitate his independence?

**Interviewee:** Not without following his lead, because my experience is, it’s impossible if you don’t, but, for example, he has been interested in music the last few years, actually. And it’s really interesting because, in his sensory mode, like, the sound is so hard. So it’s sort of interesting that it’s both, but he likes to sing and he’s been in a band, and so he’s taking drum lessons now. So that has provided him with some social opportunities, you know, and a particular band program that tends to be a little bit more quirky, friendly. So that helps him develop the social skills and the, you know, this and that. So that’s how I think we would do it.

**Interviewer:** Got you.Thank you. And now putting these two things together—his sensory sensitivities and his transition to adulthood—how do those things intersect for your son?

**Interviewee:** Well, I mean, I think his sensitivity to noise and to just general, like, having too much stimulus, but he won’t say that to you. He won’t say, “*I don’t like to be there because it’s too noisy, or there are too many people around*.” But you can just tell it’s a mismatch. So I think that that’s what’s difficult because adulthood—not entirely, but, like, does require you to be out in the world a bit, that’s not where he’s super comfortable. So I think that’s challenging. So but, doing those surveys and things, I do feel like I’ve seen progress like, “*Oh, that’s* …” so I would imagine that that would continue to be the case.

**Interviewer:** And you said, like, being out in society is kind of what you have to do as you transition and you imagine that being hard for him because of all those sensory experiences—is that what you’re saying?

**Interviewee:** Yeah, I mean, in part, along with a lot of other things, but yeah.

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

**Interviewee:** I do not see them as a vehicle. I see them as an obstacle.

**Interviewer:** In what ways or what way?

**Interviewee:** Well, I mean, for example, if you think about making connections, like, food is a way that people connect with each other, I mean food, the cooking of food, the …. you know, the sitting down at a meal together. And that’s one of the areas that he has, you know, some significant sensitivities in terms of what he’s willing to eat, how he eats, when he’s willing to eat, you know, so that’s just like an example.

**Interviewer:** Yeah. It’s a perfect example. Thank you. And then, relatedly: what do you anticipate as being challenging for your son as he does gain more independence, in relation to his sensory sensitivities?

**Interviewee:** That and the music are the two big ones because, like, if you’re hanging out with kids and they’re listening to music, and you don’t like the music and you only want to listen to your music, that’s definitely going to get in your way. Now, on a one-on-one thing, which is probably more where he would wind up being, it could be a conversation, but just his lack of flexibility around some of what, you know, his sensitivities are is going to be hard for him.

**Interviewer:** Absolutely. Thank you. And then, do you think he’s … **[crosstalk at 49:53]**

**Interviewee:** I think he’s not going to like being in a workplace where there’s background music and that’s an issue **[50:00]** and then if you put on top of that you that you are not comfortable wearing earphones, you’re kind of stuck.

**Interviewer:** Yeah, absolutely. That could be hard. And then, what do you think could help your son at this intersection of sensory and transition?

**Interviewee:** I mean, I just think the conversations that we have with Nathan sometimes can move him forward. So one example of, like, he was in a program that was actual mental health related, but that he met a girl that he really liked. And that has been a mental focus of his for quite a while, but it has led to his interest in music, listening, writing music, etc., etc. And also, you know, we’ll say things like, “*Well, if you want to meet girls, like, this person’s gone, it was two years ago, and she lives in a different state, but, like, you know, you need to connect with people around things that you like to do and make.*”So again,“*and philosophy take a class*.” So it’s using his interests and, and encouraging him to get out of his comfort zone a little bit. He’s certainly said that about the food piece, too. Like, “*Make sure you*,” and he’ll say things to us. Like, he gets very annoyed. But like, “*When I’m at school, I don’t, you know, I’ll make sure that my mouth is clean and da da da da*.” But like, it’s also habit formation. So we’ll talk to him about that kind of stuff. It won’t be anything radical. It’s just sort of, you know, inch forward.

**Interviewer:** That makes sense. And, besides these conversations, do you think there are any specific services or interventions that could help him at this intersection?

**Interviewee:** Not directly. Like, at this point, with him being 18, not like, “*We’re going to take you to this person who’s going to, you know, teach you how to …*” in the waythat early intervention was “*try different foods*,” you know, you have to be sort of, like, in the environment. And yeah, so I, you know, at this point, and it’s true of, like, social pragmatics, too, it just needs to be integrated.

**Interviewer:** Yeah, absolutely.

**Interviewee:** I’m not saying that’s true with every 18 year old who’s transitioning. I mean, there are some people who are more open to that, but Nathan would not be.

**Interviewer:** That makes sense. Thank you. And then, relatedly, do you feel like there are gaps in the available services and interventions?

**Interviewee:** Well, in the last couple of years, you know, we’ve had conversations. I’m talking about the school system now. Because, like, if you’re getting at what do people need toward transition, OT is something that usually goes by the wayside in high school. And that’s unfortunate. So that is a gap in service. I mean, I have to say, like, where we live and with … we don’t have endless resources, but we have more than other people do. And so we’ve been able to get him the services. One example is, you know, we have a—this isn’t about sensory stuff, but—like, we’ve very good health insurance. And Nathan—this is another example of following his lead—he does have some speech stuff and, when he was younger, he got speech therapy in school, but then it turned to speech and language and the articulation piece went away. But we have really good health insurance, and he wanted to make a change. And now he was talking, and we’ve been able to work with a speech therapist and have it completely covered by insurance. So that’s something that, you know, depends on your insurance, but **[54:00]** OT really is not covered in the same way. And, in school, they stopped doing it in high school. So I think that’s a major gap. So even if you had a kid who was, you know, open to that sort of targeted work, I don’t know that there is anything except if you pay for it.

**Interviewer:** Got you. Thank you so much. And now again, thinking broadly: how have your son’s sensory sensitivities impacted your goals, hopes and expectations for him as he does navigate adulthood?

**Interviewee:** I mean, this is way beyond his sensory sensitivities. But it’s also true on that topic, it’s just like, slow down your expectations, because everything’s going to be a lot slower than you think it will be.

**Interviewer:** Got you, thank you. And now, last chunk of questions …

**Interviewee:** And I think it’s really just about, like … Nathan is a smart, intelligent person who you can communicate with. And so it’s really saying, “*OK, I get that this is, you know, something that you feel strongly about or that you have a sensitivity to*.” And he’ll say, “*I could do it, but I don’t want to*,” you know, that’s how he’ll talk about it. And you can say, “*OK, I get that, but, like, here’s where I think it might get in your way.*”Like, that’s really what you … you know what you have to do.

**Interviewer:** And he is sometimes receptive to that?

**Interviewee: [affirmative noises at 55:24]**

**Interviewer:** That’s great. And then so, finally, as a caregiver, as a mom, as a parent of someone with autism, but also these sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee:** I think my attitude and my husband’s attitude as, like, co-parent has always been to not assume any limitations and to just make sure that Nathan is continuing to make progress, even if it’s on his … at his pace. Although I don’t think that we have primarily focused on the sensitivities. I feel like our … that’s …. there’s always been so much work to do with Nathan. You know, I almost feel like, with the sensitivities is, it’s been like, it’s something that we’ve needed to accommodate more than anything else. Because it’s so … and, you know, like, what do I care—when he was a kid, as an example—if he doesn’t want to wear a print shirt, like, of all the things I need to work with Nathan on, that’s like, not important. He wants to wear green, let him wear green, I don’t care, you know, so there’s that. The other ones that have been harder, the ones that impact the rest of the family system or his success at school. And those are ones that we’ve, you know, tried to work with a little bit, but I will say that I do think that the sensory sensitivities are really the hardest. Because they’re really, really sort of elemental. And so I would say it’s been accommodation of accommodation and attempt to, like, stretches the muscles of managing the discomfort.

**Interviewer:** For sure. Thank you. And has this perspective changed over time?

**Interviewee:** No, only maybe a little bit, like, in terms of an expectation of what Nathan should be able to do just because he’s a little bit older.

**Interviewer:** And like, by “*a little bit*,” you mean, you expect a little bit, like, what direction, I guess, do you mean?

**Interviewee:** When he’s older you expect a little bit more, like, for example, “*If you need to negotiate around what’s happening at the dinner table, we might still wind up with one of us leaving instead of you, but we expect you to be able to have a conversation about it for 10* **[58:00]** *minutes*.” When he was younger and he might have, you know, had a temper tantrum, you know, we’d say, “*OK, he’s too elevated. We can’t talk about this now, just leave*.” So that would be a difference.

**Interviewer:** For sure. Thank you. And what do you see happening in your son’s future?

**Interviewee:** In general, you mean. I mean, it’s really hard to know. But I think we see him living here for a while more. Hopefully staying within the school system in some way for a couple more years. But not really in the high school. He’s already in a fifth year. And maybe exploring taking a couple of college classes, having an internship. And then, I don’t … you know, I hope then he’ll get to a place where he will want to be living somewhere else with other people. But we’ll see.

**Interviewer:** Do you see him having a job of sorts some day?

**Interviewee:** I do. But I really do have a hard time seeing him in a full-time job. You know, if my husband were here, he might tell you, “*Sky’s the limit*.” He’s always been more of the … you know, “*We don’t know, don’t put any limits on it*.” And it’s been great for me to be married to him in that way. And, you know, I generally, like, agree with that philosophy. But when I think about who Nathan is and how tired he gets, living in the world, it’s hard for me to imagine him in a full-time job, living entirely independently.

**Interviewer:** Do you see him having a family of sorts?

**Interviewee:** Possibly. You know, he actually talks about it and he toggles back and forth between, “*I don’t think I’ll ever get married or have kids*” to “*I want to have a kid*,” you know, “*I want to get married and have a kid*” and so I really don’t know. I mean, he clearly has the ability to have the feelings, you know.

**Interviewer:** And then, last question: how have your son’s sensory sensitivities impacted this perspective you described in terms of what it means for him to transition?

**Interviewee:** Oh, I think, at this point in my life, with the family that I have, and having four kids and seeing all their differences, not much … like, all of us have sensory sensitivities, they’re just different. And his are, like, hyper, you know, on hyper thing. And I’ve, you know … just as an example, because this is on one of the sheets, like, other people in the family who seem to either be on it, have ASD or whatever, like, my husband’s sister is … I don’t think ever got any diagnosis, but I suspect, you know, and she and her husband require quiet. Like it, you know, it is a sensory and a mental thing. And, you know, they’re living their lives, and they just have a more quiet life. And so I have hope that, you know, it’s a big world and Nathan will find his place in it with who he is.

**Interviewer:** Yeah, absolutely. Thank you. That’s all I have. Would you like to add anything else?

**Interviewee:** No, just that I’m glad you’re all doing the research. Thank you. The more we can do about this, the better.

**Interviewer:** Thank you. Well, I appreciate your time and your effort. It’s been such a pleasure to learn from you. And I appreciate all your time. It’s been wonderful.

**Interviewee:** Thank you.

**Interviewer:** Thank you. Do you know anyone else who might want to participate? We’re still looking for a handful of more folks.

**Interviewee:** If you resend me just, like, a paragraph, I can share it with an e-list that I’m part of.

**Interviewer:** That would be wonderful. Thank you, I can definitely do that. So, as soon as this audio file renders and I delete your video, I will send you an email. It will have a gift card as compensation for all of your time and effort. And we’ll also include that flyer for you and some kind of blurb.

**Interviewee:** Great. Sounds good.

**Interviewer:** Can I answer any final questions? Can I do anything else for you?

**Interviewee:** No, I’m good. Thank you. All right.

**Interviewer:** Thank you. I hope you have a great rest of your day and talk to you soon.

**Interviewee:** OK, take care. Bye.

**Interviewer:** Bye.

**[End of interview]**