**[Start of transcript]**

**Interviewer**: Great, we are recording and I will be asking you questions about your perspective regarding your child’s transition to adulthood in relation to his sensory sensitivities and sensory interests.

**Interviewee:** Got it.

**Interviewer**: And I’ll be doing something called a semi-structured interview and that means I have my planned questions on my script, but I’ll be adapting them and following our conversation to make sure things actually make sense for what we’re talking about.

**Interviewee:** That sounds great.

**Interviewer**: Awesome. Any questions?

**Interviewee:** No, none at all.

**Interviewer**: Great and if there are any questions that make you uncomfortable, you don’t have to answer them, that’s perfectly ok.

**Interviewee:** Ok.

**Interviewer**: And if there are things that you think about later you are welcome to jump in, it doesn’t have to be a linear conversation.

**Interviewee:** Got you, no problem.

**Interviewer**: Awesome, ok. So could you please start off by telling me about your son’s sensory sensitivities and sensory interests?

[0:52]

**Interviewee:** His sensitivities started when he was, I would say between the ages of two to three years. I could tell that – and this was even before we had an official diagnosis – I would take him and his sister into the grocery store and we’d get like, we’d go by the seafood aisle and all of a sudden I would look at my child and he was gagging because of the smell of the seafood.

**Interviewer**: Yeah.

**Interviewee:** And I’d have to run past that aisle real quick. And now, since he’s grown up, he doesn’t have to run so quick, he can kind of control it now. But loud noises still bother his ears. If the dogs bark, you know, he gets agitated quickly to tell them, you know, to get the dogs to calm down so that they stop barking, so that’s a cue for me, because I know that has to bother his ears. Because I remember also when they were littler, I’d take him into a public restroom, I would flush the toilet, both of them in unison their hands would go over their ears because of that loud noise. So I knew early on, ok is this just my child or, you know, I didn’t know any different, so to speak.

**Interviewer**: Yeah, absolutely. Is it all loud noises or is it certain loud noises?

[2:29]

**Interviewee:** It’s certain loud noises. It seems to be like a dog barking. When the dogs bark real loudly that will bother him. Music, he loves music. He can listen to that loudly [*laughs*]. Doesn’t it seem like all kids can do that? And, let’s see … high-pitched noises seem to bother him … and let’s see … I think that’s about it.

**Interviewer**: Yeah. And for smells [*inaudible* …] [You mentioned the seafood?]

**Interviewee:** Yes, seafood is very pungent, yes. What other smells bother him … he explained something to me today and he said, if I could … like vegetables, he doesn’t like the smell of vegetables cooking. To him he said it smells like bad eggs.

**Interviewer**: Oh!

**Interviewee:** Yeah, that was his description [*laughs*]. I thought, ok! [*laughs*]

**Interviewer**: So kind of like a sulphury kind of component?

[3:43]

**Interviewee:** Yes, like a sulphury kind of smell, yes.

**Interviewer**: And is it just food then or is it, like what if someone had really strong perfume or deodorant?

**Interviewee:** The perfume or deodorant doesn’t bother him, but like any bad smells will bother him like the smell of a garbage can. Cat litter bothers him and I mean he, he is to the point where he will gag. He will gag, he’s got to walk away from it real quick.

**Interviewer**: And then in your interest form that you sent in a while ago you also mentioned taste, I believe?

**Interviewee:** Yes, yes. Here’s the funniest thing, like they both love refried beans, but if they get a chunk of the not mashed-up bean, that will be it, that will be it. And for him, what other taste does he not prefer … vegetables for him is a big one, vegetables, he doesn’t like the way it feels in his mouth is what he told me.

**Interviewer**: Is that similar to the beans where he likes the smoothness of the refried beans?

**Interviewee:** Yes, yes. They like the smoothness, but no chunky [*laughs*], no chunky!

[5:17]

**Interviewer**: [*laughs*] Are there other foods that he has like a textural or like touch preference to or maybe a flavor preference?

**Interviewee:** He likes spicy, and I noticed when I was filling out the questionnaires, it kind of kept going to spicy. He likes to put sauce on everything, like ketchup on his eggs, he wants to add hot spicy, hot sauce to basically everything. So yes, I don’t know if it’s that food tastes bland to him, because he is so cute, he will eat stuff that’s hot and spicy and then while he’s eating it he’ll have both hands over his ears and go “*Phhhhhh*!” [*laughs*] … [*inaudible* …] he did, oh my goodness, he’s, like I said, he likes to do hot and spicy. So my husband, his dad, bought him home the Paqui one-chip challenge.

**Interviewer**: What’s that?

[6:23]

**Interviewee:** It is a potato chip that’s like in hot sauce and it’s, yes, it’s a challenge, so he had just a little bit of the chip, boy oh boy was it hot [*laughs*], he was, yeah, but he tried it.

**Interviewer**: Good for him, I’m not that brave.

**Interviewee:** No, me either, no way [*laughs*].

**Interviewer**: And then what about vision? Does he have any like visual sensitivities or preferences?

**Interviewee:** Nothing visually jumps out at me that’s in the negative. He’s pretty, pretty even there.

[7:07]

**Interviewer**: Yeah, and what about touch in like other capacities besides textures of food?

**Interviewee:** Yes, he likes to have [*dogs bark in background*] … Hey, girls! … They’re cutting my grass out there [*laughs*]. He likes to have his back rubbed and he likes to have his arm rubbed, but if he is in an agitated state then it quickly becomes, “*Don’t touch me*.” So it is dependent on his mood, I guess you would say.

**Interviewer**: Yeah, absolutely.

**Interviewee:** Yeah.

**Interviewer**: And then what do you do when he is not agitated and you’re rubbing his back or you’re rubbing his arm. Is it like a deep-pressure rub or like a light-pressure rub?

**Interviewee:** Very light. Very light pressure, very light pressure. And that’s usually been our evening ritual since he’s been a little guy to go to bed [*laughs*].

**Interviewer**: Yeah. And then how does he manage or cope with his sensitivities when he is faced with them, like say smells or foods that he doesn’t like or things like that, or sounds?

[8:25]

**Interviewee:** He will, you know, when it comes to a food, especially, you know, like when he’s in school, he’ll just alert the teacher, let them know, you know, and he won’t eat it. If it’s a sound, he has really got well at adapting to the sounds. Smells, he’ll just leave the room. If it’s a smell that bothers him he’ll just walk away and say, “*I can’t handle this*,” and excuse himself.

**Interviewer**: Yeah, absolutely. So you said he’s good at adapting to the sound, what do you mean by that?

**Interviewee:** Yes, adapt means the sounds, the loud sounds, he’s not … it doesn’t bother him if the dogs bark all the time, but it just depends on the day and his mood if the dogs barking [*dogs bark in background*] – like that – cause him to have any issues. Now he’s upstairs, he’s of course doing homeschool, he’s not going back till October, but it doesn’t bother him in as much as he’s in a good mood, but if he’s in an agitated state, then as soon as the bark comes out of their mouth he’s, “*Stop it, stop it dogs*.”

[9:54]

**Interviewer**: Will he like use headphones or cover his ears when, when the sound …

**Interviewee:** He will cover his ears, yes, yes. Hands over the ears.

**Interviewer**: Yeah. No headphones or no earbuds?

**Interviewee:** No. Well, he does have, he does have … oh what are those called, iPods, Apple iPods.

**Interviewer**: AirPods?

**Interviewee:** AirPods, yes, he has those in his ears a lot.

**Interviewer**: Absolutely. And has he ever received services or interventions to help him with his sensory sensitivities or sensory interests?

[10:26]

**Interviewee:** No.

**Interviewer**: Got you. And then, you talked about how when he was younger smells would really bother him more or like sounds would bother him more, how else have his sensitivities changed over time?

**Interviewee:** I noticed, I’ve noticed since he’s gotten older he learns, or he’s learned or taught himself, how to deal with them in his own way. You know, for instance, if it’s a smell he’ll walk out of the room. If it’s … something … sound he’ll still cover his ears and he reminds me of when he was a little guy, you know, covering his ears.

**Interviewer**: Yeah.

**Interviewee:** And he would cover his ears and whistle when he was little. And still he just covers his ears and he’s just, I think the older he’s gotten he’s learned to adapt. And of course, we around here are more conscious about it, so we don’t, we don’t push the envelope for him. We don’t want to make him miserable at home.

**Interviewer**: Absolutely. And then in terms of taste, has he always disliked vegetables, has he always liked the smooth beans, liked spicy food?

**Interviewee:** Well, he used to like, he used to like broccoli, cauliflower, corn, and now it’s the only type of vegetable that he wants to eat when there’s a preference he likes raw carrots, he likes salad, but any other cooked vegetable – because we were just talking about this the other day – he was like, “*No, no, I like salads*.” And that was that, “*That’s all I’m eating is salad*” [*laughs*]. That’s ok, you know, that’s ok.

**Interviewer**: Yeah.

**Interviewee:** And when he was little, when I would feed him, like, you know, teaching him to eat new foods, I noticed that his, as a baby, his gag reflex was more … he would gag quicker on certain types of foods and then he wouldn’t. And it was more of the, it was more of the chunky foods, like chunky apple sauce I can remember feeding him as a baby and I put one scoop in his mouth and there the rest of it went … [*laughs*].

**Interviewer**: Nope! [*laughs*]

**Interviewee:** Yeah, not doing it! [*laughs*]

**Interviewer**: Yeah. Will he eat things like apple sauce now?

**Interviewee:** Yes, he likes apple sauce. He doesn’t care for pudding or Jell-O. He’ll, you know, he’ll eat Popsicles. It’s kind of, it’s hard to explain what kind of, you know, because I’ll ask him and he’s really a trooper, he will try something.

**Interviewer**: That’s great.

[13:40]

**Interviewee:** He will try it. Now when he was maybe seven, eight, nine, “*No, not trying it and you’re not going to make me*!” [*laughs*] But he’s willing to try.

**Interviewer**: Is he able to articulate when he doesn’t like a bunch of things after he’s tried them?

**Interviewee:** Yes, which is a help for us.

**Interviewer**: What does he say, like can you think of a theme that connects the foods that he likes and doesn’t like?

**Interviewee:** The theme seems to be the chunky stuff, like, I think … Oh he doesn’t like oatmeal raisin cookies, he doesn’t like the chunks …

**Interviewer**: They’re kind of chunky.

**Interviewee:** Right. See, there again it’s the chunky, he doesn’t like the chunky stuff, and he just said, “*It should just all go in my mouth one way and then I chew it all*” [*laughs*]. Yeah.

**Interviewer**: That’s fair, I understand that [*laughs*].

**Interviewee:** Yeah, yeah [*laughs*].

**Interviewer**: So these changes that you have noticed, like being a little bit less sensitive to loud noises, or a little bit less sensitive to smells, or maybe just better at coping with them, do you think those changes are related to any independence that he’s gained over time?

[14:54]

**Interviewee:** I think it has been because of his independence and getting older, because when he was younger he, he didn’t know how to deal with the, you know, the sensory issues, the smells, the sights, the sounds. And he used to be, well, he didn’t start talking until he was, well he started talking and then he started regressing and lost lots of words. But he would let us know with something that he didn’t like or he liked or he would want more, or didn’t want any more of [*laughs*]. But now, since he’s been in school and doing, you know, working with his teachers and his therapists there, he’s able to articulate more of what he likes and doesn’t like.

**Interviewer**: That’s great.

**Interviewee:** So that’s been a big help.

[16:02]

**Interviewer**: That’s awesome, that is really helpful. And then, when he is in scenarios where he’s faced with things he doesn’t like, does it cause or increase anxiety?

**Interviewee:** Yes.

**Interviewer**: What does that look like?

**Interviewee:** It causes some anxiety for him. He’ll get upset, you know, and if I tell him, you know, “*It’s ok, it’s ok, you know, you don’t have to get upset, this is nothing that we’re going to get upset about*,” once I, once I reassure him then he’s ok. But it’s got to be, you know, if I see, you know, something … I look for his … for me … his visual cues would be hands over ears or if he’s gagging on something, you know, then I’m like, “*Oh, hey what can I do*?” You know, “*What can I do to help you*?” You know, and he’ll immediately – I don’t want to say get agitated – but he gets upset, you know, and I let him know, “*It’s ok, you don’t have to have this, you don’t need to be upset, you know, you’re good*.”

**Interviewer**: Yeah, absolutely. So that’s like you helping him manage his anxieties?

**Interviewee:** Yes.

**Interviewer**: Is he able to manage them without you? Is that hard for him?

[17:24]

**Interviewee:** He can, he does perfectly well in school all day, so I’m going to say that he can manage them without me as well.

**Interviewer**: Yeah. And so what does his anxiety look like? You just mentioned like hands over the ears?

**Interviewee:** He will get, he’ll start talking a little bit louder, talking a little bit faster, and that’s usually my first sign … is he’ll, immediately his voice gets louder.

**Interviewer**: Yeah, absolutely.

**Interviewee:** You know, yeah. So I don’t know if he’s trying to, you know, make it go away with his, you know, trying to make things go away that he dislikes with his voice being loud or what, but yeah, I’ve noticed he gets louder when something is irritating to him.

[18:15]

**Interviewer**: Totally. And then, has like sensory things that he doesn’t like, has that always caused or increased anxiety for him?

**Interviewee:** No. When he was little it really didn’t, because of course we would take the, we would take the anxiety, I mean we would take the sensory issue away [*laughs*]. So yeah, it didn’t cause any issues with him when he was little.

**Interviewer**: He just wasn’t exposed to it?

**Interviewee:** Yeah, well no.

**Interviewer**: Got you. And then, thinking to the future, what goals or hopes do you have for your son in terms of his sensory sensitivities and sensory interests?

[18:58]

**Interviewee:** I would hope that, you know, he continues on the path that he’s on, you know, especially, his thing is he wants to go to a concert.

**Interviewer**: Ok.

**Interviewee:** And I’ve been to concerts, I know how loud concerts are.

**Interviewer**: Yeah.

**Interviewee:** So and he doesn’t have any idea of what to expect, so I’m trying to get him, I want him to be able to experience a concert of course, but I want him to be, I want to make sure that I prepare him very well for the concert, you know, by either wearing earplugs or headphones, you know. And in the future, I think the way that he’s going and how well his therapists and his teachers are, I think he’ll, I think he’ll continue to do well.

**Interviewer**: That’s great.

[19:56]

**Interviewee:** I think something is always going to bother him sensory-wise because that just seems like the way it is, but I think he can get past it.

**Interviewer**: Yeah, absolutely. That’s awesome to hear. And we’re going to move on to our next chunk of questions, we’re going to shift gears a little bit.

**Interviewee:** Ok, sure.

**Interviewer**: Thinking about community, so as your son has grown up and aged, how has his and your community reacted to his sensory sensitivities and sensory interests?

[20:28]

**Interviewee:** Meaning like my community in general, like where we live in the neighborhood?

**Interviewer**: Yeah, like where you live, maybe your school, family.

**Interviewee:** The school is great, because he goes to a regular public school, he doesn’t go to a specialized school or anything, they have adjusted well with him.

**Interviewer**: That’s awesome.

**Interviewee:** I know that we do regular ARDs is what they’re called, ARDs [admission, review, and dismissal processes], to set up his goals for the year and how he’s progressing during those goals, so the community in general is very supportive for him, very, yes it is.

**Interviewer**: That’s great, I’m really glad to hear that.

**Interviewee:** Yes.

**Interviewer**: And what about when he was younger, was the community more or less accepting?

[21:19]

**Interviewee:** The community was less accepting. I remember even before we had got them diagnosed we were very avid in church and the church that we were going to at the time just [chalked it up to?] bad behavior.

**Interviewer**: Oh.

**Interviewee:** Yeah and not, “*Hey, maybe there’s a problem*,” but he, him and, well he was in choir, you know, he did all the, you know, all the stuff and it was just bad, you know, “*Tyler is misbehaving*.” It wasn’t, so they weren’t very accepting and that was at the point where I was thinking, ok, you know, he doesn’t do this at home, or he doesn’t have these issues at home, so you know, it was, I was starting to think maybe there’s an issue.

**Interviewer**: Yeah.

**Interviewee:** So that’s when we started with the school and the testing and everything.

**Interviewer**: Got you.

**Interviewee:** But believe it or not church was less accepting, when he was younger.

**Interviewer**: Are they more accepting now?

**Interviewee:** Yes, yes they are, which is a plus, yes.

**Interviewer**: Absolutely. What about other parts of the community, like family, maybe work friends?

[22:42]

**Interviewee:** My work friends are great. The rest … we have a very big house here, I have … all of my children except for one lives at home, and their wives, and my granddaughter, and they’re all very accepting of Tyler. They will help him, you know, however they can help him, you know, so it’s … Tyler’s I think growing up in a home that has a lot of advantages instead of disadvantages.

**Interviewer**: That’s awesome.

**Interviewee:** Yeah.

**Interviewer**: I’m happy to hear that for you.

**Interviewee:** Yeah, great.

**Interviewer**: And then thinking to the future again, what are your hopes or worries for how his community will react regarding his sensory sensitivities and sensory interests?

[23:32]

**Interviewee:** What I worry about is that he is so trusting and so kind, I’m afraid that people will take advantage of him and I don’t, that’s what scares me [*Madison comes into the room*] … [*inaudible …*] You can come down honey, it’s ok, you can get your snack sweetie [*inaudible …*] Oh, you need a notebook, ok honey, ok we’ll get you a notebook darling, thank you [*laughs*]. My other twin, she needs a notebook [*laughs*].

**Interviewer**: Oh, do you need to go get it for her?

**Interviewee:** Do you want me to get you a notebook now? [*inaudible* …] Joe, would you get her that little yellow notepad over there? That should be able to give her, to like be able to write notes down, notepad? One of the little small legal pads, there you go Mase, right there [*laughs*] [*inaudible*…] Yes, we will get you one this weekend, ok? Thank you sweetheart [*laughs*].

**Interviewer**: Busy household!

**Interviewee:** It is a very busy household, yes it is! [*laughs*]

**Interviewer**: Awesome. Did you want to say anything more about that?

[24:57]

**Interviewee:** Oh, yes, I’m just worried that people will take advantage of his kindness and his kind nature and that’s the one thing that scares me because he is very trusting. I don’t, you know, and I don’t know how to teach him, you know, I don’t want to teach him that people are bad, but I want to teach him, you know, that these are the things he’s got to look for and I don’t know how to do that.

**Interviewer**: Yeah, absolutely.

**Interviewee:** You know, I don’t know and it just, it … he thinks that … you know, he doesn’t watch the news, he doesn’t like to hear the news, you know, they think that everybody is just, everybody is great in the world, and I don’t, I don’t want to spoil that for them, you know?

**Interviewer**: No, they’ll figure it out at some point [*laughs*].

**Interviewee:** Yeah, exactly, exactly [*laughs*] and I would rather him figure it out while he’s … and I, I look forward that he will probably always be here with us at home, and I would rather him figure it out with us than something happen to him, you know?

**Interviewer**: Yeah, absolutely, that makes sense. Do you want to go on to our next chunk of questions now?

**Interviewee:** Ok, sure.

**Interviewer**: In the like transition to adulthood, where do you see your son?

[26:30]

**Interviewee:** Sometimes transitioning well, physically. Mentally, I would say he’s at, mentally I would say he’s about the age of my granddaughter, who is eight.

**Interviewer**: Ok and what makes you think that or feel that?

**Interviewee:** Just some of the way that he talks. You know, he will, if a friend tells him, “*Oh, you need to think this way*,” then he will think that way. He’s just very, I don’t want to say gullible, but you know, we try to make sure that, you know, you have your own thoughts, your own ideas. He’s very easily influenced. So that’s, you know, that’s what I said, you know, like yeah physically he looks, he looks, you know like an adult, but mentally he’s not there, he’s got some catching up to do that’s all.

**Interviewer**: Totally. And then in terms of independence skills, can you talk a little bit about what he is able to do by himself, what he needs some help with?

[27:47]

**Interviewee:** Oh yeah, absolutely. He is a typical boy [*laughs*], he will put his laundry away, clean laundry away, he brings his dirty laundry downstairs, he’s able to bathe himself, he’s able to brush his teeth, wash his hair, get dressed, you know, he follows the bedtime routine. So, he’s able to feed himself, he can cook, he can make himself breakfast in the morning as long as he’s supervised, and he can feed himself, so that’s a plus. So he’s pretty independent when it comes to stuff like that.

**Interviewer**: That’s awesome.

**Interviewee:** And he can read directions, you know, he can follow simple directions, so when it comes to like, if it were a simple recipe, he can do that. One thing that was great last year when all this pandemic started, his, one of his teachers would on Tuesdays they would have the class make different recipes. So last year he made us tacos, he made us corn dogs, no not corn dogs, chili dogs.

**Interviewer**: Nice!

**Interviewee:** Yeah and he, you know, he did it, we got him, you know, all of the things prepared for him and measured out and he did it. He followed all the directions and put it all together for a meal and he fed all of us.

**Interviewer**: That’s fantastic.

[29:22]

**Interviewee:** Yeah, yeah.

**Interviewer**: That’s great. And then, is he able to like go shopping for himself? Did he help you go shopping prior to COVID? [*Laughs*]

**Interviewee:** Yes, yes, the nice thing was, at school they had a community-based, it was called community-based therapy and they would take them out and buy things for the classroom and he would, they would each get, you know, X number of things that they needed to get and then they would be given, you know, cash to pay and so they, you know, would purchase as a classroom different things and they would pay and they would have to interact with the cashier. So yes, he’s really good at that, yes, from his community-based therapy, yes.

[30:11]

**Interviewer**: That’s awesome.

**Interviewee:** They taught well with that, yes.

**Interviewer**: Did they also teach him like money, like as a concept does he understand money?

**Interviewee:** Yes, yes, yes. He still doesn’t understand, he thinks that I just go to the bank to get money, not, you know, and I’m still trying to explain to him, we just don’t have money in the bank, we have to work for the money, then it gets into the bank. So that seems the hardest part to grasp [*laughs*].

**Interviewer**: Yeah, it’s like how the money gets to the bank that’s the problem?

**Interviewee:** Yes, yes.

**Interviewer**: Got you. And then does he express interest in ever wanting to have a job in the future?

[30:57]

**Interviewee:** He does, he’s already told us he wants to work at Whataburger.

**Interviewer**: Ok.

**Interviewee:** Yeah, he does. He tells us he wants to work at Whataburger and he wants to go to college, and he still doesn’t say what he wants to be when he goes to college. You know, I’ll say, “*Well what do you want to be when you go to college*?” “*I want to be with my friends*” [*laughs*].

**Interviewer**: Got you.

**Interviewee:** Yeah.

**Interviewer**: And does he have friends? Does he manage a social life to some extent?

[31:24]

**Interviewee:** He does, he has a lot of friends. A lot of them are in his class. His closest friend is Travis. They usually, it’s so cute, he has Travis and Aiden and they talk together on the telephone and we’re trying to get him to learn to put his … [*Tyler speaks in background*: Don’t forget Taje!] … Oh, ok, I won’t forget Taje, thank you [*laughs*], and we’re trying to get him to put his AirPods in to talk to his friends because he has to have it and it could be because of a sensory issue, he doesn’t like to hold the phone up to his ear, he likes to talk on speakerphone, so … and we’re trying to get him to learn to use his AirPods and talk on the telephone so that not everybody wants to – not that we don’t want to hear his conversation – but he might, you know, he might want to have a little privacy, that’s all.

**Interviewer**: Absolutely. And does he usually initiate these phone calls, do his friends initiate them?

[32:31]

**Interviewee:** He, I would say he initiates the calls more than they do, yes.

**Interviewer**: That’s great. And then you said you think he’ll probably be at home with you forever. Does he ever say that he wants to live by himself or does he …?

**Interviewee:** He does.

**Interviewer**: Oh yeah?

**Interviewee:** He does, yes he does, he does.

**Interviewer**: And when he says that does he talk about like what he wants in that scenario or just more broadly?

**Interviewee:** He does, he wants to, he says he wants to live like in a group home.

**Interviewer**: Ok.

**Interviewee:** And he says, “*I can get an Uber and I can go to work*,” and, you know, he does, you know, I’m not ruling it out, so we just have to kind of wait and see.

**Interviewer**: Absolutely. Going back to …

**Interviewee:** He does want to be independent though, yes.

**Interviewer**: Yeah, it sounds like it. Going back to the idea of the phone being maybe like a sensory thing, does he not like other things on his face?

[33:30]

**Interviewee:** No, it just seems to be the phone.

**Interviewer**: Ok.

**Interviewee:** It just seems to be the phone, he’s, and, you know, he’s, he shaves, so that’s another thing, and he’ll let his beard grow out for like maybe two or three days and then he’ll say, “*Well I think I’m going to shave on this day*” or “*I’m going to shave on that day*.” So yeah, he doesn’t mind things on his face. So I just wonder if it’s got to do with the hearing with the phone, you know, maybe it’s too loud for him in his ear, you know? That’s the only thing I can think of.

**Interviewer**: No it sounds reasonable to me [*laughs*]. And then do you think he’ll be able to achieve more independence in the future?

[34:16]

**Interviewee:** I do, I really do. Yeah, I do.

**Interviewer**: And what do you think that would look like for him?

**Interviewee:** I would think that he would have a job, a forty-hour week job, with guidance to be able, to be able to pay his rent, be able to pay his bills, save money, and be able to get to where he wants to go, you know, with transportation he could arrange that for himself, absolutely.

**Interviewer**: And then what do you think will help him move more into adulthood and to achieve these things that you just articulated?

[34:55]

**Interviewee:** I think the more patience that we have here at home with him, you know, not, not pushing too much, you know, not trying to push him out, but, you know, and to … I like to give him, well we all like to give him like real-world scenarios. Like, what do you do if somebody says this, or what do you do if somebody says that? You know, that, we like to give him real-world scenarios that he can really learn to live by.

**Interviewer**: Yeah, that’s helpful for sure. Do you think there are other like services or interventions that might help him move into adulthood?

[35:42]

**Interviewee:** I, I have to really check out where we live to see what other type of services or interventions that are available, the school though has been wonderful and I’m sure I’ll check with the school. They’ve been wonderful in helping, you know, with what, with how he’s got so far already.

**Interviewer**: That’s awesome.

**Interviewee:** Yeah, they’re just wonderful.

**Interviewer**: That’s great. And now putting these two things together, his sensory sensitivities and his sensory interests and then his transition to adulthood, how do they intersect for your son?

[36:22]

**Interviewee:** I think they would intersect that … the more he grows and goes and gets independent, the more, not that he, not that they won’t bother him, but he won’t let other people know that they bother him. You know, he can just say, “*No thank you*,” you know, like at something, you know, foodwise, you know he could maybe just say, “*No thank you*,” or, you know, walk to another room if it bothers him, or say, “*Oh excuse me for just a moment*,” you know, and go outside, that type of thing. I think, you know, he won’t let on to other people that do not know him well enough to not say anything.

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

[37:29]

**Interviewee:** I would say … neither.

**Interviewer**: Yeah?

**Interviewee:** Yeah.

**Interviewer**: Why? What makes you say that?

**Interviewee:** Well because he can, he can … not let them … they’re not so great that they hinder anything for him.

**Interviewer**: Not a hindrance, absolutely.

**Interviewee:** Yeah.

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

[38:04]

**Interviewee:** The challenging would be the loud noises.

**Interviewer**: Yeah.

**Interviewee:** Yeah, yeah, the loud different noises, because, you know, in his seventeen years we haven’t come across, you know, every single thing, so we don’t know if there are things that could bother him that we don’t even realize bother him, that he could run across it one day and be, you know, really freaked out about. So you know, yeah.

**Interviewer**: Yeah, so like lack of knowing what is out there?

**Interviewee:** Exactly.

**Interviewer**: And then what do you think will help him in this intersection of adulthood and his sensory sensitivities?

[38:49]

**Interviewee:** I think his family.

**Interviewer**: Yeah.

**Interviewee:** I really do, I really do, because there’s so many of us, you know, we all have so many different personalities, you know, and everybody, you know, everybody has so much patience with him and we all want to see him succeed.

**Interviewer**: Yeah, absolutely, that’s wonderful. Do you think there are any services or interventions that could help him in this intersection as well?

[39:19]

**Interviewee:** I think it’s called the Arc of San Antonio, so and then also once he graduates there’s, he’s going to like move on to, it’s called the Reddix Center.

**Interviewer**: What’s that?

**Interviewee:** It is for kids, kids that graduate and then it’s to get them ready for college and so he’ll go two years there after he’s done at high school.

**Interviewer**: That’s awesome.

**Interviewee:** And it’s called the Reddix Center, yes. So [*inaudible* …] the community is really great.

**Interviewer**: Sounds like it. Does that provide, like what are the skills that they provide, is it more vocational training, more life skills?

**Interviewee:** More vocational training, yeah. Vocational training, like learning anything additional that they need to learn and basically getting them ready for college, for college prep.

**Interviewer**: Awesome.

**Interviewee:** So, yeah. So I’m, I’m excited to learn more about it and actually once I learn more about it I will gladly let you know, in the future, ok?

[40:27]

**Interviewer**: Yes, I’d love that.

**Interviewee:** Yeah, absolutely.

**Interviewer**: Perfect, that would be wonderful. My plan is after this, the parents tell me all their, what they use and I’m going to try and distribute it to everyone so that way at least everyone I talk to can provide support for each other in that way.

**Interviewee:** Absolutely, yeah.

**Interviewer**: It’s the least I can do [*laughs*]. Do you think there are gaps in the available services and interventions for kids like your son?

[40:52]

**Interviewee:** I don’t think there’s a lot available. Now I know in the community here there are Chick-fil-A they hire, they hire autistic and … autistic and … intellectually disabled, Whataburger does, and HEB, that’s a real big grocery store, that’s our, that’s Texas’s chain of groceries.

**Interviewer**: Sure.

**Interviewee:** And let’s see, what else … Walmart in this area does and also Joann Fabrics.

**Interviewer**: Oh, that’s a lot.

[41:44]

**Interviewee:** Yeah. It’s really great and I know, I don’t know if it’s nationwide or if it’s just community- based, but that’s what I know of so far in our community that’s community- based.

**Interviewer**: Yeah, that’s still plenty though. Before we were recording you mentioned that felt that like insurance should pay for more services. Do you think that’s also a gap in what’s happening?

**Interviewee:** Yes I do, I really do. It’s like insurance doesn’t think that autism is a medically enough of something to pay for, you know? It’s like, I was so disheartened because I remember driving back from Austin, you know, after one of their, visiting the neurologist, and I was so upset because I was like, “*You’re not paying for ABA* [applied behavior analysis] *therapy*? *It’s, the doctor ordered it*!” You know, and I was that, I was really upset with that.

**Interviewer**: It is upsetting, it’s counter-intuitive, you know, your doctor said you should do it, it ought to be covered.

**Interviewee:** Exactly, you know, and like I said, it’s like do they not think that, you know, autism is not … medically … a good enough diagnosis or what? You know?

**Interviewer**: Absolutely. And then thinking a little bit more broadly, how have your son’s sensory sensitivities and sensory interests impacted your hopes, goals, and expectations for him as he does navigate adulthood?

[43:31]

**Interviewee:** I just want to make sure that he’s able to navigate and not, not have, I don’t think he’ll have too many bumps in the road, so to speak. I really have a lot of confidence that he’ll be able to navigate things, I really do, because I’ve seen how far he’s come and when he was smaller, no, not so good, but the older he gets it seems like the better he is at coping skills.

**Interviewer**: Yeah, that’s fantastic.

**Interviewee:** Yes.

**Interviewer**: So I have one last chunk of questions, we’re almost done.

**Interviewee:** Sure.

**Interviewer**: As a caregiver, as a parent, as a mom of a child – or two children – with ASD [autism spectrum disorder] and sensory sensitivities, what does the transition to adulthood mean to you?

[44:27]

**Interviewee:** Transition to adulthood means that they would … it’s not the typical when you turn eighteen, it is when you are ready, when you are capable of discerning between the different types of personalities out there, when you feel comfortable, not when you’re, you’re not pushed out of the nest [*laughs*]. There’s no time limit on, you know, how long you need to be at home.

**Interviewer**: Got you.

**Interviewee:** And I think we’ve kind of shown them that, with, with living with their brothers here at the house, because my oldest is thirty-two and my middle is twenty-five and my daughter who is in Missouri, her husband is a pilot in the air force, and so, and she’s almost nine months pregnant, yeah with a girl [*laughs*], so … you know, it shows, well it’s ok to live at home. It’s not this bad thing to, you know, live at home.

**Interviewer**: Absolutely, it saves a lot of money too [*laughs*].

**Interviewee:** It sure does, absolutely [*laughs*].

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

[45:51]

**Interviewee:** No, no. I can honestly say that from when they were first diagnosed, when he was first diagnosed to now, I have more, I have more hope that he will be able to accomplish those things.

**Interviewer**: That’s awesome, that’s great to hear.

**Interviewee:** Yes.

**Interviewer**: And then a little bit more specifically, what do you see happening in his future?

**Interviewee:** In his future I look for him to be able to live in a group home, be able to hold a job, a forty-hour a week job, able to pay his bills and manage his money, and even save and go to college.

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

**Interviewee:** I do. I would see him having a family of sorts. I do see him getting married. He always says that he doesn’t want to have any children though [*laughs*].

**Interviewer**: That’s ok.

**Interviewee:** And I said, “*That’s ok*!”

**Interviewer**: You don’t have to have kids.

**Interviewee:** No, nobody says you have to do anything, absolutely.

**Interviewer**: Right, I have one final question for you.

**Interviewee:** Sure.

**Interviewer**: How have his sensory sensitivities impacted this perspective that you just articulated?

[47:08]

**Interviewee:** It’s not that it’s slowed them down, it’s kind of made us look at doing things differently.

**Interviewer**: Yeah.

**Interviewee:** You know, ok so like the loud noises, you know, we try to find out what types of loud noises bother him and we still, we’re still on what kind of loud noises bother him. We don’t know everything out there, so we try to prepare him, you know, and if it is something that bothers him, we’ll tell him, “*Ok, well you know, you’d want to do, you’d want to let somebody know, you know, that that bothers you, or remove yourself from the situation, instead of, you know, you don’t want to yell because you might scare somebody*” [*laughs*]. You know like yelling at the dogs, you know, if it’s somebody else’s dog they’re not going to take too kindly to you yelling at their dog!

**Interviewer**: Yeah, absolutely.

**Interviewee:** You know, and so you would have to, you know, move yourself out of the situation. So yeah.

**Interviewer**: And this kind of like preparing him and kind of like teaching him how to navigate this, how does that intersect with this idea that you just talked about in terms of like, the timeline is different for kids like your son?

[48:36]

**Interviewee:** Yes, if I know if there’s anything that he needs help with or needs questions answered I know he would know that anybody, especially me being his main caregiver, would be able to try and help him with it and definitely try and help him overcome any type of adversity that he may have.

**Interviewer**: Absolutely.

**Interviewee:** Yeah.

**Interviewer**: That’s all I have for my questions, would you like to add anything?

**Interviewee:** No, I think I’m good.

**Interviewer**: Ok, awesome.

**Interviewee:** This has really actually helped me a lot because what, that last one where, you know, it was him and I, you know, him, I was asking the questions, helped me actually kind of learn, yes.

**Interviewer**: Oh, awesome.

**Interviewee:** Yes, because I have never done a survey where they wanted any input from him, but I guess because they’re older now, so it’s going to be, I think it’s going to be just as interesting doing it with my daughter too.

**Interviewer**: Excellent. Would you like me to send you the report for that, would that be helpful?

**Interviewee:** Sure, that would be great.

**Interviewer**: Ok, I can do that for you. And so would you still like to participate for your daughter?

**Interviewee:** Absolutely.

**Interviewer**: Ok awesome, thank you, I appreciate this, and I appreciate the effort you have put into that too, it’s so helpful.

**Interviewee:** No problem. Yes I just want to, you know, I want to help as many people as we can, you know.

**Interviewer**: Well you are, you absolutely are. When would you like to do our next interview?

**Interviewee:** Let’s see … this is the 25th September … you want to shoot for like, when is October 8th … I’m just like shooting out a day.

**Interviewer**: October 8th is in two Thursdays.

**Interviewee:** Ok, let’s shoot for October 8th.

**Interviewer**: I have literally nothing on my schedule, what time would suit you?

**Interviewee:** 3 o’clock central time would be great.

**Interviewer**: Great, alright, so we’re going to do October 8th, 3 p.m. central time, 4 p.m. for me. I will, after this, I will send you the report for your son, do you want the other reports too?

**Interviewee:** No, you don’t have to send the other one.

**Interviewer**: Ok, I’ll send that one, and I’ll also send links for the surveys for your daughter, and I’ll send you a gift card for this.

**Interviewee:** Oh, thank you, thank you so much.

**Interviewer**: Thank you. Can I answer any final questions, can I help you with anything else?

**Interviewee:** No. I think this has been, I think it’s been even just more … answering the questions and doing the questions and asking myself these things, it’s actually helped me to see that, you know, it’s all a continual learning process.

**Interviewer**: Yeah, it is, and it sounds like he’s going on the right track and doing great.

**Interviewee:** He is, he’s doing really good. We’re really, really proud of him, very proud of him.

**Interviewer**: That’s great.

**Interviewee:** Yes.

**Interviewer**: Well I hope you have a nice evening.

**Interviewee:** You too! Yes, I’m going to put my knee up and put some ice on it! [*laughs*]

**Interviewer**: [*laughs*] Yes you should, relax and rest and I’ll see you in about two weeks.

**Interviewee:** Alright then, that sounds good Rachel, thank you so much.

**Interviewer**: Thank you, bye.

**Interviewee:** Bye.

**[End of transcript]**