**[Start of transcript]**

**Interviewer:** Okay. We are recording. And I’ll be asking you questions about your perspective about your child’s transition to adulthood in relation to her sensory sensitivities and sensory interests.

**Interviewee:** Mmhmm.

**Interviewer:** And we’ll be doing something called a semi-structured interview, and this means I have my set of planned questions here but I’ll be adapting the questions to follow our conversation to make sure they actually fit for us. How does that sound?

**Interviewee:** Fine.

**Interviewer:** Okay. If you have any questions, let me know. You’re also welcome to back-track if, like, something comes to mind later on. And if anything makes you uncomfortable and you don’t want to answer, that’s perfectly okay. We want to make this a positive experience.

**Interviewee:** Okay.

**Interviewer:** Alright. So, for my first question, could you please start off by telling me about your child’s sensory sensitives and sensory interests?

**Interviewee:** Well, the biggest issue for her, of course, is food related.

**Interviewer:** Yeah.

**Interviewee:** Yeah. So, she does have a diagnosis of ARFID.

**Interviewer:** Mmhmm.

**Interviewee:** She has spent time in the hospital because it’s gotten bad enough where she just doesn’t know what to eat.

**Interviewer:** Mmhmm.

**Interviewee:** She has an extremely restricted diet.

**Interviewer:** Mmhmm.

**Interviewee:** And it is very much about the sensory part of it. What does it look like, what does it smell like…

**Interviewer:** Mmhmm.

**Interviewee:** You know? It’s beyond the taste because she can’t get it in her mouth to taste it.

**Interviewer:** Mm. Gotcha.

**Interviewee:** And that’s been going on since she was really little.

**Interviewer:** Which… So, you mentioned, like, smell and, like, what it looks like. Like, what… Could you talk a little bit more about that and describe which smells are harder for her or which smells maybe are easier for her? Same with texture?

**Interviewee:** I would say, like, anything with, like, the smell of pickles…

**Interviewer:** Mmhmm.

**Interviewee:** …she can smell from…it---you would be amazed. From so far away.

**Interviewer:** Mmhmm.

**Interviewee:** She can be on a separate floor of the house or out on the deck and she will know if you opened a jar of pickles.

**Interviewer:** Mmhmm.

**Interviewee:** And she’ll yell. You’ll hear her yell, “*who opened pickles*?”

**Interviewer:** Yeah.

**Interviewee:** She won’t touch the jar. If it’s sitting on a shelf in a fridge, she won’t touch anything that’s on that shelf in the fridge.

**Interviewer:** Mmhmm.

**Interviewee:** Or that might have touched the jar of pickles. So, that’s a huge trigger for her.

**Interviewer:** Mmhmm.

**Interviewee:** She will eat things like…well, she won’t anymore, but she used to eat, like, say, a cheese wrap, a cheese tortilla…tortilla? Tortilla.

**Interviewer:** Yeah.

**Interviewee:** Oh, that was bad.

**Interviewer:** Nah, you’re good.

**Interviewee:** But if there was, like, the tiniest little speck of green or red on there, maybe from a tomato or a lettuce leaf or something, she won’t eat it.

**Interviewer:** Mm.

**Interviewee:** And it can be microscopic, **[0:03:00]** practically.

**Interviewer:** Yeah.

**Interviewee:** And so, she very carefully inspects her food.

**Interviewer:** Mmhmm.

**Interviewee:** And anything amiss and it’s…she’s not gonna eat it.

**Interviewer:** Mmhmm.

**Interviewee:** So, that’s kind of where she is with food. [Laughs.]

**Interviewer:** What does she eat, then? Or how does she get her calories?

**Interviewee:** Her diet is pretty much cheese [pizza? inaudible – 0:03:29] and French fries.

**Interviewer:** Mmhmm.

**Interviewee:** Occasionally a grilled cheese or chicken nuggets, but it really depends on where they come from. She’s very specific about that.

**Interviewer:** Mmhmm. Which places does she prefer?

**Interviewee:** It changes. So, like, she used to eat chicken nuggets from, like, Checkers or Burger King but now she won’t.

**Interviewer:** Mmhmm.

**Interviewee:** Sometimes she’ll eat them from Chick-Fil-A. She will not allow me to make them at home.

**Interviewer:** Mm.

**Interviewee:** I’ve tried that.

**Interviewer:** Yeah.

**Interviewee:** You know, it just…the older she gets, the more restrictive it gets. And she keeps… It’s not for lack of trying. She’s really trying.

**Interviewer:** Yeah.

**Interviewee:** But it’s just hard for her. Occasionally she will eat some green veggies. She will eat cooked broccoli or cooked peas once in a while.

**Interviewer:** Yeah.

**Interviewee:** I think that’s it for her green veggies.

**Interviewer:** Mmhmm.

**Interviewee:** She will occasionally eat a baby carrot.

**Interviewer:** Mmhmm.

**Interviewee:** And then she has some fruit that she will eat once in a while. Peaches, plums…

**Interviewer:** Mmhmm. You talked about kind of occasionally eating other things.

**Interviewee:** Mmhmm.

**Interviewer:** Do you know what…like, what scenario…what are the scenarios where she will maybe eat those other things? Can you tell if there’s, like, a pattern there?

**Interviewee:** It’s… She can’t be stressed, so if she’s stressed about anything else?

**Interviewer:** Mm.

**Interviewee:** Forget it. So, she has to be, like, mentally in a good place.

**Interviewer:** Mmhmm.

**Interviewee:** Because it takes pushing. She has to push herself to do that.

**Interviewer:** Yeah.

**Interviewee:** And it has to be…it has to look right. Because even if she’s in a good place and she picks up a plum and it has, like, a little spot or something, then she can’t eat it.

**Interviewer:** Gotcha.

**Interviewee:** So, it’s kind of like that.

**Interviewer:** Yeah. You talked about pickles. Are there other, like, sour-smelling things that she dislikes as well?

**Interviewee:** She probably doesn’t like cooking smells at all.

**Interviewer:** Hm.

**Interviewee:** She doesn’t like the way it smells to cook food.

**Interviewer:** Okay.

**Interviewee:** So…

**Interviewer:** So, kind of just general food odors are kind of a no. **[0:06:00]**

**Interviewee:** Hm. I mean, she definitely has a much stronger sense of smell than I do for anything.

**Interviewer:** Mmhmm.

**Interviewee:** Like, she can smell things and she’ll---you know, she’ll bring this and, like, “T*his thing smells awful*!” And I’ll be like, “*I don’t smell anything*…”

**Interviewer:** Yeah.

**Interviewee:** Or, “I*t doesn’t smell bad to me*.” And she’s like, “N*o, it’s off, there’s something wrong*.” So, she has a very, very keen sense of smell. [Laughs.]

**Interviewer:** Yeah, absolutely. And do, like, other non-food scents, like, bother her? Like, maybe someone’s strong, like, deodorant or perfume?

**Interviewee:** She doesn’t so much care about those things.

**Interviewer:** Mmhmm.

**Interviewee:** Like, if other people are wearing perfume or something.

**Interviewer:** Yeah.

**Interviewee:** But she does…like, she has wax melts she likes, and there’s…she’s very specific about what kind of scent she likes to put in there. Like, we buy them for her for Christmas or something and…

**Interviewer:** Yeah.

**Interviewee:** …most of them will just stay in the box.

**Interviewer:** Gotcha.

**Interviewee:** And there are some she’ll pull out and use.

**Interviewer:** Mmhmm.

**Interviewee:** She likes scents that are kind of sweet. So, things that smell like, you know, vanilla or sugar cookies.

**Interviewer:** Mmhmm.

**Interviewee:** She likes those.

**Interviewer:** Yeah.

**Interviewee:** Mm… So…

**Interviewer:** How do you help her, or how does she kind of cope with her, like, sensitivities to food and to smell?

**Interviewee:** It’s very tough. It’s very tough for her.

**Interviewer:** Aw.

**Interviewee:** Like I said, she’s been hospitalized, and she actually just completed another partial hospitalization this spring.

**Interviewer:** Mmhmm.

**Interviewee:** So, it’s kind of an up and down. There’s times when she just can’t do it at all and other times when she seems to be doing okay.

**Interviewer:** Yeah.

**Interviewee:** The fact that she’s 20 now, I pretty much stay out of her food choices, like, just about 100 percent right now.

**Interviewer:** Mmhmm.

**Interviewee:** Because she really needs to be able to handle that. Like, if she asks me to do something for her, I will, but I just don’t volunteer anything anymore.

**Interviewer:** Mmhmm.

**Interviewee:** Because I get frustrated and she gets frustrated and then it’s just a bad circle.

**Interviewer:** [Crosstalk] Yeah. Mmhmm. So, you kind of let her just kind of do her own thing, it seems like.

**Interviewee:** So, she orders her food generally. She has it…she uses, like…you know, like, the Grubhub apps or DoorDash, that kind of thing.

**Interviewer:** Yeah.

**Interviewee:** But now she’s trying to learn how to budget because that stuff’s expensive, so…

**Interviewer:** Yeah, it is. [Laughs.]

**Interviewee:** It’s a…just, it’s a constant, every single--- Oops! I just dropped my phone, I’m so sorry! [Laughs.] **[0:09:00]**

**Interviewer:** [Laughs.] No, it’s okay! You’re alright.

**Interviewee:** This is a struggle! I have a phone-holder – maybe I should use this. Hold on.

**Interviewer:** Sure! No worries. It’s just the realities of where we are right now, you know?

**Interviewee:** [Inaudible – 0:09:11].

**Interviewer:** [Laughs.]

**Interviewee:** I don’t know if this is gonna work because that’s gonna change my background. Wait…I’m gonna try it…

**Interviewer:** Sure.

**Interviewee:** Okay. One second.

**Interviewer:** No worries.

**Interviewee:** Adjust it a little bit…

**Interviewer:** Sure.

**Interviewee:** This is gonna be me teaching. It’s gonna be awful. [Laughs.]

**Interviewer:** [Laughs.] Beautiful.

**Interviewee:** It’s very jumpy. Okay. But when that stops bouncing, I think it’ll be better, though.

**Interviewer:** [Laughs.] Sounds good.

**Interviewee:**  Okay.

**Interviewer:** So, you were talking about how your daughter usually orders her own food but now she’s trying to budget a little bit more.

**Interviewee:** Mmhmm. Yeah. So, yeah, she gets to a point where she’s running out of money and I’m…like, don’t give her money anymore, so she has to earn her money.

**Interviewer:** Mmhmm.

**Interviewee:** Because those kind of things just allow her to even become more restrictive, so…

**Interviewer:** Mmhmm.

**Interviewee:** Letting her be in charge of everything and knowing what her boundaries are…

**Interviewer:** Mmhmm.

**Interviewee:** …helps her to push herself a little bit more than she would otherwise.

**Interviewer:** Absolutely. You mentioned that she also, like, forces---like, is---forces herself. Could you talk a little bit more about that?

**Interviewee:** Well, I don’t know if it’s so much forces herself… Like, when she was younger, we had so many fights at the table. Like, you know, her dad would be, or I would be, like, “N*o, you have to eat – this is your dinner*.” And then she would just throw up. But…so, we---that ended. But now she will try and say, “O*kay, today I’m gonna do better*,” and…

**Interviewer:** Mm.

**Interviewee:** You know, she’ll make herself, like…like I said, like, broccoli or something.

**Interviewer:** Yeah.

**Interviewee:** And she will really try, and then, but some---there are times where, you know, it’ll end up back in the sink or the trash and she’ll just say, “*I couldn’t do it*.”

**Interviewer:** Mmhmm.

**Interviewee:** So…

**Interviewer:** Yeah. And you mentioned some hospitalizations. Has she received other interventions or other therapies to help her with her diet and her sensitivity to smells?

**Interviewee:** When she was five, I tried with occupational therapy, but they didn’t really know what to do with her at that time.

**Interviewer:** Yeah.

**Interviewee:** So, they were like, “W*e’ll just give her milkshakes*,” but that didn’t work. And then…let’s see… It was middle school, beginning of high school, in there.

**Interviewer:** Mmhmm.

**Interviewee:** She was, like…she got really, really sick. So, we tried occupational therapy again and that was actually starting to make tiny little bits of progress **[0:12:00]** and then the insurance company cut her off.

**Interviewer:** Mmhmm.

**Interviewee:** And ended the program. So, from there, she went into a residential. For a week, she was in residential.

**Interviewer:** Mmhmm.

**Interviewee:** And then they moved her to, like, a full-day partial hospitalization. It was seven days a week.

**Interviewer:** Yeah.

**Interviewee:** From, like, seven in the morning to seven at night.

**Interviewer:** Mmhmm.

**Interviewee:** But she came [inaudible – 0:12:28] at night.

**Interviewer:** But she what? Sorry?

**Interviewee:** She came home at night to sleep.

**Interviewer:** Sure.

**Interviewee:** That was really hard, but… And then… So, she’s had nutritionists…

**Interviewer:** Mmhmm.

**Interviewee:** And a therapist. She’s been with one in particular for a long time.

**Interviewer:** Mmhmm.

**Interviewee:** She’s had a few different therapists.

**Interviewer:** Mmhmm.

**Interviewee:** And then, this year things got really hard for her again. So, she did another partial hospitalization.

**Interviewer:** Mmhmm.

**Interviewee:** But that one, they didn’t really so much address the food… Like, she wasn’t eating there. They didn’t do food there.

**Interviewer:** Oh.

**Interviewee:** So, it was kind of weird. But it did kind of give her a bit of a reset, though, and give her a jumping-off spot again.

**Interviewer:** That’s good. When you say, like, things have gotten hard for her, do you mean that, like, she is having trouble eating anything at all and she’s getting ill because of that?

**Interviewee:** Yeah. Mmhmm.

**Interviewer:** Okay. Thanks for sharing that.

**Interviewee:** Mmhmm.

**Interviewer:** We appreciate it. I’m sure it’s not the easiest thing to talk about. And how have her sensitivities changed over time, or have they not changed?

**Interviewee:** Well, I think as she’s gotten older, she’s just more aware.

**Interviewer:** Mmhmm.

**Interviewee:** For herself. Rather than…you know, like, she knows, like…for instance, using puddy. Like, just using up puddy or a… I don’t know. We keep…we have baskets of sensory toys in my house. [Laughs.]

**Interviewer:** Yeah!

**Interviewee:** Actually, they’re everywhere. We all use them! But she’s learning, like, what sorts of things like that help her.

**Interviewer:** Mmhmm.

**Interviewee:** With the food, it’s just being more aware, I think, of herself. What works for her and what doesn’t work for her has come with time, age, and knowing what her own issues are exactly.

**Interviewer:** Mmhmm. Absolutely. And would you say this, like, increase in, like, self-awareness and **[0:15:00]** perhaps even some, like, motivation a little bit you’re talking about, do you think that’s related to any changes in independence that she’s gained?

**Interviewee:** Maybe a little bit just because of having---you know, having a job and having the money to buy her own food---

**Interviewer:** Yeah.

**Interviewee:** ---without any parental unit there. [Laughs.]

**Interviewer:** Yeah.

**Interviewee:** That has, I think, both helped and hurt in a way, but probably more helped.

**Interviewer:** Mmhmm. How helped? How hurt?

**Interviewee:** Helped because she has complete choice over what she eats and what she buys to eat.

**Interviewer:** Mmhmm.

**Interviewee:** And then also hurt because she’ll use up her money.

**Interviewer:** Mm.

**Interviewee:** [Inaudible – 0:15:51] because she’s got to figure this out.

**Interviewer:** Mmhmm.

**Interviewee:** How to make this work. And then, so, what she would do for a while is just, like, not eat. “*Oh, I’m out of money – I’m just not gonna eat*.”

**Interviewer:** Mm.

**Interviewee:** [Inaudible – 0:16:05]. “*I’m gonna go blow my money and buy a teddy bear. And I’m twenty*.” So, that, as a parent, is very difficult to balance.

**Interviewer:** Mmhmm.

**Interviewee:** Trying to help her to learn responsibility for her money with the budgeting, not wanting to give her more money just so she can blow it on what I consider to be stupid stuff. [Laughs.] And then not have money to eat. So, knowing that eating, for her, is such a huge issue and then saying, “N*o, you can’t have more money*,” is incredibly difficult as a parent.

**Interviewer:** Yeah. I’m sure. Because, you know, you don’t want her to starve but you probably want to give her some skills to keep on moving forward.

**Interviewee:** Yes.

**Interviewer:** And if she is faced with a scenario where she, like, has foods that she does not like or, like, cannot tolerate, does that cause or increase anxiety for her?

**Interviewee:** Absolutely. It’s huge.

**Interviewer:** Yeah. And what does---

**Interviewee:** Yes, very.

**Interviewer:** And what does that anxiety look like for her?

**Interviewee:** It’s anger. It can be slamming doors, it can be screaming at people, but it’s very self-protective. It’s a way to push everyone away so she can, you know, go hide in her room in her safe space and not have anyone want to interfere.

**Interviewer:** Mmhmm. How does she manage those anxieties?

**Interviewee:** It’s still hard for her in the moment, but she’s been learning a lot of tools. She has some apps on her phone that help manage, like, breathing and calming, that kind of thing. She’s got, you know, tons of sensory toys, she’s got… She likes the computer. She’s got some computer **[0:18:00]** games that---

**Interviewer:** Mmhmm.

**Interviewee:** ---really help her relax. So, she has a lot of tools and she’s… I don’t know. [Laughs.]

**Interviewer:** Yeah.

**Interviewee:** [Inaudible – 0:18:13].

**Interviewer:** That’s good. I’m glad she’s getting better. What types of sensory tools does she…or the toys that you talked about. Which ones does she like?

**Interviewee:** She has a couple of shaker things that she’s made. She really likes the puddy that, like… I have some here. I have some here. I have this, like…

**Interviewer:** Yeah! Oh, I love that stuff.

**Interviewee:** But she has some kind of slime puddy that’s scented.

**Interviewer:** Mm.

**Interviewee:** She really likes it. She’ll actually just sit there and breathe it. [Laughs.] Another favorite in my house are these kind of things.

**Interviewer:** Are those--- Oh! They’re like stretchy worms. [Laughs.]

**Interviewee:** [Inaudible – 0:19:01]. And I…actually, I keep… These are one of my favorites. [Laughs.]

**Interviewer:** What are those?

**Interviewee:** They’re just…it’s just stretchy.

**Interviewer:** Oh, it’s fun!

**Interviewee:** Like, a thick rubber band, kinda.

**Interviewer:** It looks like a lot of fun.

**Interviewee:** [Crosstalk] And you can--- Yeah, those are good ones.

**Interviewer:** [Laughs.] Awesome. Alright.

**Interviewee:** So, she’s got some ones that click that are like…almost like popping bubble wrap.

**Interviewer:** Mm.

**Interviewee:** Like, [inaudible – 0:19:38]. We’ve got a few of those. She likes those.

**Interviewer:** Mmhmm.

**Interviewee:** And just some different ones that click or snap, that make a hard kind of a crack-y feel and noise.

**Interviewer:** Mmhmm.

**Interviewee:** So, both ways for those.

**Interviewer:** Mmhmm. And has food and, like, scents always caused anxiety for her?

**Interviewee:** Yes.

**Interviewer:** Yeah.

**Interviewee:** Since about age two.

**Interviewer:** Age two? Is that what you just said?

**Interviewee:** I would say…it might have been before… Well, I’m sure it’s before then, but I think around age two is when it really started blossoming out to where we’re like, “*okay, this is a real problem*.”

**Interviewer:** Mmhmm.

**Interviewee:** Before, with an infant, you have a screaming baby, do you know is it colic, is it sensory overload…what is it with an infant? It’s very tough to tell. But, I mean, those types of things have been there since she was really very young. At night, I would just have to let her scream because there was nothing, nothing, we could do to stop that.

**Interviewer:** Yeah.

**Interviewee:** So, 15, 20 minutes of solid scream time and then she could just settle herself and go to sleep.

**Interviewer:** Mmhmm. Gotcha. Do you think, like, **[0:21:00]** how she’s presented or, like, managed her anxiety, has that changed or is it also pretty much the same throughout her life?

**Interviewee:** No, I think…I don’t think we had any kind of grasp on that before middle school, at all. And in high school, it was only, like, just starting to figure this out for her.

**Interviewer:** Hm.

**Interviewee:** So, it’s definitely come with age and time. And I think one of the big reasons for that is, number one, she’s a girl. And I have four boys and the boys’ issues were so different from her issues that it took me a long time to recognize what was happening with her.

**Interviewer:** Mmhmm.

**Interviewee:** It’s kind of the same thing as some of the boys but it just looked different.

**Interviewer:** Yeah. Are your boys also on the spectrum?

**Interviewee:** A couple of them. [Laughs.]

**Interviewer:** Gotcha.

**Interviewee:** Probably all of them. [Laughs.] [Inaudible – 0:22:11]. [Laughs.]

**Interviewer:** Gotcha. What…like, at what point were you able to connect the two things? Like, her anxiety and her sensitivities?

**Interviewee:** I would say it was probably right there, early high school.

**Interviewer:** Mmhmm.

**Interviewee:** In high school. Yeah.

**Interviewer:** Did, like, something happen around then or was it just kind of like a lightbulb, you know? Which happens sometimes.

**Interviewee:** So, in sixth grade she was actually doing really well. She got a concussion, and it was bad enough that everything just started going haywire, and she got diagnosed with POTS.

**Interviewer:** Mm! Yeah, I know POTS. [Laughs.]

**Interviewee:** [Laughs.]

**Interviewer:** Yeah, no, I have three people in my family who have it, so I understand.

**Interviewee:** She was so sick.

**Interviewer:** Yeah.

**Interviewee:** Then she started…you know, she missed a lot of school.

**Interviewer:** Yeah.

**Interviewee:** And then you could just see the anxiety about going back to school beginning to build, and everything just kind of came crashing down around her.

**Interviewer:** Yeah.

**Interviewee:** So, that was between sixth and seventh grade.

**Interviewer:** Mmhmm.

**Interviewee:** And we’ve struggled ever since with lots of anxiety about doing all sorts of things. But working is a huge help for her. She’s learning to do a lot of things and be a lot more independent.

**Interviewer:** That’s awesome. That’s really great. I’ll have a bunch of questions about that in a little bit. [Laughs.] So, thinking kind of, like, largely about her sensory sensitivities, what are your goals or hopes for her **[0:24:00]**in regards to how she will manage her sensitivities in the future?

**Interviewee:** Well, of course, you know, you want her to be able to have, like, the kind of life where she can go out to dinner and, you know, go do activities where there’s food and things involved and be okay with that, and I’m not sure that she…at this point, I don’t know that she ever will be.

**Interviewer:** Mmhmm.

**Interviewee:** I mean, I’m hopeful that she will be, but the reality, to me, says maybe not.

**Interviewer:** Yeah.

**Interviewee:** I mean… So, really, ultimately, you just want your kids to be happy, right?

**Interviewer:** Yeah.

**Interviewee:** To be fulfilled, to have a good job, to have a family. And whatever that looks like, if it’s okay with her, then it’s okay with me.

**Interviewer:** Yeah.

**Interviewee:** Right? So… But as far as being hopeful that she’s gonna just overcome this one day and eat normally…not…well, you know… I don’t see that happening.

**Interviewer:** Mmhmm.

**Interviewee:** But you never know! [Laughs.]

**Interviewer:** You never know! So, we’re gonna switch gears a little bit to my next chunk of questions. We have five, so, we we’re in the second one. As your daughter has grown up and aged, how has her and your community reacted to her sensory sensitivities?

**Interviewee:** The community meaning, like, family, school, that kind of thing?

**Interviewer:** Yeah. Whomever---like, whatever community is to you, whether it’s school, friends, work, people in your stores that you go to.

**Interviewee:** Well, at home when she was younger, her brothers teased her a lot. Especially her oldest brother who would stick a finger in her food, her dinner plate, and then she would have to throw all her food away. She wouldn’t eat it.

**Interviewer:** Hm.

**Interviewee:** That was always contentious.

**Interviewer:** Yeah.

**Interviewee:** He did it on purpose. Or he’d take a little green bean and flick it on her plate and that would [inaudible – 0:26:10]. So, there was lots of craziness in our house around mealtimes with them growing up. But it has affected the family in that, like, we would go out to dinner and it---there would be a meltdown at the restaurant every time.

**Interviewer:** Mmhmm.

**Interviewee:** I mean, there was time I would have to leave the restaurant to bring her home and go back. My dinner would be there and be getting cold. It would just, like…we just quit doing that. You know, like, we just don’t really go out to eat. And then what modified us was, we would start to order food. If we wanted to go out, we would just order it and have it here and then we would have to get **[0:27:00]** something else for her.

**Interviewer:** Mmhmm.

**Interviewee:** And that caused a lot of just frustrations within the family.

**Interviewer:** [Crosstalk] Mmhmm.

**Interviewee:** A lot of frustrations. With her friends, you know, she’d go to a birthday party and ten minutes in, she’d be calling me. “*Can you come get me? I’m done*.”

**Interviewer:** Mmhmm.

**Interviewee:** So, it’s been hard for her to keep friends. So, she has two friends pretty much right now that have kind of stuck with her.

**Interviewer:** Yeah.

**Interviewee:** But I know that even they get kind of fed up with her every now and then. They’ll tell her that she’s annoying and… [Laughs.] It frustrates them too.

**Interviewer:** Mmhmm.

**Interviewee:** So…but at the same time, they’re kind of like her little circle. They have---they all have their quirks together.

**Interviewer:** Yeah.

**Interviewee:** So, yeah… She does have a boyfriend which is kind of helpful because he’ll bring her food.

**Interviewer:** Yeah.

**Interviewee:** He’s pretty understanding.

**Interviewer:** What? Sorry.

**Interviewee:** He’s pretty understanding.

**Interviewer:** That’s good. That’s really important. [Laughs.]

**Interviewee:** Yeah. [Laughs.] It’s nice.

**Interviewer:** Yeah! Was her community, like, more or less accepting when she was younger?

**Interviewee:** When she was really young, probably more until about third or fourth grade, I think, when the other kids started, like, going… You know. [Laughs.] It just…when you’re, you know, 10, 11, 12 and you try and do something and you can’t because this one kid derails the plans, it’s hard to maintain friendships like that.

**Interviewer:** Mmhmm.

**Interviewee:** And she’s a plan-derailer. [Laughs.]

**Interviewer:** Gotcha.

**Interviewee:** [Laughs.]

**Interviewer:** [Laughs.] What about, like, different, like, spaces and places? Like, you’ve talked about your family, you’ve talked about your friends…like, what about school? Was school accepting and accommodating of her?

**Interviewee:** I think they worked pretty well. What she used to do in high school, she couldn’t eat in the cafeteria so she would go to the nurse’s office.

**Interviewer:** Hm.

**Interviewee:** And, like, drink a Boost or eat a bag of chips. That’s all she ever ate in high school. She wouldn’t eat food, she wouldn’t pack a lunch or take things.

**Interviewer:** Mmhmm.

**Interviewee:** So, what I would do is I would buy a case of, like, Ensure or something like that and a case of basically, like, **[0:30:00]** granola bars to keep there, but she wouldn’t eat the granola bars, so… [Laughs.] I was like, “*Just give them to the other kids who need a snack*.”

**Interviewer:** Yeah. [Laughs.]

**Interviewee:** But she would go there and be in the nurse’s office where she could just, like, lay down and be quiet by herself for 20 minutes, and she would drink an Ensure and then go to class.

**Interviewer:** Mmhmm.

**Interviewee:** Probably at least three days a week, she either didn’t go to school or she would have someone come pick her up to bring her home within a couple hours of being there.

**Interviewer:** Mmhmm.

**Interviewee:** At least three days a week, all the way through high school.

**Interviewer:** Was it---

**Interviewee:** [Crosstalk] I don’t know how she--- [Laughs.]

**Interviewer:** You don’t know what? Sorry.

**Interviewee:** I don’t know how she graduated. But she did okay.

**Interviewer:** Good! Was school just, like, too overwhelming for her? Or was it a food thing?

**Interviewee:** No, it was everything. It was anxiety about being in school, it was food, it was the kids are too loud, there’s too many of them… She felt, like, overwhelmed with the work. And she’s a very bright kid. I mean, she was diagnosed as a…not diagnosed, but she was identified as gifted.

**Interviewer:** Mmhmm.

**Interviewee:** [Inaudible – 0:31:18]. So, she participated in the gifted program. But she---what she would do is… This is how she graduated because the teachers all knew how smart she was. She would sit in class, she could listen to the information, and she [inaudible – 0:31:37].

**Interviewer:** [Crosstalk] Mm.

**Interviewee:** ---every test they gave her with ease. And she’s a really good writer and she could write stuff off the cuff in a moment. So, the teachers gave her a lot of grace with the work and they just kept saying, “*Oh, she’s gonna be fine, she’ll be alright, she’s smart, she can do all this stuff*.” But what did she really learn in school? I don’t really know. [Laughs.]

**Interviewer:** Mmhmm. Gotcha.

**Interviewee:** I think she just got through it

**Interviewer:** Yeah. I mean, it’s important to get through it, so it’s good that she was able to in her own way.

**Interviewee:** Yep.

**Interviewer:** You talked about, like, the kids being loud. Is she sensitive to other noises or was it just kind of, like, the context of high school?

**Interviewee:** She…even here at our home, if, like, the family comes over and the grandkids are here, she will escape to her room. She just says it’s too overwhelming for her; it’s too loud.

**Interviewer:** Mmhmm.

**Interviewee:** She was [inaudible – 0:32:38] everywhere.

**Interviewer:** She---

**Interviewee:** [Crosstalk] She [inaudible – 0:32:41] headphones are on her head.

**Interviewer:** Sorry, you cut out. Did you say she wears headphones all the time?

**Interviewee:** Yes. [Laughs.]

**Interviewer:** Like, are there certain types of noises that are more bothersome to her?

**Interviewee:** I just think it’s kind of, like, the chaos of it **[0:33:00]** when there’s a lot of people and everyone’s talking.

**Interviewer:** Mm.

**Interviewee:** You know, you discern and keep up with the conversation. I know that’s also a problem for me and for my younger son very much so. It makes him really angry. But it just---it’s just too much sometimes. So, the headphones help but sometimes she just has to escape.

**Interviewer:** Mmhmm. Absolutely. You’ve talked about her having a job. How is her job, like, accepting in terms of her sensitivities? Or does it not come up?

**Interviewee:** No, it does. [Laughs.] She’s been there for a couple years now, but when she first started, she had so much anxiety about going. Like, she kept calling out sick.

**Interviewer:** Mmhmm.

**Interviewee:** And calling out sick. And I was like, “*You’re gonna lose your job – you can’t do that*.” But her boss, you know, they would have these conversations about her anxiety and he was so understanding, so he also gave her a lot of grace and just kept her coming back until she got used to it. It took a really, really long time. And I think without that kind of understanding from her supervisor, it wouldn’t have happened.

**Interviewer:** Mmhmm.

**Interviewee:** Like, at a typical job, I think they would have just said, “*Forget it*.” I know in my day, I would have been fired the second time I called out. [Laughs.]

**Interviewer:** Yeah.

**Interviewee:** So, maybe times are changing. But now she’s, like, top dog at her store.

**Interviewer:** That’s awesome!

**Interviewee:** The floor manager. And she’s been there the longest now of anyone else there. So, it’s still very stressful for her, but she’s making it work.

**Interviewer:** Good! I’m so glad to hear that. And then, thinking towards the future again, what are your hope or worries in terms of how her community will react in the future regarding her sensitivities?

**Interviewee:** Well, I think as far as food goes, everybody has weird diets anymore and I don’t know that that’s gonna be such a big deal.

**Interviewer:** Fair.

**Interviewee:** Really. But I think where the struggle may be is, you know, getting overwhelmed at work. Because depending on where she ends up… She wants to be a nurse ultimately, but she’s really struggling to go to school to do that. So, at some point she’s gonna have to kinda figure out how to control the anxiety enough that she can get to where she wants to be.

**Interviewer:** Mmhmm.

**Interviewee:** [Inaudible – 0:35:59].

**Interviewer:** [Crosstalk] Is she having **[0:36:00]** trouble--- Oh, I’m sorry.

**Interviewee:** [Laughs.] I said I don’t think that answered your question.

**Interviewer:** Yeah it did! No, that was perfect! You answered it perfectly. Thank you. [Laughs.] You said she’s struggling to, like, go to---to finish school for nursing. Is it, like, she’s having trouble enrolling or, like, just with the classes? Like, which parts are hard for her?

**Interviewee:** All of the above.

**Interviewer:** Fair.

**Interviewee:** So, the first few semesters, she just wouldn’t go to class, so, she would fail the class.

**Interviewer:** Mmhmm.

**Interviewee:** And then she figured out, she would enroll in the class and then drop the class. So, her GPA right now is probably like a 0.8. I mean, it’s very, very low. But she finally had a success last semester and finished one class.

**Interviewer:** That’s awesome! That’s great.

**Interviewee:** So, I’m happy about that. She’s taking a class right now in forensic science. Struggling to go. It’s online – it’s a virtual class. But, you know, this is where she and I will struggle because I’m trying to get her, like… Set yourself up for success, right? You create your space, you have your desk, your computer, and you have to tell your brain, “*This is school for me and this is where I need to go*.” She wants to, like, lay in her bed and have her laptop and her headphones and her stuffed animals. So, part of it is a---I feel like a maturity thing still. Like, how do you… She has to motivate herself to do this, right?

**Interviewer:** Mmhmm.

**Interviewee:** Still, she’s 20. This isn’t something I can tell her--- If she was away at college, she could do it however she wants to. But the fact that she struggles so hard to get through the class, she has to figure out that there are steps that you can take that help to bolster the possibility that you’re going to be successful. And if you’re not willing to take any of those steps, then I don’t know what to tell her, you know?

**Interviewer:** Yeah. Absolutely. You just gave me some great segues into my next chunk of questions, so thank you. So, in this part we’re gonna talk about her independence levels. So, in the transition to adulthood, where do you see your daughter?

**Interviewee:** Well, she certainly is not ready to move out. I would love it if she was, but I don’t see that.

**Interviewer:** Mmhmm.

**Interviewee:** She hasn’t real concept still of **[0:39:00]** how to control and spend money in a way that is sustainable. Just your normal day to day things like making sure you get the oil changed on your car and did you pay this bill on time…like, all of those things she finds very overwhelming.

**Interviewer:** Gotcha.

**Interviewee:** So, I’m trying to help her do one thing at a time. Just pick this one thing and work at it until it becomes a habit, then you pick the next thing. [Laughs.] Kinda like that.

**Interviewer:** Mmhmm. Absolutely. Go ahead.

**Interviewee:** I just… She’s supposed to be making car payments, right? She has a car. So, this morning she says to me, “*Can you take a hundred dollars out of my bank and set it aside towards the car payment*?” And I told her no because it’s her bank and her budget and I expect the car payment on the day it’s due. She did not like that answer.

**Interviewer:** Gotcha.

**Interviewee:** [Laughs.] So, where do we go from here? [Laughs.]

**Interviewer:** Yeah. Absolutely. How is she with, like, daily living skills like hygiene and, like, cleaning up her room or, like, helping with chores? Things like that. No? [Laughs.]

**Interviewee:** I generally leave her stuff alone until it gets so gross that she can’t stand it. [Laughs.] So, I actually did go through her room this morning just to pull out the dirty fishes and stuff because it’s smelly. And, okay, in a way, I completely understand this brain function because I work the same way. It’s like your brain has to be in a space where you’re like, “*Okay, today I’m gonna clean my room*,” and all the stars have to align. [Laughs.] And everything has to be good and then you can go for it and get the room clean. She is exactly like that. So, if she’s stressed or she worked that day or whatever, nothing is gonna happen. She will re-wear dirty clothes to work and then she’ll be mad at me because I didn’t do her laundry. I don’t do her laundry. [Laughs.] So… But she’ll still get mad at me because she has to wear dirty things to work.

**Interviewer:** Mm.

**Interviewee:** So, it’s like planning…the executive functioning for her is just a massive struggle.

**Interviewer:** Yeah.

**Interviewee:** That kind of planning is really---is hard, and I **[0:42:00]** don’t know, maybe she just has to move out to figure some of that stuff out, or maybe she really just needs someone else. Some kind---more kind of a life coach or someone to get her to do these things where I’m not involved in it.

**Interviewer:** [Crosstalk] Mmhmm.

**Interviewee:** Because then she wouldn’t be made at someone else, you know, that’s not her mom.

**Interviewer:** Yeah. I understand. I was mad at my mom too for a bit. [Laughs.] What about hyenine? Is she okay with, like, brushing teeth regularly? Bathing?

**Interviewee:** No. None of the above. And even, like… [Laughs.] She would be mortified to know I said this to you, but even her boyfriend will say, ‘*You know, like, you probably should take a shower today*!’ [Laughs.] I mean, it’s not because she doesn’t want to or it’s just…maybe it’s…I really don’t know what it is. If it’s a task initiation thing with her.

**Interviewer:** Mmhmm.

**Interviewee:** But it’s hard for her to do that sort of thing. Like, she’ll get in a routine and she’ll be really good for a while and then she’ll miss a day and then it just falls apart.

**Interviewer:** Gotcha. That makes sense. In the beginning, you talked about how she’ll, like, order Grubhub or, like, order food for herself. Will she cook or, like, shop for food, or is, like, delivery her main source of taking care of her food?

**Interviewee:** The grocery store is very overwhelming for her, so she really hates to go to the grocery store. So, she avoids that if at all possible.

**Interviewer:** Mmhmm.

**Interviewee:** Really hates to do it. She doesn’t like to shop for clothes, she doesn’t like to shop. But she goes like to go to Target and look at make-up, so that could be a segue. [Laughs.]

**Interviewer:** Yeah! They have a nice make-up section. [Laughs.]

**Interviewee:** She does a lot---she does… It’s funny, I’ll know when she’s struggling because she wears very heavy make-up, and she does it very fancy. She looks like a make-up artist.

**Interviewer:** Oh, when she’s having a hard time, she does that?

**Interviewee:** Yes. Yep.

**Interviewer:** Interesting.

**Interviewee:** So, I know she’s had a really bad day if I come home and her make-up just looks like she should be on the stage.

**Interviewer:** [Laughs.] I mean, it can be very therapeutic. It’s very calming.

**Interviewee:** Yeah. Yeah.

**Interviewer:** What about cooking? Oh, sorry, I didn’t mean to cut you off.

**Interviewee:** She… Going in the fridge is hard for her. She does do a little bit of cooking.

**Interviewer:** Mmhmm.

**Interviewee:** A very little bit. Usually if she wants something, she’ll ask me to make it for her or heat it up for her.

**Interviewer:** Mmhmm.

**Interviewee:** Something here. **[0:45:00]** But last night she did cook herself pasta, so there’s that.

**Interviewer:** That’s great!

**Interviewee:** Yeah.

**Interviewer:** You talked about she has two friends, and you mentioned her boyfriend. Does she, like, manage that social life? Does she, like, initiate interactions with, like, her boyfriend and her friends?

**Interviewee:** Yes, she does. Now, her two friends, they don’t see each other a lot.

**Interviewer:** Mmhmm.

**Interviewee:** But they do. Like, they’ll say, “*Oh, we’re all gonna get together and have a game night tonight*.” Or the girls are getting together for the girls’ night or whatever.

**Interviewer:** Yeah.

**Interviewee:** And it’s never like…I don’t know. When I think of college, you know, when you go to parties or stuff and stay out – it’s never like that. It’ll be, like, from seven to eight-thirty. Or from seven to nine because they watched a movie and then it’s over and she comes home. You know? It’s just…it’s different. [Laughs.]

**Interviewer:** Yeah. Yeah. And you talked about her having a job. How did she get the job? What is her job?

**Interviewee:** So, her job…she works at Build-A-Bear Workshop.

**Interviewer:** Mmhmm.

**Interviewee:** It’s not her first job. Her first job was working at a farm. [Laughs.] Oddly enough, as a scarer.

**Interviewer:** What’s that?

**Interviewee:** [Inaudible – 0:46:32] festival. So, she could, you know, dress up in a costume and make-up.

**Interviewer:** Oh! Like, literally scaring people.

**Interviewee:** And so, very quickly she became someone who could do make-up for the other actors.

**Interviewer:** Mmhmm.

**Interviewee:** Because she’s really good at the make-up. And that I think gave her a boost of confidence to be able to manage a schedule of going to work.

**Interviewer:** Mmhmm.

**Interviewee:** So, then… I did do a fair amount of pushing, though, and told her she had to have a job. She either---I told her she either had to be going to school or have a job – she couldn’t just sit around the house and do nothing.

**Interviewer:** Mmhmm.

**Interviewee:** Because you just couldn’t. So, she applied for Build-A-Bear and went for the interview. She handled it all. It was really hard for her. She, like, wouldn’t call the guy back forever and that kind of thing, but… And then, like I said, it took her a really long time to get used to the job and used to going to the job and not calling out sick every second day. [Laughs.]

**Interviewer:** Hm.

**Interviewee:** Yeah. She’s done it.

**Interviewer:** That’s awesome. That’s really great. And does she ever express interest in wanting to live on her own?

**Interviewee:** Yes. I mean, I think she would really like that. But then she will tell me **[0:48:00]** ---she goes, “*I can’t handle it*.”

**Interviewer:** Mmhmm.

**Interviewee:** “*I don’t know how to do it*.” So…

**Interviewer:** Mmhmm.

**Interviewee:** We’re working on it.

**Interviewer:** Absolutely. And do you think she will be able to achieve more independence in the future?

**Interviewee:** Yes. I mean, I think she will move out eventually. I think she needs a better job because she doesn’t earn enough.

**Interviewer:** Mmhmm.

**Interviewee:** Around here is expensive. But I think she will. And I probably think even within the next two years she should be able to do that.

**Interviewer:** That’s awesome. What do you---besides a new job---like, a job that pays a little bit more, what else do you think will help her move into adulthood?

**Interviewee:** Well, she’s got the car. We just got her a car. Yeah, but… [Laughs.] Her brothers, like… I didn’t help them as much as I’m helping her, so I’m hearing about it from them.

**Interviewer:** [Laughs.]

**Interviewee:** [Laughs.] “*You guys got to know, I want her to move out*!” [Laughs.]

**Interviewer:** Is she the last one?

**Interviewee:** She has a younger brother but he’s down---he’s away at college.

**Interviewer:** Gotcha.

**Interviewee:** So, even though he also has autism and really struggles… He’s been texting me – he’s really struggling. But he has been able to make the transition to moving out, to be able to do that.

**Interviewer:** That’s awesome. Like, back to your daughter, you talked a little bit about, like, a life coach. Do you think there are other services or interventions that might be helpful for her as she does continue on this transition?

**Interviewee:** Yeah, well, she has her therapist still that she sees.

**Interviewer:** Mmhmm.

**Interviewee:** Which is really helpful. I probably think she does need to go back and see a nutritionist again to help a little bit with that.

**Interviewer:** Mmhmm.

**Interviewee:** But really, it’s almost like… I think that having a coach that can help her making decisions and just to keep practicing the tools that she has would be really helpful because it’s like she knows what to do but she just can’t make herself do it.

**Interviewer:** Mm. Yeah. That makes sense. Thank you. And so, now putting these two things together, her sensory sensitives and her transition to adulthood, how do they intersect for your daughter?

**Interviewee:** Well, when you’re thinking about food all the time because, you know… “*How do I go to work and I can’t get food? What happens if I, you know, go to class and I can’t eat?* **[0:51:00]** *What*---” I mean, it’s always like that. “*What if I go on vacation and there’s nowhere for me to get food*?” So, that’s always on her mind.

**Interviewer:** Mmhmm.

**Interviewee:** “*Do I want to go to this mall with these people? What’s there that I can eat? If all the friends are going to a party or out to dinner, it’s---not only is it that I can’t eat, but that restaurant is too noisy and I’m not going there*.”

**Interviewer:** Mmhmm.

**Interviewee:** “*What happens if I get anxiety and I have to go home? How will I get home*?”

**Interviewer:** Mmhmm.

**Interviewee:** There are times when we’ve had to go pick her up from work because she’s been too anxious to drive, to where she’s, like, shaking. So, I think it’s a matter of knowing what her boundaries are but also being able to have a Plan B. [Laughs.]

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

**Interviewee:** An obstacle, definitely.

**Interviewer:** Yeah.

**Interviewee:** Yeah.

**Interviewer:** Can you talk a little bit more about that?

**Interviewee:** Well, I think if she could be in the world more, around people more, around a little bit more chaos and…not chaos, but just being able… Like, to find a job or to stay at school, to be able to work into that. I mean, that’s really the key for her right now, is being able to support herself and how do you get from here to there.

**Interviewer:** Mmhmm.

**Interviewee:** So, if you’re afraid of the world and you can’t handle things that are…you know… Driving, because you’re visually overstimulated, or… You know, driving is---learning to drive has been really hard for her. I mean, she does really well; she’s a good driver now. But predicting what other people are going to do is scary for her.

**Interviewer:** Mmhmm.

**Interviewee:** So, there’s a lot. There’s just so much. [Laughs.]

**Interviewer:** Yes. Yeah. Absolutely. Thank you. And what do you anticipate as being challenging for your daughter as she does gain more independence in regards to her sensory sensitivities?

**Interviewee:** I think it’ll just be managing things on her own. **[0:54:00]**

**Interviewer:** Mmhmm.

**Interviewee:** Going to the grocery store. You have to be able to do that. You can’t spend your life ordering every single meal. Can you? I don’t know, maybe she can. [Laughs.] But I don’t think so. I mean, if you want a family, and I know she does, she’s going to have to provide food for children someday.

**Interviewer:** Yeah.

**Interviewee:** So, there has to be some kind of segue from here to there.

**Interviewer:** Mmhmm. Absolutely. And what do you think will---would help your daughter, like, in this intersection of her sensory sensitivities and this transition?

**Interviewee:** I honestly just don’t know. We’re actually looking into hypnosis right now. [Laughs.] Like, I’m like, is there something that could help her just, like, get a little leg up and just do something to get over… I don’t know. I really don’t know. I think I’m---I feel like I’m out of options.

**Interviewer:** Mm.

**Interviewee:** Like, I feel like we have tried and tried and tried, and I don’t know what else there is to try.

**Interviewer:** Yeah. Absolutely. So, you mentioned hypnosis. Are there other, like, interventions or therapies that you think could help her? Or, again, you kind of said you feel like you’re out of options.

**Interviewee:** [Inaudible – 0:55:22] what there is.

**Interviewer:** You said---

**Interviewee:** [Crosstalk] I’m…I really don’t know---

**Interviewer:** You said you don’t know?

**Interviewee:** There’s a doctor in England who seems to be having some good success with his particular type of hypnosis for people with ARFID. So, I’m like, “*Let’s go to England*!” [Laughs.]

**Interviewer:** [Laughs.]

**Interviewee:** And that sounds crazy to me when I say that to myself but I think, you know, you get to a point of desperation where you start looking at crazy things. And I don’t…like, I don’t think that’s gonna happen. [Laughs.] I’m pretty sure. But we---I did spend money and buy his online package for her to try at home. She won’t do it. She’s done one session.

**Interviewer:** Mm.

**Interviewee:** So, you know, I really…I don’t even know what to do.

**Interviewer:** Yeah, absolutely. I don’t think you’re alone in that. A lot of parents I talk to say they just don’t know. Do you feel like there are gaps in the available services and interventions for kids like your daughter?

**Interviewee:** Yes.

**Interviewer:** Yeah?

**Interviewee:** Because for her, like, the go-to is to treat her as if she has anorexia. She does not have anorexia.

**Interviewer:** No.

**Interviewee:** She’s willing to eat. She wants to eat. But if you can’t get the food **[0:57:00]**in your mouth… [Laughs.]

**Interviewer:** Yeah.

**Interviewee:** …because it smells funny or it looks funny, that’s a very different thing from you can’t put the food in your mouth because it has 50 calories in it. I mean, that’s…it’s a very different take on food.

**Interviewer:** Yeah. It’s a whole different ball game. And then, how have your daughter’s sensory sensitivities impacted your goals, hopes, and expectations for her as she does navigate adulthood?

**Interviewee:** Well, you know, I expected what my other kids did. They went to school, they graduated, they went off to college, they now have careers… I never expected to have her here post-high school, not being able to go to college.

**Interviewer:** Gotcha.

**Interviewee:** I mean, she is so smart. She’s---since she was a little tot, she wanted to be a doctor. That’s all she talked about for, like, 10 years.

**Interviewer:** Mmhmm.

**Interviewee:** She used to play doctor. She had this massive doctor set-up. Every time she went to the doctor, she would come home with masks and tubing and you can’t even name. Whatever she would pull away that he would give her, she would take it. She had an anatomy book, this giant anatomy book that she would just study for hours. And then it just melted. It just melted, and now she feels like she’s really lost something because she says that’s never gonna happen. That’s hard.

**Interviewer:** Yeah. Doe she still want to be a doctor but doesn’t think it’s possible?

**Interviewee:** She doesn’t think it’s possible. So, then she said, “*Well, I could do nursing; I could be a really good nurse*.” And she wanted to be an ICU nurse. And I think she’s realizing that that’s not gonna happen. Like, I keep telling her, it still can. “*You’re very young, you know, you can do what you want to do when you figure this out.”* But I think, you know, as you have failure after failure, it’s hard to maintain that kind of thinking.

**Interviewer:** Yeah. Absolutely.

**Interviewee:** So, now it’s almost like a step down. It’s not a step down, but in her mind, it’s a step down. So, now she’s like, “*Well, maybe I can be some kind of a scientist*.” So, now she’s taking the forensic science class.

**Interviewer:** Mmhmm.

**Interviewee:** She’s like, “*Then I can work inside of a lab and not have to be around people*.” I’m like, “*You’re always gonna be around people. It doesn’t matter what the job is*.” **[1:00:00]**

**Interviewer:** Yeah.

**Interviewee:** So, I don’t know where we go from here.

**Interviewer:** Mmhmm. Absolutely. Thank you for sharing that. I have one last tiny chunk of questions, but we’re almost done. So, like, finally, as a caregiver, as a mom, as a parent of someone with ASD and also some sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee:** It---to me, it’s like, being ready to move out and be on your own. To be self-supporting, to be able to hold a job that will pay for your apartment and your car and your food and all that kind of stuff. You have to be self-supporting. But also, you have a handle on, you know, life. Take a shower every day. Brush your teeth. Go to the dentist to get your teeth cleaned. Get the oil changed in your car. Like, just all the normal stuff you have to do.

**Interviewer:** Yeah.

**Interviewee:** You have to be able to function in the world to do those things. You can’t just…you know, in her way, I think she has the---a very immature view of, she’s gonna move out into an apartment and everything is gonna be just perfect and roses without thinking of any other this other stuff.

**Interviewer:** Gotcha. Mmhmm. Has this perspective changed for you over time?

**Interviewee:** Yes, I think it has. I think my expectations are much lower. [Laughs.]

**Interviewer:** Yeah.

**Interviewee:** [Laughs.]

**Interviewer:** Mmhmm.

**Interviewee:** Yeah. I mean, at this point, I’m like, “*Okay, we’ll just skip college, and you can get an office job*.” Two of her brothers actually work for the same company and they’ve offered her to come have an interview, and she won’t do it.

**Interviewer:** Hm.

**Interviewee:** I’m like, “*That would be a really safe space. Two of your brothers work there who would be looking out for you*.”

**Interviewer:** [Crosstalk] Yeah.

**Interviewee:** You know? It wouldn’t be so scary. And it terrifies her. She’s, like, not gonna do it. She won’t do it.

**Interviewer:** Is it because it’s new? Is, like, the newness scary for her?

**Interviewee:** Very. And then---but then she’ll throw an excuse like, “*Oh, I would hate working in an office*.” No, she wouldn’t. [Laughs.]

**Interviewer:** Yeah.

**Interviewee:** She wouldn’t. It’s just scary and different and she doesn’t…I mean, how can you know you would hate it when you’ve never done it?

**Interviewer:** Yeah. Absolutely. And what do you see happening in her future? **[1:03:00]**

**Interviewee:** You know, I hope that one day she can figure out that the world isn’t such a horrible place, and she can really---she really can do what she wants to do. But I think really what she’ll probably end up doing is getting married and having some kids and working a retail job.

**Interviewer:** Mmhmm.

**Interviewee:** Until she figures that out. I think, you know, I was a pretty late bloomer and I think she may follow that path as well. But I think it’s just gonna take her a really long time.

**Interviewer:** Mmhmm. But, like, you do see her being able to move out and, like, have her own family of sorts?

**Interviewee:** Yeah, I do. I don’t think it’s gonna be in the way that she envisioned or wanted, and I…you know, that’s really hard. It’s hard to look back on your life and say, “*What was I thinking and how did I---why was I like that*?” And I think she’s gonna have those moments. Yeah.

**Interviewer:** Yeah. That would be hard.

**Interviewee:** Yeah. [Laughs.]

**Interviewer:** I have one final question for you. How have your daughter’s sensory sensitivities impacted this current perspective that you just articulated?

**Interviewee:** You know, I kind of feel like, if it had been possible that we could have had a better handle on the sensory issues when she was two, three, four, five, that the outcome might have been different because there wouldn’t have been as much anxiety about being a human being. But because we didn’t know how to address it then, and the help we were getting was so off…it was so off…it kind of just had, like, a snowball effect in a way.

**Interviewer:** Mmhmm. Absolutely. Thank you for sharing all that. I really appreciate you taking the time to share all those very personal feelings with me and with our---with the study. That’s all I have? Would you like to add anything else?

**Interviewee:** No, I can’t really… No, I mean, I think we pretty much covered it. [Laughs.]

**Interviewer:** Yeah, definitely. But truly, thank you so much for taking time out of your day. Especially right now, you’re doing so much **[1:06:00]**to share your experience with us. We really appreciate it.

**Interviewee:** No problem.

**Interviewer:** Yeah.

**Interviewee:** Alright, I’ll get these forms done for you too.

**Interviewer:** Thank you, that would be lovely. As soon as they’re in, I will send you a gift card as a thank you. We appreciate it. Do you know anyone else who actually might want to enroll in this study?

**Interviewee:** Possibly. Do you want… Oh, my phone is gonna die soon.

**Interviewer:** Oh no! Well, we’re basically done. If anyone comes to mind, if you want to pass my information along to them or vice versa, we’d love to have anyone else. But no pressure if they don’t work.

**Interviewee:** Alright. Thank you.

**Interviewer:** Thank you! Good luck on teaching, good luck on your house and your remote life. And thank you so much – truly, we really appreciate it.

**Interviewee:** Alrighty!

**Interviewer:** Have a great weekend. Have a nice long weekend! [Laughs.]

**Interviewee:** You too!

**Interviewer:** [Laughs.] Bye!