**[Start of transcript]**

**Interviewer:** And we’re recording. And I will be asking you questions about your perspective about your child’s transition to adulthood in relation to his sensory sensitivities and interests. And we’ll be doing a semi-structured interview, so, I have my set questions but I’m gonna be adapting them to follow our conversation. Do you have any questions?

**Interviewee:** No.

**Interviewer:** Okay. You’re a pro. [Laughs.] I’m excited for this one. So, could you start off by telling me about your child’s sensory sensitivities and interests, please?

**Interviewee:** They have largely waned over the years.

**Interviewer:** Yeah.

**Interviewee:** And because Grayson, my other son, is so extreme...

**Interviewer:** Mmhmm.

**Interviewee:** ...William really was often overlooked because they were so subtle and so mild. For many years, he couldn’t tolerate singing or music.

**Interviewer:** Mmhmm.

**Interviewee:** And that has gone away. In fact, most of his recent birthday wish list were soundtracks.

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

**Interviewee:** Yes! Exactly. So, he’s a music-phile now.

**Interviewer:** Yeah.

**Interviewee:** Took a very long time to get there. He still inspects his food.

**Interviewer:** Mmhmm.

**Interviewee:** Thoroughly. He will inspect his silverware and then he will inspect the food and smell it.

**Interviewer:** Mmhmm.

**Interviewee:** At first, it was incredibly insulting, obviously, but that’s just what he does. And he does it everywhere and it’s…that’s just one of his things.

**Interviewer:** Mmhmm.

**Interviewee:** He enjoys being out but it’s stressful after a long period of time.

**Interviewer:** Mmhmm.

**Interviewee:** In doses.

**Interviewer:** Yeah.

**Interviewee:** Things like… Oh, hold on just a second.

**Interviewer:** No worries.

**Interviewee:** Okay! Chicken feed. He’s headed out to get chicken feed.

**Interviewer:** It’s important. [Laughs.]

**Interviewee:** It never ends! Yeah. So, he does. He likes social situations and he likes the lights and excitement and stuff, but it can’t go on too long. And you can kind of tell when he’s starting to…

**Interviewer:** Mmhmm.

**Interviewee:** You know, he’ll start getting a little shut down and you can tell when it’s time to go.

**Interviewer:** Mmhmm.

**Interviewee:** Birthday parties… Anything that’s fun and stimulating, he’ll give it a try, but there are limits.

**Interviewer:** Mmhmm.

**Interviewee:** That he can do.

**Interviewer:** And what’s that limit for him? Is it, like, temporal? Is it, like, based upon how many people are around him?

**Interviewee:** I would say that it’s everything combined. At birthday parties, there’s a lot of running around and noise laughter and so much going on in different activities.

**Interviewer:** Mmhmm.

**Interviewee:** And it’s the whole picture. **[0:03:00]** It’s everything: sights, sounds, smells…

**Interviewer:** Mmhmm.

**Interviewee:** And, you know…and he’s into it and he’s into it and then, you know, he’ll just start not being into it.

**Interviewer:** Mmhmm.

**Interviewee:** So…

**Interviewer:** Absolutely.

**Interviewee:** Yeah.

**Interviewer:** And for the smelling of the food and then the inspecting, has it always been the case? Is that something that developed over time and is now constant?

**Interviewee:** It’s pretty much always been the case and it is not something that has ever gone away. We’re so accustomed to his habits, we really…we never jump on him about it. We never…we just… It’s something that he does and it’s okay.

**Interviewer:** Mmhmm.

**Interviewee:** You know?

**Interviewer:** Absolutely. Yeah.

**Interviewee:** Yeah. So… But it is. It’s something that he’s always done. He also…and this is very tactile. And this is really over the past…well, no, he’s actually done this off and on forever, but really in the past year or so, it’s become where I can’t give him a pair of socks.

**Interviewer:** Okay.

**Interviewee:** In winter, I’ll give him a really hardcore pair of wool socks to wear around the house, but if I give him a regular pair of just little white cotton socks or something?

**Interviewer:** Sure.

**Interviewee:** He’ll take them down to a pile of threads.

**Interviewer:** Oh.

**Interviewee:** [Inaudible – 0:04:20] about it, just he works them in his hands until they’re...it’s literally reduced to a pile of thread.

**Interviewer:** Mmhmm.

**Interviewee:** And he does…it’s not something he’s thinking about, it’s just something he does. And he’ll do this… If he’s got a little hole in his shirt, he’ll take that down to a pile of threads.

**Interviewer:** Mmhmm.

**Interviewee:** Paper, plastic…anything that he can work in his hands.

**Interviewer:** Yeah.

**Interviewee:** Yeah. And he destroys it.

**Interviewer:** Mmhmm.

**Interviewee:** But not meaning to destroy it – it’s just something that he does.

**Interviewer:** Yeah. And so, are you saying that he, like, unravels things? Or he just will, like, kind of disintegrate them?

**Interviewee:** He works it until it’s just completely unrecognizable to what it was.

**Interviewer:** [Crosstalk] Mmhmm.

**Interviewee:** And it’s mostly clothing, and it is literally a pile of thread.

**Interviewer:** Mmhmm.

**Interviewee:** I mean, there’s just nothing…

**Interviewer:** Wow.

**Interviewee:** You know, the bottom of his shirt…he separated the bottom of his shirt maybe a month ago.

**Interviewer:** Mmhmm.

**Interviewee:** It looks like a cutoff shirt, but he took the bottom of the shirt…

**Interviewer:** Yeah.

**Interviewee:** I found this pile of blue thread in his room. And he just takes it down.

**Interviewer:** Yeah. And did this happen sort of, like, a year and a half ago?

**Interviewee:** It’s off and on. If he had a garment that had a flaw, it was done for. [Laughs.]

**Interviewer:** Yeah.

**Interviewee:** But it…yeah. In maybe the past year and a half, two years, he will create a flaw.

**Interviewer:** Mm.

**Interviewee:** And take it down.

**Interviewer:** Did anything happen at that, like, a year and a half mark? **[0:06:00]** That you might have noticed the change corelate with?

**Interviewee:** He’s had a lot of changes in the past couple of years.

**Interviewer:** Mmhmm.

**Interviewee:** Mentally.

**Interviewer:** Mmhmm. How so?

**Interviewee:** He’s had some erratic behavior.

**Interviewer:** Okay.

**Interviewee:** And it’s not characteristic of him. He’s a really sweet, kind of easygoing guy, and there have been some outbursts.

**Interviewer:** Mmhmm.

**Interviewee:** There have been… You know, and obviously, I mean, everything aside, autism aside, all that, he is a teenage boy.

**Interviewer:** Totally.

**Interviewee:** We take that into account. He’s hormonal, he’s emotion, and that’s…we get it, right?

**Interviewer:** Yeah.

**Interviewee:** And in that regard, I think that he’s completely normal.

**Interviewer:** Totally.

**Interviewee:** Just, some things don’t seem that normal.

**Interviewer:** Mmhmm.

**Interviewee:** So… And this kind of correlates with that. I don’t know if he finds that activity comforting perhaps, or perhaps he’s focused on something else. I’ve never actually watched him do it. Maybe he is totally focused on taking this thing down.

**Interviewer:** Yeah.

**Interviewee:** He attacks certain projects, certain interests, that way.

**Interviewer:** Mmhmm.

**Interviewee:** If he’s interested in something, he will learn it, memorize it, become the best in the world at it, dissect it, turn it inside out… He will completely assemble and disassemble [inaudible – 0:07:41] an item, a game, something, and take it down to where, you know…

**Interviewer:** Yeah.

**Interviewee:** He’ll…that’s his focus. So, I don’t know if he’s that way about this tactile thing or not. But, yeah, it’s really just been over the past couple of years. We did move but that was about three years ago.

**Interviewer:** Mmhmm. Gotcha.

**Interviewee:** So, this has changed. And, again, they’re not currently in the public-school system anymore, so there has been a touch of isolation. I have no doubt that he misses his friends. He was very successful at school.

**Interviewer:** Mm.

**Interviewee:** Not only socially but academically. And I think that he really, really misses that. I think he was looking forward to it.

**Interviewer:** Mmhmm.

**Interviewee:** And that’s been rough. It’s been rough trying to fill that gap and, you know, keep him engaged, keep him busy, keep him out.

**Interviewer:** Mmhmm.

**Interviewee:** Especially with COVID-19, that’s not even a possibility anymore with him.

**Interviewer:** [Crosstalk] Yeah.

**Interviewee:** Whenever I do happen to go out, maybe for grocery pickup or something of that nature, we try to take him on errands as much as possible just to get him out.

**Interviewer:** Totally.

**Interviewee:** Which we do. **[0:09:00]**

**Interviewer:** Mmhmm.

**Interviewee:** But that’s really been the only change. And it was a big one. It was a big one.

**Interviewer:** Yeah. Absolutely. Does he have any other…does he have other tactile sensory inputs?

**Interviewee:** He has a tendency to listen to things too loudly.

**Interviewer:** Mmhmm.

**Interviewee:** And he has a tendency to talk very loudly.

**Interviewer:** Mmhmm.

**Interviewee:** Other than that, no. [Inaudible – 0:09:37]. For Grayson, it’s water and stuff like that. And not really.

**Interviewer:** And then, going back, at first you talked about how he really disliked music and he disliked people talking. What did that look like for him and what has this changed in him now?

**Interviewee:** It was music and singing.And it was a complete intolerance of it. He would scream and cry, cover his ears, throw his body to the ground. We spent many, many years, birthdays, having a moment of silence versus singing Happy Birthday.Which was kind of a bummer for everybody, but it was just something that we had to do.

**Interviewer:** Totally.

**Interviewee:** Because he could absolutely not take it. There was no music in the car, no music in the house really. If we were watching a movie as a family or something, as soon as the movie ended, he wanted it cut off.

**Interviewer:** Mmhmm.

**Interviewee:** Because, you know, the music starts. And it’s over and just cut it off, because he just couldn’t...

**Interviewer:** Yeah.

**Interviewee:** He just couldn’t take the music. It went on until he went to school and I told his teacher about it and I said, *“Well, whoa…”* You know, because, obviously, it’s elementary school; there’s going to be a lot!

**Interviewer:** Yeah!

**Interviewee:** And music therapy and music class and birthdays. And, yeah, the first incident, she was like, *“Wow, you weren’t kidding!”*

**Interviewer:** [Laughs.]

**Interviewee:** Really gradually, slowly, with tiny, tiny doses of exposure...

**Interviewer:** Mmhmm.

**Interviewee:** ...she got him over that. And he was probably…gosh, he was probably eight or nine years old and we were able to sing Happy Birthday. And that was…it was a milestone! It was a huge, huge deal.

**Interviewer:** Yeah!

**Interviewee:** And he was okay. It was…you know, he was actually really proud of himself for being able to tolerate.

**Interviewer:** Yeah.

**Interviewee:** Yeah. So…

**Interviewer:** [Crosstalk] I’m sure.

**Interviewee:** And that’s...that was another thing I had mentioned with Grayson is, it seems like little gradual exposures to these things are actually really beneficial. But I point to that...William’s thing, because that was very extreme.

**Interviewer:** Yeah.

**Interviewee:** He’s also a toe-walker, and this has been misdiagnosed **[0:12:00]** and diagnosed many times. And, again, I don’t know if that is… It was diagnosed as just a neurological thing.

**Interviewer:** Mmhmm.

**Interviewee:** And then diagnosed as possibly Tourette’s. Then it was diagnosed as a physical thing that, you know, he was just growing so fast that his…he needed to stretch his tendons.

**Interviewer:** [Crosstalk] Hm.

**Interviewee:** Then it was diagnosed that he had severe gut pain. And a lot of children that have leaky gut apparently compensate by causing themselves utter forms of discomfort including toe-walking...

**Interviewer:** Hm.

**Interviewee:** ...to take their minds off their stomachs.

**Interviewer:** Interesting.

**Interviewee:** All these things. No idea. It’s something he has always done, and he continues to do whether he has shoes on or not.

**Interviewer:** Mmhmm.

**Interviewee:** And, again, we’re both pretty cool with it simply because we don’t know why he’s doing it, but it’s his thing, and, you know, if that’s something he needs to do, cool.

**Interviewer:** Yeah. Absolutely. This is another good segue. So, how has he coped with or managed these sensitivities?

**Interviewee:** My husband practiced… He’s…socially, he loves to be around people, but he does not like to be in the spotlight. He’s kind of the guy in the back of the crowd. He just wants to be part of the group, but he doesn’t want a lot of attention.

**Interviewer:** Mmhmm.

**Interviewee:** And so, being around normally-functioning children really makes him nervous. He’s afraid they might talk to him. He has delayed speech.

**Interviewer:** Mmhmm.

**Interviewee:** But I think that these little habits that he has, these little foibles, I’m afraid…I think he’s afraid they’re gonna put him in the spotlight. And so, my husband worked with him for a long time on meditation and deep breathing.

**Interviewer:** Mmhmm.

**Interviewee:** First off, very obviously. But then they worked on how to do it in a crowd.

**Interviewer:** Yeah.

**Interviewee:** Or sitting at his desk. Or just taking a moment and, you know, feeling the air run through his nose…

**Interviewer:** Mmhmm.

**Interviewee:** …and into his chest and allowing his shoulders to relax and just…you know, and really focusing himself and being able to control these little foibles that make him nervous.

**Interviewer:** Mmhmm.

**Interviewee:** You know, that helped immensely, and I like to think that’s something that he still draws on sometimes. He…it seems to me it’s something that he still practices on occasion.

**Interviewer:** Mmhmm.

**Interviewee:** So, that’s helped.

**Interviewer:** Yeah.

**Interviewee:** I can’t...

**Interviewer:** [Crosstalk] And you talk about exposure a lot.

**Interviewee:** Right. Right. I can’t think of another… I can’t think of another example.

**Interviewer:** Yeah. That is plenty. **[0:15:00]** So, you talked about change also. You talked about how he smells things – that’s been pretty constant. He’s become less sensitive to sounds. Has this…do you think this is related to any independence that he’s gained over time?

**Interviewee:** Absolutely.

**Interviewer:** Yeah?

**Interviewee:** He requires directions and sometimes he requires directions to be told to him several different ways.

**Interviewer:** Mmhmm.

**Interviewee:** Once he’s got the directions, he follows them step-by-step, rule-by-rule. Yes. So… And I think that has come on with maturity. I think that’s helped a lot. He’s got a lot of responsibilities around the house. I think that has helped a lot as well.

**Interviewer:** Mmhmm.

**Interviewee:** He’s responsible for his garbage can, he folds his own clothes. There were nights… He hasn’t done it in a while, but there were nights that he would make dinner.

**Interviewer:** Oh!

**Interviewee:** Yeah!

**Interviewer:** That’s great! That sounds great!

**Interviewee:** Yeah. Well...

**Interviewer:** What would he make?

**Interviewee:** Tacos.

**Interviewer:** Nice!

**Interviewee:** Yeah. Those are his favorite, and so, yeah, we would have taco night and he would make dinner.

**Interviewer:** That’s so nice.

**Interviewee:** But I think… And all of that has come along, you know, with him getting older and… And that’s why I think these outbursts recently have a lot more to do with teenage angst versus other things. I mean, the...it’s concerning some of the things that he’s done and said, but I think they can be worked through.

**Interviewer:** Totally. Absolutely. And then, perhaps thinking back… Sorry, were you gonna say something?

**Interviewee:** No, I was just crossing my fingers.

**Interviewer:** Oh! I didn’t...I looked down. I missed that. [Laughs.] In the past, for his sound [inaudible – 0:16:51], like singing and voices, did it cause anxiety for him?

**Interviewee:** I don’t know.

**Interviewer:** Mmhmm.

**Interviewee:** He was nonverbal at the time.

**Interviewer:** Gotcha.

**Interviewee:** So, there were a lot of…he had a lot of triggers, and not all sensory. I don’t know.

**Interviewer:** Mmhmm. Yeah. What about now? So, like, if he can’t smell or inspect food, does that cause anxiety for him?

**Interviewee:** It might. He’s not in that position.

**Interviewer:** Mmhmm.

**Interviewee:** Yeah, he’s not in that position. And he, even if we’re out in public… Before COVID-19.

**Interviewer:** Of course.

**Interviewee:** He goes through his process and it does not cause him any anxiety to be out in public and do this thing.

**Interviewer:** Mmhmm.

**Interviewee:** So, no.

**Interviewer:** Mmhmm.

**Interviewee:** I would say no.

**Interviewer:** And then you also talked about, like, if he goes out too much, like, to birthday parties, sometimes he kind of shuts down. Do you think that’s anxiety for him?

**Interviewee:** Not initially. **[0:18:00]** I think there’s always excitement about going to do these things.

**Interviewer:** Yeah.

**Interviewee:** Again, that’s something… I don’t think so.

**Interviewer:** Mmhmm.

**Interviewee:** I don’t think so. I think it’s just something that comes on, and it’s just too much time spent in that particular environment. I think over time it has gotten longer and longer that he can tolerate those things. We took a vacation about five years ago kind of locally – we went down to a little town south of Houston and there’s a...it’s a giant amusement park.

**Interviewer:** Mmhmm.

**Interviewee:** And a boardwalk and lots of restaurants and there’s fireworks and there was a roller coaster and there’s cotton candy and there was tons going on.

**Interviewer:** Yeah.

**Interviewee:** And, you know, Grayson had his earplugs in, and we were a little concerned, you know, how long William was going to be able to do this. And, you know, right through.

**Interviewer:** That’s awesome.

**Interviewee:** No problems. Everyone…it was a family vacation. My daughter was there. So, everyone was kind of satiated and good and tired when the day ended, and we went back to the hotel. There wasn’t a cut-off point where, you know, we were, *“Uh-oh, it’s time to go.”*

**Interviewer:** Yeah, absolutely.

**Interviewee:** That point. So, that was cool and probably a first.

**Interviewer:** Yeah! That sounds awesome. And this lack of anxiety, do you feel like that’s been constant?

**Interviewee:** It’s hard to say.

**Interviewer:** Sure.

**Interviewee:** It’s hard to say. We have not had a lot of opportunities here to… There’s the… We’ve gone to the movie theater several times since we’ve lived here. He loves movies. And there’s a lot going on at the movie theater.

**Interviewer:** Mmhmm.

**Interviewee:** There’s people coming and going, there’s food, there’s lots of lights, there’s tons of things to look at and everything. And a couple of times after we’ve gone, he’s gotten a little anxious afterwards.

**Interviewer:** Mmhmm.

**Interviewee:** It’s been a little much, you can tell.

**Interviewer:** Mmhmm.

**Interviewee:** I don’t know if he was just tired, you know?

**Interviewer:** Yeah.

**Interviewee:** I mean, that plays a factor too. So…

**Interviewer:** Totally.

**Interviewee:** Yeah, so, I think it’s situational. It depends on, you know, how long the movie is, how long the activity is, his…you know, well-rested or…

**Interviewer:** Mmhmm.

**Interviewee:** I think there’s a lot of factors. I don’t think it’s completely gone. I don’t think the anxiety can...is completely gone, but I think it’s much improved.

**Interviewer:** Mmhmm. Sure. Absolutely. And what hopes or goals do you have for him in regards to his sensitivities?

**Interviewee:** Oh…gosh. I don’t. I’m not sure I would change anything. **[0:21:00]** He’s very functional.

**Interviewer:** Yeah.

**Interviewee:** Obviously, I don’t want him to draw… I told you the story about taking them out in public here, and I don’t want that for them. You know, I don’t…personally, I don’t want him to have behaviors that are gonna draw negative attention.

**Interviewer:** Mmhmm.

**Interviewee:** Non-understanding attention. And perhaps, you know, smelling his piece of pizza, you know, as an adult might bring questions or looks, but, you know, if that’s the worst it’s going to be, it’s okay.

**Interviewer:** Yeah.

**Interviewee:** The toe-walking, you know, if it’s something that he does forever, then that’s…it’s just something… Hey, hey! Hey. I’m having a meeting right now.

**Grayson**: Yeah!

**Interviewee:** Yeah. Go. Grayson. I think he was riding his horse. Anyway, no, his sensory… Like I said, I don’t know if it’s more my problem. I don’t know if it would be a problem for him, at least until someone said something to him.

**Interviewer:** Mmhmm.

**Interviewee:** That maybe he wasn’t prepared for. That could happen, you know?

**Interviewer:**  Mmhmm.

**Interviewee:** But…yeah.

**Interviewer:** Yeah. No, absolutely. Thank you. And then moving onto our next chunk of questions, you actually gave me a really nice segue. As he has grown up and aged, how has the community reacted to him and his sensory sensitivities?

**Interviewee:** When we go in public, it’s Grayson that draws the attention.So, I can…

**Grayson**: [Inaudible – 0:22:52].

**Interviewee:**  Before we moved here, we came by to look at the house and we stopped at Pizza Hut to each before we went home. And Grayson was sitting there covering his ears. We were sitting close to a speaker, and the waitress ... you know, foreshadowing ... asked, you know, *“What’s wrong with him?”* And…right. And my husband gently explained, you know, and she reached across me and she patted him like a dog.

**Interviewer:** Wow.

**Interviewee:** And William is sitting across from me and his face… I mean, he was as astonished as I was. I mean, we’ve never…

**Interviewer:** Yeah.

**Interviewee:** We’ve never encountered something like this. And he was just slowly tried to become invisible and sink into the booth, and he was mortified. **[0:24:00]**

**Interviewer:** Mmhmm.

**Interviewee:** He was. And I… He was anxious that she was gonna direct her attention on him.

**Interviewer:** Mmhmm.

**Interviewee:** Yeah.

**Interviewer:** Yeah. I’m sorry that happened. That must have been very unsettling.

**Interviewee:** It’s been a journey! [Laughs.]

**Interviewer:** Yeah!

**Interviewee:** It’s been interesting. I know that it’s probably an opportunity, you know, to educate the community on disabilities and that kind of thing. I guess you could look at it that way. But I would prefer to be somewhere where, you know, people already knew. [Laughs.]

**Interviewer:** Yeah. Absolutely. I mean, who wants to go through that? Even if it is an opportunity for people to learn, it still would be...

**Interviewee:** Yeah.

**Interviewer:** ...very taxing and emotionally burdensome on you. [Laughs.]

**Interviewee:** Yeah. It’s a weird thing and it makes me really uncomfortable to put them in those situations.

**Interviewer:** Yeah, absolutely. I’m sure.

**Interviewee:** And for the future, it’s not something I want for them.

**Interviewer:** Mmhmm. I’m sure it’s not. Thinking back to when he was younger, was the community more accepting of him?

**Interviewee:** Oh, yeah.

**Interviewer:** Mmhmm.

**Interviewee:** Yeah, we could go anywhere, we could do anything. I remember one incident, but it was something that he didn’t…he was…he didn’t even…was aware what was happening. It was just...it was a couple of little boys looking at him kind of oddly.

**Interviewer:** Mmhmm.

**Interviewee:** You know? I forget exactly what he was doing but it was odd. And…but he didn’t see, and it was…yeah. it was no big deal. And it was normal for him to look at him oddly – they’re kids. And little. They were little kids.

**Interviewer:** Sure.

**Interviewee:** So, no, he hasn’t…we haven’t been the focus, he hasn’t been the focus of any kind of negative attention or questioning attention or anything of that nature.

**Interviewer:** [Crosstalk] Mmhmm. Gotcha. And were there different or spaces, like, different aspects of the community that were more or less accepting of him?

**Interviewee:** Kid-friendly places. He really enjoyed the arcade.

**Interviewer:** Mmhmm.

**Interviewee:** Never had a bad experience there. And it was obvious that both of them were, you know, autistic, and, yeah, everyone was just cool.

**Interviewer:** Yeah.

**Interviewee:** Cause [Inaudible – 0:26:25] there for the same reason.

**Interviewer:** And it wasn’t too loud or overstimulating or him?

**Interviewee:** We did not stay very long. Like I said, my husband and I, they have us trained extremely well.

**Interviewer:** [Laughs.]

**Interviewee:** So, we pretty much go into any situation knowing what they can handle.

**Interviewer:** Cool.

**Interviewee:** And knowing what [inaudible – 0:26:51]. Knowing the nights, perhaps, that there aren’t gonna be a lot of people, there’s not gonna be a lot of noise. **[0:27:00]**

**Interviewer:** Mmhmm.

**Interviewee:** It was totally normal [cutting out] for us to go on a weekend night, you know, [inaudible – 0:27:10] nights that we would go out [inaudible – 0:27:13].

**Interviewer:** Can you hear me okay? You’re cutting out a little bit.

**Interviewee:** ...since last year.

**Interviewer:** For a little bit off and on. Can you hear me now?

**Interviewee:** I can hear you.

**Interviewer:** Okay. You’re frozen, but that’s okay. Cool.

**Interviewee:** Okay.

**Interviewer:** Yeah. We’re gonna continue.

**Interviewee:** Okay. [Laughs.]

**Interviewer:** Sorry! No, I mean, it’s fine. Oh! You’re back! Hello! [Laughs.] Okay! Alright.

**Interviewee:** Hi! So, we would plan our events for weeknights versus weekend nights. It wasn’t uncommon for us to go and do stuff on a school night.

**Interviewer:** Mmhmm.

**Interviewee:** Totally fine. There’s gonna be less people, there’s gonna be less noise, and we pretty much knew their parameters of tolerance unless it was a brand new activity.

**Interviewer:** Totally.

**Interviewee:** Yeah. But we had a circuit of restaurants that were very friendly to them, we had a…you know, the arcade. We would go to the mall and walk the mall sometimes. We went to the park quite a bit.

**Interviewer:** Mmhmm.

**Interviewee:** Yeah, so, we had, you know, places in our community that were normal and regular for us.

**Interviewer:** Yeah. and was this in Houston or is this in Rusk? Or both?

**Interviewee:** This was in Houston.

**Interviewer:** Gotcha.

**Interviewee:** Yeah.

**Interviewer:** Mmhmm.

**Interviewee:** We haven’t gotten a routine in Rusk. And I suspect that there are some great natural places that we could actually go and enjoy in the area.

**Interviewer:** Mmhmm.

**Interviewee:** It’s just a matter of getting out there and exploring. And it’s a little daunting right now. Our cases are going up rapidly.

**Interviewer:** Yeah.

**Interviewee:** So… But, I mean, it’s nothing that we couldn’t, you know, pack a picnic in the car some weekend and just jump in the car and just drive around and look around and look at stuff.

**Interviewer:** Mmhmm.

**Interviewee:** And picnic in the car, or…

**Interviewer:** Yeah, absolutely.

**Interviewee:** [Inaudible – 0:29:00]. I mean, it’s…there are possibilities here – it’s just a matter of finding them.

**Interviewer:** Mmhmm. Absolutely. I mean, it’s all hard during COVID. It’s, like, just a whole new territory for everyone. [Laughs.]

**Interviewee:** [Crosstalk] Sure. Sure. Sure.

**Interviewer:** Yeah. And then, thinking to the future, what are your hopes or worries about how his community will react to him in regards to his sensitivities?

**Interviewee:** I would love to see him in a situation, a social situation, where he has responsibilities but he’s not the star of the show.

**Interviewer:** Mmhmm.

**Interviewee:** That’s where he’s most comfortable. Whether it’s working in a place in a support capacity… I have always imagined setting him up with some kind of little business, like a half pizza place half arcade. You now? Just a pizza by the slice and then an arcade. Somewhere where he **[0:30:00]** owns it but he’s cooking and someone else is managing it.

**Interviewer:** Yeah.

**Interviewee:** You know what I mean? Somewhere that he can be kind of a usual and be around everybody but not…

**Interviewer:** Mmhmm.

**Interviewee:** Not be the center of attention. Be safe in the kitchen and just be able to do his thing. Or, again, being in a satiation where he’s a part of something but perhaps not the key component. There’s a business in Dallas that hires nothing but autistic people and it’s a computer business. He’s great at that. So, you know, maybe learning how to code or something of that nature. Being in a little community but not being team lead.

**Interviewer:** Yeah.

**Interviewee:** Or somewhere that he’s gonna be constantly put on the spot. And even if it’s as simple as being the janitor at a business or something, just being part of the team. He’s very good at working, he’s very meticulous, he…

**Interviewer:** Mmhmm.

**Interviewee:** You know, he does a good job. He needs direction, but once he has that direction, he’ll do it.

**Interviewer:** Mmhmm.

**Interviewee:** And so, that’s what I would really, really love to see for him in the future is that kind of situation. It would be wonderful to set him up here...

**Interviewer:** Mmhmm.

**Interviewee:** ...in a kind of farming infrastructure where he could take care of the cows, sell the eggs from the chickens…

**Interviewer:** Mmhmm.

**Interviewee:** Sell the milk from the cows. Grow his own produce. Not only is he sustaining himself, but it’s...he could have a little business doing those kinds of things. That would be great.

**Interviewer:** Yeah.

**Interviewee:** You know, and even having someone else manage it while he does the different tasks involved.

**Interviewer:** Mmhmm.

**Interviewee:** And I think really fulfilling for him as well.

**Interviewer:** Yeah, it sounds like it. And now, shifting gears a little bit, in the, like, transition to adulthood, where do you see him?

**Interviewee:** It’s been rocky.

**Interviewer:** Yeah.

**Interviewee:** It’s been rocky.

**Interviewer:** How so?

**Interviewee:** Well, like I said, the past couple of years there’s been some behaviors. And they’re worrisome. And, you know, I think it would be really beneficial to get him…to get someone for him to talk to. We’ve talked about this for months.

**Interviewer:** Mmhmm.

**Interviewee:** And we’ve tried, but we’ve called one psychiatrist and two psychologists and one expert...

**Interviewer:** Mmhmm.

**Interviewee:** ...on children. A psychologist. Two of them never called us back. One of them called us back and we talked for, like, an hour, and then she never called us back.

**Interviewer:** Oh.

**Interviewee:** And the expert said he was too old. So, we’re still looking.

**Interviewer:** Yeah. **[0:33:00]**

**Interviewee:** Like, you would think during this time… You hear over and over, you know, people are having mental issues and need some guidance, need some counseling, need some companionship.

**Interviewer:** [Crosstalk] Yeah.

**Interviewee:** And mental needs are paramount right now, and you would think they’d be coming out of the woodwork. And, no, it’s really difficult to find. He will be starting...

**Interviewer:** [Crosstalk] Sorry to hear that.

**Interviewee:** Yeah. We’re still looking. He’ll be starting speech next week.

**Interviewer:** Oh!

**Interviewee:** Online. She’s fantastic.

**Interviewer:** That’s awesome.

**Interviewee:** That’s gonna give him a boost. That’s gonna give him a little bit of company.

**Interviewer:** Mmhmm.

**Interviewee:** And, you know, gonna engage him in conversation, which will be great for him. So, that’s a good thing. We need to get these issues ironed out. These sudden bursts of unpredictable behavior and anger, they will not be acceptable in the situations that I have imagined for him. And so, we need to determine if this is just teenage angst or if this...if more is needed.

**Interviewer:** Mmhmm. You said you don’t think they will be acceptable in the things that you’ve imagined. Do you mean, like, in owning his own business, he wouldn’t be able to have these outbursts?

**Interviewee:** Right. Yes. I cannot see being in a work situation and having these outbursts, no matter how understanding or accommodating...

**Interviewer:** Mmhmm.

**Interviewee:** ...the work situation might be.

**Interviewer:** Yeah, absolutely. And then, like, at what stage of independence would you consider him? Like, you’ve talked about how he can make dinner for you all – what else?

**Interviewee:** I feel like he could handle pretty much anything that we throw at him. He drives around the property.

**Interviewer:** Mmhmm.

**Interviewee:** He knows how to operate the vehicles. He drives our tractor loader backhoe.

**Interviewer:** Nice.

**Interviewee:** Which is a giant piece of farm equipment. He drives that. Like I said, he requires instruction...

**Interviewer:** Yup.

**Interviewee:** ...until he gets it. But once he’s got it, no, I feel really confident he’ll be able to handle things. And I described to you before with Grayson, we have the cottage.

**Interviewer:** Mmhmm.

**Interviewee:** So, that’s gonna be…William will be transitioning in there probably over the next two or three years.

**Interviewer:** Yeah.

**Interviewee:** So, he will be living in there independently. I told you they were gonna take turns. But he’s gonna have a good chunk of time in there by himself to navigate that world of living independently, of washing his own laundry and making his own dinner, of having us over for dinner, of, you know, regulating, *“Oh, it’s time to go to sleep…oh, it’s time to wake up, I need to start my day.”*

**Interviewer:** Yeah. **[0:36:00]**

**Interviewee:** So, he’s gonna…that’s gonna be fantastic for him and I can see him being very successful at it.

**Interviewer:** Yeah, absolutely. That’s, like, such a great experience for anyone to learn how to be an adult. Like, everyone could really benefit from something like that. [Laughs.]

**Interviewee:** Exactly. And we’re right here for questions. *“I don’t remember how to work the stove.”* Okay! You know, and two seconds and we’re there.

**Interviewer:** Yeah.

**Interviewee:** And, you know, *“I don’t remember…what is this for? And is this the heater or the A/C?”* Or, you know, *“How do I go about…”* We’re right there.

**Interviewer:** Yeah.

**Interviewee:** So, questions will be answered. No, and we can write directions for certain things and leave them for him. I can have a sticky on the fridge. Little reminders of the order of things that need to be done.

**Interviewer:** Mmhmm.

**Interviewee:** So, and I can take those away gradually. You know?

**Interviewer:** [Crosstalk] Yeah. Absolutely.

**Interviewee:** He gets his routine going.

**Interviewer:** Mmhmm.

**Interviewee:** So…yeah.

**Interviewer:** [Crosstalk] Yeah. And thinking about, like, other, like, stages of independence, you said that he was looking forward to school because he was doing really well socially. Was he able…beforehand, was be able to, like, manage his own friendships and his social life to a degree?

**Interviewee:** Yeah. like I said, being in the spotlight really made him nervous. But his old school had a mentorship, and so, the really outstanding students, all-A, whatever students, got to volunteer for a program where they would come in and hang out with the special needs classes once a week.

**Interviewer:** Yeah.

**Interviewee:** They’d play games, they’d hang out, they’d have social time. William was in several regular classes on top of his… So, he already knew some of these kids from those classes.

**Interviewer:** Hm.

**Interviewee:** And the teacher said that some of them would just come by just to say hi to him. They genuinely liked him.

**Interviewer:** Yeah.

**Interviewee:** They liked his company. He was…he’s not a big talker, but the principle said if there’s something going on, that he’s the first one to volunteer. And I’m like, *“Really!”*

**Interviewer:** [Laughs.]

**Interviewee:** There was some kind of ice cream thing and somebody was coming out and everybody was gonna get ice cream, and William was the first one to volunteer to scoop the ice cream.He was [inaudible – 0:38:19] the scoopers. And he said, *“No, William’s in the thick of it. If there is something going on, William wants to be a part of it.”*I was like, *“Wow!”* I mean, that was fantastic to hear.

**Interviewer:** Yeah, absolutely.

**Interviewee:** He just...he loved being around everything, just not being the star.

**Interviewer:** Mmhmm. Absolutely. Is he able to, like, take care of himself physically on the day to do?

**Interviewee:** Yes. All of his grooming, all of his...all of that. He makes his own breakfast, he makes his own lunch. He’s got a pile of laundry in his room.

**Interviewer:** [Laughs.]

**Interviewee:** Again: teenager. **[0:39:00]** But they’ll get put away.

**Interviewer:** Yeah.

**Interviewee:** Yeah. He manages himself really well.

**Interviewer:** Mmhmm.

**Interviewee:** His appearance is very important to him. He’s going for kind of a 70s look right now. [Inaudible – 0:39:17] and he’s got kind of curly hair. And he does, he looks like some…you know, a picture that you’d see from the 1970s of a... like a surfer dude...

**Interviewer:** [Laughs.]

**Interviewee:** ...coming up from the beach or something. It’s awesome. He’s rocking it. And I’m sure that he’s gotten these influences from movies and, you know, from seeing things online and everything, but that was the way he wanted to go. And I think that it’s great that he’s cultivating his own thing.

**Interviewer:** Yeah!

**Interviewee:** He’s not… Yeah. Yeah, and, well he...and he’s so conservative, I was a little surprised that he wanted to go with something a little out of the norm.

**Interviewer:** [Laughs.]

**Interviewee:** He’s very by the book. He’s like a little policeman. But, yeah, he’s going for this more [inaudible – 0:40:03] and I thought it was very cool.

**Interviewer:** It is really cool. Do you think he’s excited to live on his own on that cottage on your property?

**Interviewee:** [Coughs.] Excuse me. I think it’ll be a blend. I think it’ll be a blend of excitement and I think he’ll...at first, he will find it very daunting.

**Interviewer:** Totally.

**Interviewee:** I won’t be surprised if the first few nights, he ended up in his room.

**Interviewer:** Mmhmm.

**Interviewee:** And that’s totally okay.

**Interviewer:** Absolutely.

**Interviewee:** Yeah. then again, he might jump out there and we don’t see him for two weeks. I...

**Interviewer:** [Laughs.]

**Interviewee:** [Inaudible – 0:40:42]. I mean, he might, you know, *“Ah, finally!”* Right? No, I suspect it will be a combination.

**Interviewer:** Mmhmm. Yeah.

**Interviewee:** He’s very much a creature of habit.

**Interviewer:** Mmhmm.

**Interviewee:** And so, he wants things to be just so, and so, I think until he gets his routine down, there may be some discomfort.

**Interviewer:** Mmhmm. Absolutely. That makes sense. And then what do you think he’ll be able… Sorry. Do you think he’ll be able to choose more independence in the future?

**Interviewee:** Yeah. Absolutely.

**Interviewer:** Yeah.

**Interviewee:** I can see him… And, again, this largely depends on, you now, how quickly civilization spreads here. [Laughs.] But I think with the right program, I think he could eventually drive. That prospect of the...at the moment scares me to some degree. I mean, you know, I… This is entirely parent talk, but, you know, I can completely see a drunken redneck hitting him from behind and leaping out of his vehicle with a tire iron, racing up to the car. Yeah. So, it may be a while. [Laughs.]

**Interviewer:** That’s fine! **[0:42:00]**

**Interviewee:** But once again, you know, we have a smart car, we have a Prius in town. Things are changing.

**Interviewer:** Yeah.

**Interviewee:** Slowly but surely, so…

**Interviewer:** Absolutely.

**Interviewee:** [Inaudible – 0:42:14] in two years, there could be a Starbucks. I mean, and who knows? Who knows what’s going to happen?

**Interviewer:** Mmhmm.

**Interviewee:** So…

**Interviewer:** And what types of independence do you see in his future?

**Interviewee:** I can see him making his own decisions.

**Interviewer:** Mmhmm.

**Interviewee:** I can see him wanting to make his own decisions. I can see that being a goal.

**Interviewer:** Awesome.

**Interviewee:** And I think for a long time, adulthood scared him. He’s always been a little anxious, a little...kind of an anxious kid. And the older he’s getting I think he’s getting a comfort level with it.

**Interviewer:** Mmhmm.

**Interviewee:** He has a man’s body and he’s starting to have, you know, a man’s mind. And his… Like I said, speech was his idea.

**Interviewer:** Oh, really?

**Interviewee:** Yeah.

**Interviewer:** Wow!

**Interviewee:** Yeah. And that’s a big deal.

**Interviewer:** Yeah, it is!

**Interviewee:** Yeah, and my husband jumped right on it. He was like, *“We’ve got to get this kid speech!”* I mean, you know, we...yeah, we were both really excited about it. He’s just having more complex thoughts, more complex ideas, more complex feelings, and I think the fact that he’s looking for a way, a more complex way to express himself…

**Interviewer:** Mmhmm.

**Interviewee:** Big positive. And it’s a...

**Interviewer:** [Crosstalk] Yeah.

**Interviewee:** Quite a big step.

**Interviewer:** Absolutely. Self-advocacy for anyone is an awesome and an important step.

**Interviewee:** Yes. So…

**Interviewer:** That’s great

**Interviewee:** That was exciting.

**Interviewer:** Awesome.

**Interviewee:** [Crosstalk] That was really exciting.

**Interviewer:** Yeah. And then what else do you think would help move him into adulthood? Like, are there certain interventions or services that you wish he had, or you want him to have?

**Interviewee:** Just like Grayson, I find the… It would be great to have help transitioning and some kind of aid into society. Placements, trainings… Businesses, local businesses, volunteering to, *“Yes, we would be open to having a disabled person doing this job.”* [Clears throat.] Excuse me. And having the staff trained, *“Okay, so, we’re gonna have a disabled person in our midst and this may arise.”*

**Interviewer:** Mmhmm.

**Interviewee:** *“What do we do?”* You know? And having those **[0:49:00]** kinds of opportunities. If there was a business that we didn’t know anything about, having some kind of training opportunity for him.

**Interviewer:** Mmhmm.

**Interviewee:** So that he would be able to step into it with a comfort level, like the local feed store.

**Interviewer:** Mmhmm.

**Interviewee:** Measuring grains. Bagging. Loading them into customer’s vehicles. Providing them with written receipts. You know, do they have the tax exemption? Are they a business…? You know, learning that process, having resources available that would aid in those things and not having to just blindly stumble around and try to figure these things out on our own.

**Interviewer:** [Crosstalk] Yeah. Mmhmm.

**Interviewee:** I don’t know if that would be local, I don’t know if that would be state, federal…I’m not sure exactly what kind of aid that would look like. I’m assuming local simply because local people know what local localities are capable of.

**Interviewer:** [Crosstalk] Yeah.

**Interviewee:** But that would be great.

**Interviewer:** Yeah. It sounds like it would be. And now, kind of putting these two things together ... sensory sensitivities and transitioning into adulthood ... how do they intersect for William? They may not intersect. [Laughs.]

**Interviewee:** I have to think about that one.

**Interviewer:** Yeah. Take your time.

**Interviewee:** He is a… Like I said, he’s not self-conscious. Though I…well… He’s only self-conscious if he’s in danger of becoming the focus of attention.

**Interviewer:** Mmhmm.

**Interviewee:** Otherwise, he doesn’t...I don’t think that he thinks about it.

**Interviewer:** Hm.

**Interviewee:** Or he might.

**Interviewer:** Yeah.

**Interviewee:** We’ve been very open and honest with him and very straight with him about his limitations and his disability overall, and we really talked about them in the positive, though, and how extraordinary they make him. I don’t know if he thinks about it.

**Interviewer:** Mmhmm.

**Interviewee:** I think he...

**Interviewer:** You think he might not? Sorry, you cut out.

**Interviewee:** I think he might.

**Interviewer:** Mm. Might. Gotcha. And then...

**Interviewee:** [Crosstalk, inaudible – 0:47:19] too much apprehension and anxiety that actually causes him. I think he’s pretty happy with who he is.

**Interviewer:** That’s important. That’s really important.

**Interviewee:** Yeah.

**Interviewer:** And then, would you say these sensitivities are an obstacle, a vehicle, or a bit of both for him? In terms of his independence.

**Interviewee:** I would say they are not going to hinder him.

**Interviewer:** Mmhmm.

**Interviewee:** I mean, sniffing his food is gonna have nothing to do with his work ethic.

**Interviewer:** Mmhmm. Absolutely.

**Interviewee:** [Inaudible – 0:47:54] around work no matter what he’s doing isn’t really gonna affect his performance. **[0:48:00]** I guess the only thing is if he can eventually outgrow that overwhelming sensation when there’s too much going on. If he can outgrow that or learn how to deal with it, you know…

**Interviewer:** Mmhmm.

**Interviewee:** That would be a [inaudible – 0:48:22]. That would be a really big deal for him. But I can’t see them being an overwhelming obstacle in any way...

**Interviewer:** Mmhmm.

**Interviewee:** ...of him moving forward.

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

**Interviewee:** In regard to his sensitivities. I would say just relationships. Forming friendships, perhaps a romance, if you will. I’m a dreamer.

**Interviewer:** [Laughs.]

**Interviewee:** There’s somebody for everybody.

**Interviewer:** Absolutely.

**Interviewee:** But, you know what, it might be kind of a turn-off to people, you know, if he does, you know, have to look at his spoon, examine his fork, stop talking while he does it.

**Interviewer:** Mm.

**Interviewee:** You know, okay, and so, here… You know, that may raise some questions.

**Interviewer:** Mmhmm.

**Interviewee:** [Laughs.] You know, especially if it’s, like, the first time that you’ve eaten with him. Yeah, and I’m not sure exactly what to do about that, and I’m not sure if we should do anything about it.

**Interviewer:** Mmhmm. Yeah.

**Interviewee:** I don’t know. It’s not hurting anything. It’s really just who he is, and I guess we could work on it, but I’m not sure what the harm is.

**Interviewer:** Yeah. Absolutely.

**Interviewee:** I mean, maybe it’s just better if he just stumbles into some people that just flat-out don’t care.

**Interviewer:** It’s...I mean, it’s not destructive, like… It’s a very passive thing.

**Interviewee:** [Crosstalk] Right. Right.

**Interviewer:** You know?

**Interviewee:** It’s not like… Yeah. It’s not like, it doesn’t measure up, so he flings it or anything. I mean, it’s…you know, it’s just one...it’s just a quirk.

**Interviewer:** Yeah. We all have quirks. And people accept our quirks, so why not?

**Interviewee:** Right. Right. I mean, I hadn’t really thought about it, but I think, if I were to be put on the spot, I’d probably just let him, you know, move forward as is.

**Interviewer:** Totally. Absolutely. And then… This may be not be so relevant for him. But what do you think will help him in the intersection of sensory sensitivities and independence and adulthood?

**Interviewee:** Well, sensory just… The first thing that pops into my mind is occupational therapy, which he stopped getting many years ago. They determined that it wasn’t…they… He actually had physical therapy for much longer. **[0:51:00]** He had trouble navigating writing, and so, they bought him a special board to use. He’s a lefty. And they really…I’m not sure what was entailed, but for over a year they worked with him in this regard. But when you ask that question, occupational therapy is the first thing that pops into my head, but obviously I’m kind of bias because that… For the other one.

**Interviewer:** Yeah.

**Interviewee:** That’s what worked for him and I’m not sure how beneficial that would be for William. Maybe ABA.

**Interviewer:** Mmhmm. Yep.

**Interviewee:** Perhaps.

**Interviewer:** Who knows? And then kind of going back to what… Oh, sorry. I didn’t mean to cut you off.

**Interviewee:** I think that there are other therapies that are popping up as well and... that have to do with social behavioral norms. I’ve read some things about that and it involves, you know, social interaction and practicing normal…you know.

**Interviewer:** Yeah.

**Interviewee:** [Inaudible – 0:52:09] confrontation and stuff. And, yeah, I mean, maybe that’s something. But I think that that’s so new that it’s not even something that’s been named.

**Interviewer:** Mmhmm.

**Interviewee:** And so...

**Interviewer:** [Crosstalk] Absolutely. I think...

**Interviewee:** Let me interrupt just for a second. Thank you so much for that link that you provided.

**Interviewer:** Oh!

**Interviewee:** That was [inaudible – 0:52:30]. Yeah.

**Interviewer:** You’re so welcome! Were you able to attend the talks?

**Interviewee:** No, but I got the…

**Interviewer:** Yeah. PDF.

**Interviewee:** Yes. Yes. The…not the transcript – the syllabus, I guess.

**Interviewer:** Mmhmm.

**Interviewee:** Yeah. It was fantastic.

**Interviewer:** Good! I’m so glad. The first talk is actually available to the public. You don’t need to be a member to view the first talk.

**Interviewee:** Okay. [Inaudible – 0:52:55].

**Interviewer:** And it’s by... Sorry.

**Interviewee:** I’ll go back and look at that.

**Interviewer:** Yeah, and it’s...the talk is provided by the woman who developed the ADOS, which is, like, one of the tools people use to diagnose autism.

**Interviewee:** Neat!

**Interviewer:** Yeah. She...it’s a great one.

**Interviewee:** I loved what I’ve read so far, so, thank you so much.

**Interviewer:** Oh, yeah! My pleasure. I’m glad I was able to share it with you.

**Interviewee:** [Crosstalk, inaudible – 0:53:15].

**Interviewer:** [Crosstalk, inaudible – 0:53:15].

**Interviewee:** [Laughs.] [Inaudible – 0:53:17].

**Interviewer:** No, it’s fine! It’s so fine! Where was it? Okay. Going back, talking about services, do you feel like there are gaps in the available interventions and services?

**Interviewee:** At our old school district, a lady came to our home and it was when William was entering high school. She gave me way more information than I could digest in an hour. Everything we needed to do, everybody we needed to contact, do this, do that… I took notes that were completely unintelligible because she was on her way to another home after seeing me and the amount of the…and none of it **[0:54:00]** was written down, and none of it was really available to look at in any way, shape, or form. This was it. And so… And she was going to be the person that was in charge of every high school in the school district, all of the transitioning. And so, I spoke for, like, two seconds. She was like, *“What interests him? What does he like to do? What can we think about for him doing in the future?”* And I said, *“Well, you know, he likes to cook, he likes...he loves pizza.”* And she says, *“Okay, great, you know, Paul’s Pizza, he often takes on these students, you know, so, try to visit there and…you know, I’ll talk to him and we’ll try to get him in there and everything, blah blah blah blah.”* And that was my entire part of this hour-long meeting. Everything she said had incredible value; I got almost none of it. And when she left… Ugh. I was just so frustrated. I was, like…I could have talked to her for three hours.

**Interviewer:** Yeah.

**Interviewee:** If she had anything written than she had told me, even just giving me a sheet of paper with the organizations, the numbers, the places not to do…you know, don’t do this, do this instead. And you have to...once you’ve contacted them, you have to keep contacting them. You know, that kind of thing. And I didn’t. I didn’t get anything. And I was like, *“Oh my God, I’ve got another son, are you gonna come back? Will you come back?”* You know, because I would have taped it! I would have, [Laughs.]

**Interviewer:** Yeah!

**Interviewee:** And I imagined every single parent to her...she visited feeling the way I did. Just dream information that we had always wanted to know given to you in a form that you couldn’t possibly...

**Interviewer:** Mmhmm.

**Interviewee:** ...intake.

**Interviewer:** Yeah.

**Interviewee:** It was so frustrating. It was so awful. Then we moved.

**Interviewer:** [Laughs.]

**Interviewee:** I do not know if they have anything like that in this area. I would imagine they do not.

**Interviewer:** Mmhmm.

**Interviewee:** So…yeah.

**Interviewer:** Yeah.

**Interviewee:** Just even a website.

**Interviewer:** Totally.

**Interviewee:** Even just the… And in regards to everything, you will get to go home at the end of your day and you’re gonna go home. There’s no going home for me or any parent. We’re 24 hours.

**Interviewer:** Totally.

**Interviewee:** You can’t keep it a secret. Tell us what to do. Right? I mean, I’m not sure I’ve ever met a single parent that wouldn’t be willing to do anything. Just some guidance.

**Interviewer:** Yeah.

**Interviewee:** Anything would be **[0:57:00]** immensely helpful in any regard.

**Interviewer:** Mmhmm.

**Interviewee:** We talked. Other parents talk to each other and, *“What did you learn? What did you find out?”* You know? *“Oh, you went...you got to go to that seminar. Oh, you got me a sheet! Fantastic! Thank you so much!”* You know, just the tiniest information is gold.

**Interviewer:** [Crosstalk] Mmhmm. Yeah.

**Interviewee:** But sometimes you feel like it’s all…it’s… Like this woman. She had all this information and they had not given her a reasonable way to disseminate it in a way that could then be useful whatsoever.

**Interviewer:** Yeah. So, I’m sure she just was trying to get it all out as soon as possible for you because she only had an hour.

**Interviewee:** [Crosstalk, inaudible – 0:57:40] retirement. She goes, *“Oh my God, what’s going to happen when I leave? Who’s going to learn all this?”* And, you know, and things change constantly. And some of it was state, some of it was local. She goes, *“They have no plan.”* The school district had no plan and she goes, *“I would need a least a couple of years with somebody for them to get this.”*

**Interviewer:** Yeah.

**Interviewee:** Because I told her at the time. She was leaving and I’m like, *“Don’t go!”* [Laughs.] And she said, you know, *“Every single parent.”* She goes, *“It’s so frustrating. Every single parent is just like you.”*

**Interviewer:** Yeah. I’m sorry it happened.

**Interviewee:** Yeah.

**Interviewer:** That’s really… I’m, like, frustrated for you.

**Interviewee:** Yeah. It was…yeah. But just anything. Anything is helpful.

**Interviewer:** Yeah.

**Interviewee:** Anything.

**Interviewer:** And kind of thinking now that more broadly… Again, this may not be super relevant for you and for William. But how did his sensitivities impact your goals, hopes, and expectations for him as he does navigate adulthood?

**Interviewee:** I’ve actually become a lot more optimistic the older that he’s gotten.

**Interviewer:** How so?

**Interviewee:** Again, the level of maturity. He has a lot of issues, not just sensory, and a lot of them have abated. A lot of his issues. And it would be great to see him able to communicate himself a little bit better, but overall, I’m much more optimistic than I was five, 10, 15 years ago. I’m not sure when he was six if I could have ever imagined him being independent in any way.

**Interviewer:** Mmhmm.

**Interviewee:** That is actually what fuels my optimism in regard to Grayson. I...you know. I mean, you never know...

**Interviewer:** Yeah.

**Interviewee:** ...how he’s going to be in 10 years.

**Interviewer:** Mmhmm.

**Interviewee:** Right? So, yeah. But, no, I’m very optimistic in regard to William.

**Interviewer:** Mmhmm. That’s wonderful to hear. And now moving onto, like, our last chunk of questions. We’re almost done. [Laughs.] As a caregiver, as a mom, as a parent of someone with ASD **[1:00:00]**and sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee:** Same as Grayson. I want him to be happy and fulfilled and self-realized.

**Interviewer:** Mmhmm.

**Interviewee:** [Inaudible – 1:00:16]. Grayson’s easy to spot, but for William, I think that there’s a lot going on. He’s got a lot of talents. I think there are many things that he could do. Yeah. I would really like for them both to end their days being gratified, tired, but in the best way.

**Interviewer:** Yeah.

**Interviewee:** Fulfilled. But…and that’s just parenthood. I’m not sure if my desires for them or my outlook would be…and it wasn’t any different for my daughter.

**Interviewer:** Yeah.

**Interviewee:** You know? So, yeah, I…yeah. I mean, autism is what it is, but, you know, that aside, they’re just little people.

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

**Interviewee:** Yes. Absolutely. Like I said, early on, I didn’t foresee a future for them. Either of them. It was grim. It was very grim and very depressing. And I’ve watched that evolution in other parents as well.

**Interviewer:** Mmhmm.

**Interviewee:** You had asked me if I had any friends, and I don’t have any friends that have kids with sensory issues, but I’ve watched parents as our children have aged together and we have all… Whatever light at the end of the tunnel might look…it looks different for every child, but I’ve seen parents become more and more proactive, more and more responsive.

**Interviewer:** Mmhmm.

**Interviewee:** Recognizing, having better ability to recognize what their kids are needing, and more optimistic as time goes by toward the outcome. If that answers your question.

**Interviewer:** Yeah! It does.

**Interviewee:** Yeah.

**Interviewer:** It answers it perfectly.

**Interviewee:** Almost very communal.

**Interviewer:** That’s lovely. And then, what do you see specifically happening in his future?

**Interviewee:** So much depends. So much depends on if we move, so much depends on, you know, if we could leave the country. So much depends on if we could find the right place for him. Get… I don’t think therapies would benefit him so much as the right social situation.

**Interviewer:** [Inaudible – 1:02:57].

**Interviewee:** Finding just the right situation for him **[1:03:00]** where he could have a social life even casually. Even online, perhaps.

**Interviewer:** Oh, yeah.

**Interviewee:** You know, just a group of friends. A group of acquaintances. Yeah. It’s such an impossible question to answer at this moment. I mean, you know, hit me up in 10 years and ask that. I will be...

**Interviewer:** [Laughs.] Great! For a follow-up study, I’ll call you.

**Interviewee:** I’ll be so much better-equipped to answer that, because we are…we’re just kind of in flux right now. We don’t even know what’s going to happen, and much of it is related to the economy, much of it is related to COVID-19, much of it is related to what we can accomplish here. You know, is it worth staying?

**Interviewer:** Mmhmm.

**Interviewee:** Like I said, [inaudible – 1:03:58] now. I mean, it’s just…we’re really kind of up in the air. We do have plans. The cottage… But I look at those as being relatively short-term. One to three years out is really all I can see.

**Interviewer:** Mmhmm. Absolutely. I mean, the world is such a...is so in a flux right now. Like, that’s a completely understandable perspective. I feel like no one really knows what’s gonna happen in a month, in two months…you know.

**Interviewee:** Yeah, it’s hard.

**Interviewer:** So, I have one last final formal question for you. How did his sensory sensitivities impact your current perspective?

**Interviewee:** I think that this has been something that’s been around forever. I mean, everybody has the quirky Uncle So-and-so, you know, who hangs out in their barn and does weird stuff. And I don’t think that it’s necessarily autism. I think that…I think a lot of people have a lot of different sensory issues. Maybe even everybody, to some degree.

**Interviewer:** Totally.

**Interviewee:** I’m not sure, but… You know, I...my husband smells his fingers.

**Interviewer:** Mmhmm.

**Interviewee:** I won’t eat anything white. So, I mean, we all have our things, right? I know: these kids didn’t have a chance. I get it.

**Interviewer:** [Laughs.]

**Interviewee:** But I’m just saying, I think that…I think everybody has a little something. These kids, that one particular, it’s a little severe. But, yeah, I think it’s alright. I think it’s okay. And I think in somebody like William, it can easily be overcome.

**Interviewer:** Absolutely. Sounds like it. Yeah. Well, that’s actually it for all of my formal questions. **[1:06:00]**

**Interviewee:** Okie doke.

**Interviewer:** Would you like to add anything else?

**Interviewee:** I don’t think so.

**Interviewer:** Okay. Well, thank you so much for giving us another hour plus of your time. It’s so wonderful to learn from you and we so appreciate it.

**Interviewee:** You’re so welcome. Go win the Nobel Prize and change these children’s’ outcome.

**Interviewer:** [Laughs] I’ll do my best.

**Interviewee:** Thank you so much. And I can go, *“I knew her!”*

**Interviewer:** Thank you! [Laughs.]

**Interviewee:** [Inaudible – 1:06:23].

**Interviewer:** Thank you. I know you said you don’t know anyone personally, but if anyone comes to mind who you think might be a good candidate, send them our way. We’re looking to learn from more parents, so…

**Interviewee:** Absolutely. I will wrack my brain.

**Interviewer:** Thank you.

**Interviewee:** I’ve known a lot of parents over the time...over time, and their teacher’s actually may know somebody. I’m still in contact with their teachers from their old school district, so…

**Interviewer:** Yeah! I mean, if you want to send our info to the teachers.

**Interviewee:** I’m sorry?

**Interviewer:** I... Sorry. I think we’re talking. If you want to send the info to the teachers and they know anyone, we’d love to hear from everyone. [Laughs.]

**Interviewee:** Sure. No, and the teachers and I may know somebody mutually.

**Interviewer:** Oh!

**Interviewee:** And I’m just not there, you know, but they may be eligible, so…

**Interviewer:** Yeah.

**Interviewee:** Yeah. If they are, I will throw them your way.

**Interviewer:** Thank you so much! But if you need anything from me, if you have any questions or, like, if I see any other resources, I mean, I’m happy...I’ll be happy to send them to you.

**Interviewee:** Absolutely! Please don’t hesitate. I just read the 2019 European… They had a convention on autism and there was so much useful information. It was pages and pages and pages. I’ll ready anything you send. I’ll visit any website.

**Interviewer:** I have a website I can send you. It’s the same website as before but they actually publish all the abstracts, and I think they publish… Yeah, so, like, you could read the abstracts and then you can reach out to authors. And, I mean, you can search the thing… I’ll send it to you.

**Interviewee:** That may be what I downloaded. That...I may have already gotten them. I got…

**Interviewer:** It’s really long. It’s, like, several hundred pages.

**Interviewee:** Okay, that’s not what I got. [Laughs.]

**Interviewer:** [Laughs.]

**Interviewee:** Cool!

**Interviewer:** Yeah, I’ll send it your way. And I actually…yesterday, I spoke to a mom and she recommended a book. I’ll send you the recommended...I’ll send it to you. It might be helpful for you.

**Interviewee:** Super!

**Interviewer:** Yeah. well, thank you so much. I hope you have a nice weekend and don’t get too hot. [Laughs.]

**Interviewee:** Thank you so much. And you stay safe and work hard.

**Interviewer:** Thank you. I’ll send you a gift card, too, as soon as it comes in.

**Interviewee:** Super!

**Interviewer:** Awesome.

**Interviewee:** Alright.

**Interviewer:** Have a nice day!

**Interviewee:** Take care.

**Interviewer:** Bye!

**Interviewee:** Bye!

**[End of transcript]**