**[Start of transcript]**

**Interviewer:** Alright, we are recording and I will be asking you questions about your perspectives regarding your child's transition to adulthood in relation to their sensory sensitivities and sensory interests. And we’ll be doing something called a semi-structured interview which means I have my planned questions, but I’ll also be adapting them to follow our conversation so they actually fit for what we’re talking about and fit for your family.

**Interviewee:** Okay.

**Interviewer:** Any questions?

**Interviewee:** No.

**Interviewer:** Okay, great. And if there are any questions that make you uncomfortable for whatever reason, you do not have to answer them. Saying *“I don’t know”* is also a perfectly okay answer. And if there is anything that comes to mind from earlier in the conversation later, feel free to bring it up, it doesn’t have to be linear.

**Interviewee:** Okay.

**Interviewer:** Alright, shall we?

**Interviewee:** Yep.

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

**Interviewee:** Sure. So, basically most of the sensory issues seem to revolve around audio. So, like, loud noises, especially if they’re startling noises, even from the time she was a baby, that has always been something that I’ve been aware that she had an issue with. But also in a more general sense, when you’re in a crowded space with a lot of voices talking all at once, like a restaurant or something, or an event, she finds that very overwhelming and distressing because it’s like she’ll usually describe it as she can’t just sort of ignore background noise, it’s like her brain is trying to follow every conversation she can hear and it’s very overwhelming and exhausting. So that’s another piece of the audio sensory stuff that has been a problem. I think I’ve noticed that a lot more as she’s gotten older in her teen years, I would say it’s been more of an issue. And then with touch, she definitely does not want to be unexpectedly touched. If you accidentally kind of brush up against her or touch her and he’s not expecting it or doesn’t see it coming, it’s kind of a startle reflex. It’s not that she resists hugging altogether, because she will seek out, especially to me, she will come to me, she wants to be hugged, or she wants me to pet her hair or whatever, something, but she doesn’t like unexpected touch and she doesn’t go to other people, she’s not a touchy sort of person and she doesn’t want other people to touch her. So, I would say that’s another sort of touch issue. As well as, like, a lot of things like with fabric and clothing, and textures, and tags, and all that kind of stuff, she’s very particular about clothing and how it feels on her and if something feels too tight or too whatever,**[03:00]**she pays a lot of attention to that. She’s always, even from the time she was very young, she likes to touch things herself. When she was young I would make these touch boxes, we put rice in them, or beans, or little toys, or whatever, and she would love to play in that kind of stuff or squishing through Oobleck, just playing and touching things, feeling things. She has always enjoyed that a lot. Even now she will do that and she is quite fidgety with her fingers. She likes to pick at things or touch things a lot. So, I would say touch is kind of a big thing to her.

**Interviewer:** Totally.

**Interviewee:** Yeah. And then more recently she has expressed that certain smells, I have noticed that very overwhelming smells, like if you go in the detergent section of the grocery story, like that kind of scent is too overwhelming, or going into a candle store would be like, forget it, there is no way I’m going in there. Which I understand, because that’s pretty powerful overwhelming smell. But there are certain smells that she really doesn’t like and she will try to avoid if she can. But it’s not something that I really noticed until kind of in more recent years, couple of years. I’ve asked her about it and she’s said that it’s been around longer than that, but it’s just something that she expresses more now. I find that the smell thing is not as, it doesn’t tend to affect everyday life nearly as much as touch or sound does, but those are the things that I’ve noticed the most with her sensory wise.

**Interviewer:** Thank you. I’m going to ask a few followup questions, if that’s okay.

**Interviewee:** Sure.

**Interviewer:** I’m going to go in order. So, for sound, you talked about loud sounds, particularly startling ones, being kind of bothersome. Is it all loud sounds or is it more like musical or mechanical, or like human sounds?

**Interviewee:** It’s any loud startling sound. So, it could be dogs barking suddenly, like if you’re walking along and all of a sudden a dog runs up to the fence and starts barking at you, that she does not like that. She has always hated thunderstorms because of the loud, unexpected booms that you can’t predict when they’re coming, just like any kind of a sort of a startling sudden sound that you’re not expecting. It’s not just the loudness itself, it’s the unexpectedness of it that is mostly, I think, is mostly the problem. If you know something is loud, like just being in a loud space, isn’t necessarily a bother, it’s the something suddenly bangs or explodes, or barks at you, or something, it’s that aspect of not expecting it, that’s startling to her. **[06:00]**

**Interviewer:** And is that also like with human noises like babies crying or like screeching?

**Interviewee:** Yeah, if something, it’s like if a baby suddenly just screeched, I think she would find that startling, yeah.

**Interviewer:** Thank you. And then for touch, you said that they were particular about certain fabrics. Can you talk a little bit more about that?

**Interviewee:** She’s very purpose about what is called the hand of a fabric, how it feels. So, she definitely seeks out fuzzy, soft, draping sorts of material to wear herself. She doesn’t want things that are scratchy or just sort of an uncomfortable texture on the skin. But she also likes things that are tight, not restrictive, like you can’t breathe, but she wants things that fit snugly up against her. Like she would want a shirt that’s a tight fitting shirt, not just a loose, baggy shirt. It’s not that she would object to the bagginess, but she just really likes something that kind of snugs up against her.

**Interviewer:** Yeah, that makes sense, thank you.

**Interviewee:** And I think it’s the pressure, the feeling of having pressure against you is what she likes.

**Interviewer:** Yeah, absolutely. And then on your screening form I believe you also mentioned that they don’t like light touch.

**Interviewee:** Yes, oh my goodness. So, like it’s what I think as like the feather touch, where you just sort of brush lightly against someone, she hates that so much, in almost any kind of form. And certain parts of her body, especially. She is especially sensitive sort of in like the back of the neck and upper shoulders, if someone puts their hand on her shoulder she will instantly flinch. But if you were firmly put your hand there, it would be okay. But you just lightly touched her there, she just doesn’t like that at all. Or if you just brushed her arm, she doesn’t like that. But if you grab her arm that’s okay, the pressure is okay, but not the light feathery touch.

**Interviewer:** Mm-hmm, thank you for sharing that. And then small, what about cooking smells, like if you’re making something with onions and garlic that’s a little bit more pungent?

**Interviewee:** No, it’s not necessarily the strongness of the scent, although that probably plays a part in it, it’s the kind of scent that it is. And I don’t know, I’m not familiar with what all she finds is too much, I just know that we’ve talked repeatedly about candles. Most candle smells are things she does not like. Detergent depends, like was have definitely, during the pandemic we ran out of the kind of detergent that we use and I couldn’t buy it in the store, they just didn’t have any, and I had to find something else to use. **[09:00]** And we brought it home and I used it, she was like,   
*“Uh, I don’t like the smell of that laundry detergent.”* So it was like ugh, because I had to try something that would be acceptable. So it’s kind of what I think of usually, it’s like the artificial trying to smell good smells, is how I think of it. Like Febreze deodorizer things, she would not like that or essential oils in the room. I remember we tried doing lavender to help her sleep and she hated it. It was like oh no, no, no, I can’t bear it, just get it out of my room.

**Interviewer:** Got you, and then do they have any sensitivities or specific interests with tastes?

**Interviewee:** No so much. She’s always done pretty well at eating most things and what not. She has some food allergies which is different in my mind than, you know, like, well okay, of course you don’t like things that you’re allergic to, but not really. I mean, she says there are certain textures she doesn’t like, like really kind of slimy kinds of things, she says cottage cheese, things that are lumpy, slimy, like cottage cheese, she doesn’t like that. But that’s, I don’t know, it’s not excessive and it’s not like she couldn’t eat it at all or something.

**Interviewer:** We all have preferences, also.

**Interviewee:** We all have our preferences, like okay, I think most people maybe don’t really like slimy things that much.

**Interviewer:** Absolutely. What about any visual sensitivities?

**Interviewee:** Not so much, although I do notice that she tends to prefer a dimmer room. It’s not that she can’t go outside and be in the sunshine, she can, and she does, but when she’s sort of felling sensory overload she will tend to try to limit all of her sensory input, so that includes like putting the shades down, being in a dim room. But I think more, it’s not so much that it’s the visualness of it, as it’s that she’s just trying to limit all sensory input.

**Interviewer:** Yeah, totally.

**Interviewee:** Because I’ve asked her about that before, like does she mind certain colors or brightness, *“Not really,”* she says, I was like, okay.

**Interviewer:** No, that makes sense, thank you. And then generally speaking, how does your child manage or cope with their sensitivities, or even how do you help them manage or cope with them?

**Interviewee:** Yeah, a lot of what she does for herself involves limiting sensory input, so like she spends a fair amount of time in any given day in what I think of as her sensory deprivation chamber. **[laughter]**. So, she will be in her own room with the door shut, the shades sort of pulled down, fairly dim. **[12:00]** She has this sort of heavy blanket on her bed that she will cocoon herself in and lay in her bed with her air filter on, so there’s sort of white noise, dim lights, and in the cocoon with sort of even pressure all around you. So, I think of that as sort of like sensory limitation in all ways, like, you know, sight, sound, feeling. There’s not usually any smells or tastes involved in laying in your bed, so it’s like limiting how much, so she does that actually quite a lot, and in general she will try to avoid situations that are going to be auditorily overwhelming. She does not enjoy going to events because there’s just too much noise going on. She is trying to experiment with some things like maybe using noise cancelling headphones, or clothing wise, trying to wear, instead of having to wrap herself up in a blanket and lay in bed, could we buy clothes that kind of provide that same pressure? We tried buying her, there’s some kind of a t-shirt type of thing that you can buy that’s like a pressure t-shirt or something, I forget what it’s called.

**Interviewer:** Like compression socks?

**Interviewee:** Yeah, kind of compression, yeah, like compression wear is how I would put it. We’ve experimented some with that. When we buy clothes we’re very particular about making sure they’re going to be very soft and fuzzy and all that kind of stuff. So, just sort of paying attention to her preferences and trying to create an environment where if you know you’re going to be in an environment that’s going to involve excessive amount of sensory input, try to limit how long you’re there or whatever, that sort of thing.

**Interviewer:** Absolutely.

**Interviewee:** I think it does help. We have always homeschooled so she has had the luxury of having a much more tailored environment for all of her life, and I think that’s probably helped her in many ways that I don’t even realize, just because I didn’t know about most of this until she was in high school. I didn’t realize there were all these sensory issues, I didn’t realize about the autism and different things. There was a lot of stuff that didn’t really show up until she hit puberty. It was like you expect little kids to act a certain way, but also expect them to outgrow it, and when they don’t, then you start going, oh, maybe it’s not just them being kid, maybe there’s actually something that’s going on that we didn’t realize.

**Interviewer:** You said a lot of things you didn’t realize them until high school hit, was that because it was also puberty or also because then they started interacting **[15:00]** with other peers?

**Interviewee:** Mostly because of puberty, I think. A lot of things, I don’t know what it is about puberty but it definitely changes your brain.

**Interviewer:** Oh yeah, hormones, everything.

**Interviewee:** Hormones just change a lot of things. It just made a lot of things more evident and also just because of age wise, when you start expecting kids to age out of certain behaviors and they don’t, then you start going, oh. So, I think some of it was puberty, some of it was just awareness of age wise, why aren’t you kind of outgrowing some of these behaviors. Yeah, I think that’s a lot of it. Also, there were so many struggles with her schoolwork that we actually did do a neuropsych evaluation because I was like, I need to know what’s going on because I don’t know how to deal with this, and that’s when a lot of these diagnoses came out. It was like, oh, there’s all these things, oh, that explains a lot of stuff.

**Interviewer:** Yeah, that makes sense, thank you. And has your child ever received specific therapies or interventions for their sensory sensitivities?

**Interviewee:** She’s current doing occupational therapy, which they are focusing a lot on these different, how can you cope, how can you lessen the impact, how can you, is there any to kind of desensitize yourself to certain things. Or, if not, then how can you set yourself up for maximum success in situations when it’s not always the best.

**Interviewer:** Totally, yeah. Do you think OT has helped in that capacity?

**Interviewee:** I do think it’s definitely made us much more aware of what are some of the specific things that are actually sensory issues. And for me, I mean, speaking for myself, I just wasn’t aware, I didn’t really even understand what occupational therapy was about and I didn’t realize that sensory processing disorders even existed, and that like, oh, and there’s maybe ways that you can help people cope better, like I just didn’t know all those things. So I feel like knowledge wise it’s made a big difference to be aware of what’s going on and why those things happen and understanding that, you know, you can have things that are wrong with your senses, like you could be blind, but you can also have something in your brain that doesn’t process what you’re seeing in a way that makes sense, so that you kind of misinterpret what you’re actually seeing, even though your eyes work fine. I didn’t realize that could be an issue, too. So for me, understanding that your brain might be having a problem dealing with something, it’s not that your senses don’t work right, it’s that your brain maybe doesn’t process the information in the same way that everyone else’s does. And that explains a lot of things to me, understanding how people work and **[18:00]** certain things can be a problem, and it’s not because you’re choosing that or something like that, it’s literally that’s just the way your brain works.

**Interviewer:** That’s wonderful. And has OT provided concrete skills for your child to help manage their life a little bit more easily?

**Interviewee:** Yes, like as an example, understanding that pressure is actually a sense thing for her, it’s very centering and grounding for her to have pressure. So, like we have developed a routine of every morning we have this big yoga ball, she’ll just lay on the floor and I’ll just roll it over her up and down, just to provide that deep pressure. She has learned some techniques like just the idea that your brain and I forget what you call it, the equilibrium...

**Interviewer:** The vestibular?

**Interviewee:** ... yeah, vestibular, like you might need to spin around because your brain needs the vestibular input to understand where you are in space and to feel comfortable. Or you might need to hang upside-down for a few minutes every morning, or whatever, just things that you can do. So, those kinds of awarenesses and actual practices, you could buy this thing and then you could to this at home, and that would be helpful, and to recognize that you can do those things when you’re feeling antsy and like aagh, you could some of those things and it would probably calm you down and make you feel like you’re more centered and grounded and not just kind of all over the place.

**Interviewer:** Yeah, that’s awesome. And you’ve kind of alluded to this, but how have your child’s sensory sensitivities changed over time?

**Interviewee:** When she was younger there were a few things that I noticed, like I think the startle of loud sounds and her definite desire to touch a lot of things and play with things. I would say, like, my only reference point is compared to her brother who is a little bit younger than her, so compared to him, she always enjoyed that type of thing much, much more than he did. So, like, I do recognize that some of these things I can see when I look back, yes, they were there, but I think a lot of these things I feel like have either become more magnified or just more obvious, or maybe they just have increased over time. Her sensitivity to so many things, her just sort of lack of ability to cope in different situations that are sort of sensorily overwhelming to her, I feel like that increased. But, I don’t know if it’s just because she’s able to verbalize it better now, and as a kid you just kind of went with the flow because what else were you going to do, I’m not really sure if the experience really **[21:00]** hasn’t changed that much but I’m just more aware of it, or if she’s also more aware of it, I don’t know, it’s hard to kind of fuss out totally. But from my perspective it definitely feels like it’s become a much, much bigger part of our picture than it used to be. I don’t remember her having, like, for example, she started stuttering as a teenager, she never stuttered as a small child. So it was like, well, that seems odd, why would you start stuttering now? Most people that stutter I think stutter young ages, at least typically. So, why are you developing a stutter now? Why are you suddenly developing all of these food allergies? It felt like a lot of changes were happening. Because I felt like up to a certain point she did okay in school, but then all of a sudden things went downhill. And there are many factors that went along with this because there were other things going on at the same time and I don’t think a lot of it is puberty and just all the hormonal changes that go on, you know, but there were multiple things happening at the same time, because she struggled a lot with depression, anxiety suddenly went up a lot. I knew that she always was a bit of a worrier as a kid, but it seems like it’s much more heightened as a young adult. So, yeah, it’s hard to know. Were these things there all along but just sort of masked and hidden under expectation and childishness, and inability to maybe express things versus now, when she can. I don’t know.

**Interviewer:** You said that from your perspective it seems their sensitivities have increased, is this across all domains or just some domains?

**Interviewee:** I feel like in most respects. I feel like everything seems much bigger and more, like everything impacts stuff so much more than it used to. I feel like it’s like when I look back, it’s like okay, maybe I can see some signs of things that were kind of in the works, but now it’s kind of like, now it’s full blown, some of it maybe is just like that you have a label for it and you’re aware of it, so now you look for it, it’s like, oh yeah, now I see it, whereas before I was the paying attention to that so I didn’t know what I was seeing sometimes, maybe.

**Interviewer:** Yeah, no, it’s definitely possible. And these changes that you observed in relation to their sensory sensitivities, do you think that might be related to any independence that they’ve gained over time?

**Interviewee:** The only thing that I might attribute to that would be just as you become a young adult **[24:00]**that you feel like you have more agency, and you definitely feel like you can speak your mind a lot more than you did as a little kid. Little kids, I think, some kids are very vocal, but a lot of kids just kind of are more compliant. But when you get older and you start asserting your own sense of self, you become more vocal about what you want and don’t want, and I think that’s part of it, at least. I kind of lost the thread of what I was talking about.

**Interviewer:** No, you answered the question beautifully. The question was any of the changes related to sensory sensitivities, to you think that’s related to independence.

**Interviewee:** Yes, independence, yes. I think yes, in the sense that you feel more a sense of who you are as a separate person from other people and not just so identified with mom or whatever. I do think some of it is that, and maybe some of it is just feeling like you understand more. I think she has much more awareness and understanding, like she reads about, you know, well, what does it mean to be on the spectrum, what does it mean to have depression, she reads about these things and explores them online, finds groups of other people that she identifies with, chats with them. So, I think just feeling like, oh, this is who I am, oh, there’s other people like me, oh, I’m not just whatever, I do think there is some of that, because she’s more aware of what kinds of things that she struggles with and what that means. I think it does help her identify and articulate those things better than she ever could have in the past.

**Interviewer:** Absolutely, absolutely. And when your child is in a scenario where they’re surrounded by sensory things that are not pleasant for them, like maybe startling noises, does that cause or increase anxiety?

**Interviewee:** Oh, yes.

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

**Interviewee:** For her, it kind of depends on what the situation is. If it’s just like a one time, oh, a dog barked at me, it’s like momentarily like, aagh, I’m distressed, but she can calm herself down. If it’s a situation that you can’t escape, like you’re at an event, you can’t just leave, and it’s becoming overwhelming, I can tell her anxiety just ratchets up rapidly and she just sort of shuts down. She will try to find a corner to go and hide in, she will try to disengage herself if she possibly can. She will go away to the bathroom, whatever, any way to escape if she can. Even at home, it’s relatively calm, there’s nothing particularly stressful going on, but if I were to come in, to come to her **[27:00]** and say, hey, have you done X, Y, and Z? What at about blah? And I suddenly hit her with a lot of information and a lot of like, do this, do this, do this, like a list of things she needed to so, sometimes almost immediately she will just panic, she’ll have a panic attack and the anxiety will just be so acute, so suddenly, that she will literally have a meltdown or cry, or just fall apart. And from my perspective I’m like, wait, what happened? There’s nothing going on, there’s no one attacking or anything, but for her it’s like suddenly there’s a feeling of being attacked, like there’s too much information, there’s too much demand. Or sometimes she’ll just get antsy about something she’s wearing or she suddenly, she discovers she has a hive, and it’s like, *“It’s itching, it’s driving me crazy!”* and the anxiety will just be very acute, very suddenly. From my perspective it seems like minor and small inconveniences, but from her perspective it’s like, gahh! This is taking over all of my ability to cope.

**Interviewer:** Totally, and when they do this kind of like this escapism behavior at a loud event or something, does that help manage the anxiety, does that help lessen the anxiety?

**Interviewee:** Yes, again, it depends on what, if it’s just an overload versus a panic attack. Overload, for sure, if you can escape it, that helps, because suddenly you don’t have the overload. In a panic attack it kind of feels like probably the only way for her to really calm down relatively quickly is for her to completely disengage from the situation, and it’s like the more you try help, the worse it is, so it’s like I am learning that slowly, stop trying to help, because you’re just making it worse and overwhelming them. It’s like just say okay, I think you need to have a break, go regroup, and just let her escape to her room and get in the blanket, and just regroup, it’s usually the fastest way for her to able to regroup. The more you try to help the worst it gets.

**Interviewer:** Makes sense, for sure. And you -- can you get that?

**Interviewee:** Probably not, it’s almost always junk calls, but I do need to shut it up so it won’t keep ringing.

**Interviewer:** No worries. And the anxiety they experience, specifically in relation to sensory experiences, has that changed over time, that anxiety?

**Interviewee:** I feel like it has, in that I feel like there is much more of a chance that it will turn into a **[30:00]** panic attack, which I don’t really remember as a younger child, I don’t remember her ever really going into a panic attack. I do know that she might withdraw or sort of like shut down, but not the acute anxiety and the panic attacks, that feels like that really has not, that came about more with puberty than anything else.

**Interviewer:** Thank you. And then kind of more broadly speaking, what goals or hopes do you have for your child in regards to their sensory sensitivities in the future?

**Interviewee:** My hope would be that she can develop and find real tactics, if you will, that she can use in the moment to deal with situations that she finds overwhelming. Whatever it may be, if it means, hey, I need to learn how to advocate for wearing noise canceling headphones when I’m in crowded situations and not for people to think I’m just zoning out or playing my music, or whatever. It’s like, no, I need these so that I don’t get overwhelmed by all the noise that’s going on. And to be able to articulate those things to other people when she needs to. It’s not like she has to explain herself all the time, but when it’s appropriate to be able to advocate for herself and say what she needs, and be able to do it, and just in a more matter of fact way, like, this is what I need, so I’m going to do it, not wait until you’re already overwhelmed or having a panic attack, because it’s very hard to engage anything that’s helpful at that point. Maybe proactively realize when you’re going into a situation, when you start feeling that anxiety going up or something happens and you recognize, oh, I need to employ some tactics to make sure I don’t just all apart here.

**Interviewer:** Yeah, absolutely, thank you. We’re going to move on to our next chunk of questions, that was the biggest one, so we’re over the big hurdle. As your child has grown up and aged, how has your and their community reacted to their sensory sensitivities?

**Interviewee:** I feel like overall there’s much more acceptance in society as a whole for younger children behaving in ways that seem sort of socially unacceptable or inappropriate. But the older you get, the less and less grace you have for that. It’s okay for a toddler to be having a meltdown in public, it is not okay for a teenager. Overall I feel like the judgment is increased the older you get because it feels less and less appropriate to be behaving in certain ways. And I do think that in your teen years, if you’re doing sensory things **[33:00]** that seem odd to other kids like if you’re flapping your hands or doing something, you know, picking your nose in public without being aware of it, those kind of things will definitely create social distance between you and other kids, because they don’t want to, you weirdo, why are you doing that, they don’t want to be associated with anybody who is doing something that’s off or odd, or not like everyone else. I get it, I’ve been a teenager, I didn’t want to have anybody standing above the crowd being weird in some way. So, it makes people uncomfortable and they don’t know how to respond, it’s like, do you say something? Do they know they’re doing that? I think a lot of people just, you don’t know what’s your appropriate role. For me as her mother, I can just matter of factly say, *“Danielle, stop picking your nose,”* and she’ll be like, *“Oh,”* and stop. But I don’t know that a friend could say that. A friend might notice it and be trying to pretend they’re not noticing, but I don’t know if they would say anything. So, I guess that’s how I see, generally speaking, I think most people feel uncomfortable when people aren’t acting in the way they expect, where they do something unexpected, and so they don’t know how to react and they feel uncomfortable. And when you feel uncomfortable, you just kind of tend to avoid people like that, because you don’t want to feel uncomfortable. So, I think it does increase her distance from people overall, like, it makes it harder for her to engage with people. She has a lot of trouble reading social cues and stuff, too, so she’s not always certain, so, you feel like, what’s going on? It’s almost like you’re in a foreign country all the time and you don’t really speak the language that well, so you’re kind of always a little bit confused about what’s happening and you’re not sure why those people are laughing, and what’s happening, are they laughing at me, or did I do something? Just a sense of being puzzled all the time about what’s happening, what’s going on, which I think makes it hard. And doing things sensorily or avoid situations because you don’t feel comfortable in a crowd, so if your friend said hey, let’s go to a concert, you’re going to be like, no way. Well then, that means you’re missing out on a social activity because you’re trying to avoid a sensory situation, or you don’t feel comfortable at a party because it’s too loud and there’s too many conversations, so you never go to parties, well, how are you going to be with your friends, then?

**Interviewer:** Yeah, it makes it hard, for sure. You’ve alluded to this, but it’s one of my questions, would you say the community was more accepting when they were younger as opposed to now?

**Interviewee:** Yes.

**Interviewer:** What about specific aspects of the community? You talked a lot about teens right now **[36:00]** are different spaces or places more or less accepting of them and their sensory sensitivities?

**Interviewee:** Well, Danielle honestly doesn’t have a ton of social opportunities, partly because we home school, so that immediately limits a lot of built in sociability of school. Only right now, that doesn’t seem to be part of anybody’s world. **[laughter]** But she does belong to a Girl Scouts troop and she has gone to church and has been part of a youth group and different things. There are some social activities that she has been able to be a part of, but again, I think she goes, but it’s not always, in her mind, I don’t think she’s always even going to socialize, because I feel concerned that she doesn’t have any friends, but she’s not concerned about it **[laughter]** so it’s kind of like, okay, why should I be unhappy? But I do know that you need people in your life, regardless. You need to have a network of people that care about you and yeah, now I kind of lost tract about what we were talking about.

**Interviewer:** That’s okay, the Girl Scouts troop that they’re a part of and the church group, have then been accepting of the sensory part of who they are?

**Interviewee:** In some ways it’s hard to separate out sensory things from social things, because it’s like I don’t know what, I know that she doesn’t have friends, I know that she doesn’t easily engage with other people, but I don’t know if that’s social things or sensory things, or both. You’re kind of acting weird so I don’t like you, but you also don’t try very hard to engage, so we don’t care whether you’re here or not. I don’t know, it’s very hard to separate out anything. I do think that there are probably some sensory things that keep her, like, because she avoids the socializing aspects of life, usually because they happen in crowded spaces where there are a lot of people talking or like even in just like the turn taking of talking in a group of people, if you’re talking to one person it’s more obvious how to turn take, when you’re in a group, it’s very, very confusing for her socially, how do you even do that? And then there’s the sensory part of trying to pay attention to everyone who’s talking, I don’t know how to separate those out, really, I guess.

**Interviewer:** No, absolutely. Because you aren’t able to separate them out and kind of figure out what came first, do you feel like those other social groups, you’re not sure if they’re accepting of her because of her sensory things or because of her social things? Is that what you’re saying?

**Interviewee:** Yeah, yeah, I would say so. I feel like there are some groups that are **[39:00]** more accepting than others, and again, like she goes to a social skills group. Well, guess what? Those people are really accepting of her because they’re all like her and they all have the same problems, and what not. So that kind of a situation she feels very comfortable in because she feels understood and these people are like, I mean, they’re not going to judge me for my strange slips and weird things that I do. Whereas just a more average group of people like Girl Scouts or the youth group at church, there might be, maybe there’s one other person that’s got a few things like her, but probably not, so it’s probably harder to gain acceptance there.

**Interviewer:** Mm-hmm, absolutely. And thinking ahead to the future again a little bit more broadly, what hopes or worries do you have for how their community will react in the future regarding their sensory needs?

**Interviewee:** Again, I would hope that over time and with coaching and this kind of social skills groups and things, being made aware of when you’re doing sensory things that are kind of odd to other people, either to find ways to limit how much you do those things, or not do them when you’re around other people, that’s one coping strategy is to learn how to be aware that you’re doing it so you don’t do it as much when it’s not appropriate. I’m not saying you can never do it, but just don’t do it when you’re with other people. But also, the advocacy thing. If you have a group of friends and you’re going to be part of this group for a while, to be able to say hey guys, I know sometimes I do some odd things, that’s just who I am. Sometimes I have trouble understanding what everybody is saying all at the same time, sometimes it’s just hard for me to be around a lot of whatever. Just to be able to simply state it, not overstate it, not explain it too much, but just to simply state it, you might see me occasionally doing this or that, sorry, it’s just me, I just do that. And just to say that’s who you are and to have it be, I feel like most people, if they just heard a very simple quick explanation like that, would be like, oh, okay. Then when they see it, they’re not like, should I say something? It lessens the uncomfortableness of other people and so they feel more comfortable and therefore they can be more accepting because they’re not uncomfortable. So, I think for her, if she can find ways to just quickly and easily defuse the uncomfortableness of other people, and to recognize that unfortunately it is her burden to have to do that, just like you would have to explain, I’m sorry, I can’t eat that, I’m diabetic, oh, okay, or I’m gluten intolerant, you just have to say it so people don’t think you’re being rude or whatever. It’s like, yeah, sorry, you’re going to have say that, and say it, and say it, and say it. **[42:00]** But to be able to be accepting of it and just to be able to do it quickly and easily and not be uncomfortable about doing it. I feel that would be a wonderful thing to be able to do.

**Interviewer:** Yeah, absolutely.

**Interviewee:** For herself, you know, to be able to explain and still be able to get what she needs.

**Interviewer:** Yes, absolutely, thank you. We’re going to move on to our next chunk of questions again. In this transition to adulthood, where do you see your child?

**Interviewee:** I see her as being, kind of like being a couple years younger than she is, in a sense. Just like socially and skill wise and confidence wise, even though she’s 17, she does not seem like a 17-year-old to me. She seems more like she’s a young teenager, like maybe she’s 13 or 14. In many of her interactions, her ways of thinking, her desire to go away from home, all of those kind of things, she does not, she seems younger than her actual age. And she herself would say that. We’ve talked about these things, which I think is good, we’ve talked about what does this transition look like. For a while she was extremely anxious about leaving home, the idea of having to leave home and be on her own just panicked her, and we would talk about, I was like, no one is going to kick you out when you turn 18, there is no hurry here, we don’t have to do anything on a particular timeline, we can take all the time we need. And I think at this point she’s starting to realize that that’s really true and no one is going to make her take on more than she can actually handle, because I think it panics her to think about trying to handle everything herself, it’s just like really overwhelming to her and it makes her kind of freak out. So, we’ve talked about it, and I think she’s kind of becoming a little more comfortable with the idea that there is no hurry. We even slowed down her graduation. It’s like, you know what, we’re going to just take an extra year in high school, we’re going to go at a slower pace so you have more time to work on things and not feel like you’re pressured to have to graduate, you know. There is no hurry, there is no timeline, we can take whatever time we need. So, I think for her, she recognizes that she’s not going to be the 18-year-old that can barely wait to get out of the house and go off to college or whatever, she wants to take her time and that’s okay, and she recognizes she might be older before she decides to go to college. She doesn’t want to go to college right now, that just makes her not feel comfortable. But she’s talking more like, **[45:00]***“But maybe when I’m older, maybe when I’m 24 or 25, maybe then I would decide I’m ready to go to college and I want to do something,”*or whatever, but right now she thinks more like, *“When I graduate I think I need to get a job,”* even if it’s just part time, just work and slowly ramp up.

**Interviewer:** And there’s nothing wrong with that.

**Interviewee:** Yeah, and I think, myself and her dad, we both are very accepting of that and there is no pressure for her to have to do something by a certain date or anything like that. And I think that she’s kind of slowly believing that we really do think that, that it’s really okay.

**Interviewer:** That’s wonderful, that’s exciting. You just talked a lot about her thought processes in terms of what it means to transition. Can you talk about what are her independent skills and what are things that she maybe still needs some more support with?

**Interviewee:** Independently, I think she’s worked a lot on self care, like, can you remember to take a shower more than once a week, can you do your laundry, can you get yourself a snack and make a meal when you need to. Some of those things in the past have been extremely low, not always because of sensory issues, sometimes it’s just been depression and other things. But I think she is starting to gain a sense that oh, I can do basic chores, I can make a snack, I can do my laundry, I can take a shower when I need to, I can comb my hair in the morning, those kind of things. So I feel like those things are, again, it’s not like your typical 17-year-old, a little lower on the scale, but it’s growing, so that’s good. I feel like intellectually she’s very bright and she’s smart. She can read all kinds of things, she’s very interested in lots of different things. And so in that sense of her awareness of the world and taking in information and knowledge and stuff, I feel like her abilities are great there. I know she has some learning disabilities that she struggles with that makes certain kinds of things more challenging and difficult. One of the things that we’re focusing on this year is very practical math skills. How do you fill out these forms, how do you figure out percentages when you do takeout, just very practical skills, and I think she’s developing a little more confidence in her ability to deal with arithmetic type math. She has a lot of math fears because of a lot of failure in the past, but now she’s realizing, oh, I can do arithmetic, especially if I have a calculator. I can put the numbers in, I know what I’m doing, I understand what I’m doing, so I can do these things. So, I think she’s gaining confidence in that. We’ve set her up with a checking account, we’re going to have her start paying for things herself and **[48:00]**trying to just build up the adult living skills as I think of them. Just, how do you do stuff, how do you get things done, how do you go grocery shopping, how do you plan meals, how do you pay your taxes, just stuff like that. So, she is very interested in learning those things and is eager and as we work on those things, she’s very engaged in learning these things and finds them empowering, like, oh, I can do these things, I can be a grownup. So, I find that encouraging that she’s growing in her skills to do those things.

**Interviewer:** That’s wonderful. And for these adult living skills as you described, is she able to do them preliminarily, like you talked about making a snack, could she also make herself a simple dinner?

**Interviewee:** Yes, she can do those things. Sometimes there are other things at play that prevent her from doing certain things, but it’s not actual ability. She literally knows how to get the pots out and do this, and do that, she can literally do those things. Sometimes it’s the overwhelm of there’s a lot of steps involved and I have to juggle a lot of things at the same time, and that might make me anxious, which might prevent me from wanting to do them in the first place, because I don’t want to be anxious about this. But she can literally follow the steps and do the things, it’s not like she doesn’t know where the pots or how to turn the stove on, she can do the things. And that’s what I find as a person who is helping her and giving her care, it’s hard sometimes when you know the ability is there, but there is something else that gets in the way of her actually performing the things. That’s very frustrating at times for me, because I find it’s like, ugh, I know you can do these things, so it’s hard when you can’t do them for other reasons than literal ability to do it.

**Interviewer:** For sure. You also talked about a checking account. How are they with money management, like understanding what money means as an adult?

**Interviewee:** I think she has a pretty good understanding of money. She’s very cautious and risk averse, so she tends to be a non-spender. She doesn’t buy things very often, but it’s not because she can’t or doesn’t understand how to do it. She’s very fond of actually making big long lists in Amazon about all kinds of random things, like, here’s all the gear you would need for surviving, like survival gear stuff, here’s all the stuff you should put on a baby registry, and she’ll make all these long lists, and they don’t have anything to do with her actual life in the moment, but she knows how to make wish lists on Amazon and plan out all the things you would need to buy if you had a baby. So, she has the ability to plan and think about those things. **[51:00]** She doesn’t actually do them most of the time, but you know, yeah, she does buy things and she knows, she understands how to pay for things either with cash, she knows how to pay for something in cash and make change, count it, keep it safe, she understands those kind of things pretty well.

**Interviewer:** That’s wonderful. You talked about a job. Do they express interest in wanting a job post high school or is it kind of more just like a very preliminary idea at this point?

**Interviewee:** It’s a little preliminary, but I do think post high school, when she thinks about what am I going to literally do when I graduate, so she will graduate in a year-and-a-half, not this year, but the following year. So like in a year-and-a-half what will I do after that? She’s starting to think about that. She said, *“I think I need to get a job,”* and we talk about what kind of jobs do you feel like you could do, just right out of high school, what kind of job could you get or do, or would you feel happy doing? And she’s just talked about just sort of a physical labor sort of job, like, you know, maybe I can bag groceries or stock shelves, or do something along those lines, where it’s I don’t have to necessarily interact with people a lot, but she said but the idea of actually doing things with my hands seems like that would make me happy, like I would enjoy doing that. It’s not going to tax her disabilities with certain things, or her social skills. So it’s like, okay, that sounds good. So I’m like, okay, those aren’t the first jobs that leap to my mind for me to do, but when I think about it for her it’s like, okay, I can see that that could be a good place to start. Just get out there and do something, do anything, anything is a good start. Go away from the house, have responsibilities, a place you have to show up at a certain time every day, get paid to do something, there’s a lot of good things I could see coming out of something like that for her for a while, it’s like I don’t know that I want to do that forever, but at least to kind of get out there and be an adult, live in the adult world. It’s like, okay, that sounds like a good way to start. It doesn’t have to be full time, it can just be a part-time job that you do at first and figure out what you actually want to do or like, or whatever.

**Interviewer:** Yeah, absolutely. And then when they’re older, do they ever express interest in wanting to live on their own eventually?

**Interviewee:** Yeah, she started talking about it, but for the longest time she would not even talk about that or think about it, it just caused too much panic. **[54:00]** But now she talks about, well, maybe someday I’ll have my own apartment or maybe someday I’ll do this or that. So I find it encouraging that she started talking about maybe someday, because she wouldn’t even talk about stuff like that.

**Interviewer:** Yeah, absolutely. Do you think they will be able to achieve more independence in the future?

**Interviewee:** I think so. I definitely am on the roller coaster, sometimes I’m like yes, I see progress, things are going to be great, some day she’ll be fine. Then there’s like oh my goodness, when you feel like you’ve taken three steps backward and things are not going that well, and you’re like why is this so hard? I did talk to her therapist at one point, just for my own, in the big picture, long term, is Danielle going to be someone that can eventually live on her own, not always have to live at home or be in a group home, like do we need to be planning financially for her to be taken care of? And she said, *“No, I think Danielle will be okay. It’s just going to take her longer to get there, but she’s a capable person and she’s making a lot of progress.”* It’s just taking her longer to grow up in a sense that it normally does. So, her younger brother is going to graduate and go off to college before she leaves home, probably, but that’s okay. It doesn’t mean she’s never going to get there. No, she’s not mentally uncapable. She has a lot of challenges and she needs to learn how to deal with all these things, but eventually she’ll probably get there. So, that helped me a lot to think like, okay, that should be my mental picture of her future, to have that hope and that yeah, eventually we’re going to get there, it might take a while, we might be on the long, windy path to get there, but it’s okay.

**Interviewer:** Yes, you’ll get there. And what do you think will help your child move into adulthood? What do you think will help them get there?

**Interviewee:** Honestly, I feel like getting done with school at home and doing something else will probably be the biggest thing that will help her get there. Like I said, for me, the thought of her, let’s get done with school, and then yes, please, go get a job, get out of the house, be forced to learn how to cope and deal with things where you don’t have mommy here all the time helping you do stuff. Sometimes I get a little concerned, am I providing too much safety? I don’t want to not provide enough safety, but at the same time it’s like, it’s so hard to know how much is enough. I think that’s the hardest part of being a caregiver, it’s like you don’t want to under-do it and let them crash and burn, but at the same time **[57:00]** you don’t want to overdo it and keep them from developing the skills that they can do. The goal is for them to be able to be an independent person. So I don’t want to hold them back or make it take longer than it needs to. So yeah, I think that’s probably one of the hardest things.

**Interviewer:** I’m sure it is. And now putting these two things together, their sensory sensitivities and their transition to adulthood, how do they intersect for your child?

**Interviewee:** I think to me the biggest piece is self advocacy, because that I think ultimately is the hallmark, well, at least one of the hallmarks of adulthood, is to be able to speak up for yourself and what you need, to be able to ask for help when you need it, but also to find the resources to do things on your own when you need to do that. So, I think for her, learning about her own diagnoses and what those things mean, what she needs to be able to do, to work with those things, to try to build up strengths where there are strengths and work with those things, and shore up the things that aren’t so great. I mean, all of us do that, and I think as adults that’s kind of what you do, you try to play to strengths as much as you can and delegate out the things you’re not so good at. And I think for her, learning how to do those things, learning how to process things, how to work with her strengths, how to understand herself and what she needs, so that she can get what she needs when she needs it, I feel like those are the biggest things.

**Interviewer:** Okay, thank you.

**Interviewee:** And I would say the other piece probably, because a lot of getting there is learning how to navigate the whole medical care system, honestly it’s quite the intimidating package. When I think about myself navigating through the waters of trying to find the help you need, figuring what you need in the first place, how do I get that, where do I go, how do I get signed up, how do I deal with insurance, you know, so many pieces, I feel like that’s one of the big things that I could see potentially becoming a problem, because it’s just such a big, overwhelming beast all the time, that learning how to navigate it well and with confident is going to be a significant piece for her to be able to continue doing what she needs to do as an adult. Because eventually that all needs to transfer from me to her doing that, or mostly her, maybe some help here and there, but you have to be able to take on that burden of finding the people you need, getting the help you need, getting the insurance you need, getting the meds you need, taking the meds **[60:00]** you need, you know, whatever it is, it’s like you’ve got to be able to do those things successfully so that you don’t fall out of the system and become a casualty somewhere. Because if you fall out of those things and you can’t get the help you need, and you start falling apart, and then you can’t hold a job, and then you lose the apartment, and then you become a homeless person, those are real things. Obviously as long as I’m around, as long as her family is around, she has a support system that would try very hard not to let that happen to her, but you just never know what’s going to happen to you, either. I won’t be here forever, so I want to see her able to very successfully navigate that whole system because that’s very key to being able to stay healthy and well and able to have what you need in life.

**Interviewer:** Absolutely. Thinking a little bit back to their sensory sensitivities, would you consider them to be an obstacle, a vehicle, a bit of both, or neither, towards their independence?

**Interviewee:** I feel like kind of a mixed bag, it can be both. Sometimes they’re a bit of an obstacle because they can get in the way of doing the things that you need to do. But if you’re aware of what you need, it always goes back to the awareness, if you’re aware of what you need and you have the confidence to be able to get what you need, then I think that sometimes those things can also become your greatest strengths. Because I think about, when I think about my own self and where do I struggle, the things that I’ve struggled with the most are also things I’ve learned the most about and I’ve learned how to use those things potentially to my help or even to be able to help other people. So I feel like the fact that Danielle has these things that she has to struggle with at times, it does give her more empathy for other people, to understand all these sort of issues that go on in the healthcare system, that a lot of people just aren’t aware of. What I see developing in her is a sense of justice for other people and a desire to make the world a better place and to be able to speak up on behalf of people that can’t speak up on their own behalf, maybe, so I feel like to me that’s a strength. It’s borne out of your own struggles, but it can become something that may be your great call in life, whether it’s a vocation or just an advocation, is to do something that would make the world better for other people that **[63:00]** struggle with things like she does. So, I can’t say that would be a bad thing, that’s not an obstacle, that’s actually the very thing that would vault you into a place to be able to do something.

**Interviewer:** Yes, absolutely. Thank you for sharing that. And then what do you anticipate as being challenging for your child as they gain more independence in relation to their sensory sensitivities?

**Interviewee:** I don’t know that I see necessarily more challenge. Who knows, I guess things could become more of a challenge, I hope not, I hope that it wouldn’t be that way. I think, ask me the question again.

**Interviewer:** Yes, absolutely. What do you anticipate as being challenging for your child as they gain more independence in relation to their sensory sensitivities?

**Interviewee:** I don’t know that there necessarily would be more challenges as she gains more independence. I’m hoping that with more independence comes more ability to work within those challenges. Not to become discouraged by them or think of them as a problem. I know sometimes things kind of are a problem, but hopefully not to see herself as a problem, if that makes sense. It’s like, okay, you may be a person who has problems or challenges, but that doesn’t mean that you are a problem or a challenge. So, I would hope that as she becomes more independent and takes on dealing with things more herself as opposed to me doing a lot of things, that she won’t become discouraged or think of herself as *“I’m a problem, I’m a hopeless mess,”* or whatever. That it wouldn’t become so overwhelming or so challenging that it just kind of takes her under. I would hope that wouldn’t happen. I would hope that along the way she’s being built up and strengthened, so that when she is taking on the burden of it, she has the strength to do it, and not like, oh no, collapse.

**Interviewer:** Yes, absolutely. Thank you. What do you think would help your child in this intersection of sensory sensitivities and the transition.

**Interviewee:** Honestly, I think the occupational therapy is super helpful. I think just learning more about how all these things work, how your brain works, how all these things intersect with one another, and how they can either amplify or dampen other things that you’re challenging. **[66:00]** It’s like sometimes they actually help because you’re not dealing with the things that other people deal with. I think sometimes it can be either an amplifier or a dampener sometimes, but I do think the occupational therapy helps a lot. I do think learning more about things, and I would hope that, I would love to see her develop just a little bit more of a social network of people who can love and care for her as the person that she is, to be accepting of her as she is. She’s a lovely person, so I don’t think that’s necessarily like a problem or anything, but it’s just the opportunities have been kind of limited for her. So, I hope that as she gets older, that she’ll find more circles of people and other opportunities to gain a network of people that could be the support network that she needs in the bigger sense of we all need support networks.

**Interviewer:** We do. So, other than OT, do you think there are other services or interventions that could help support your child?

**Interviewee:** I feel like there probably are, and sometimes it’s like just ignorance. I have recently become aware, honestly, from filling out a form asking if your child has certain, like a list of different services, and I was like, these services exist? I didn’t know, I’m finding out about it on a form, that’s crazy, but hey, at least I’m finding out about it. There are actually social service things that are to help people transition into adulthood, there are actually things out there for that in our state and our city, and I didn’t know about those things. So I think there are the social skills groups for young adults, like learning how to transition, those kind of things I think would be very helpful to her. I also feel like there are, I don’t know what to call them exactly, but like job advocacy services that help people with disabilities get jobs. I feel like that could be super helpful for her, because trying to go through job interviews and explain some of your special needs and whatever, it’s like, I don’t even know how you would do it, I feel a little at a loss myself, like how do you do that, how do you find employers that are willing with people like you? I have no idea. So I feel like those kind of services, that they are already in contact with employers and they understand the system and they know the laws about disabilities, things like that, I feel like getting connected to that kind of services would be really helpful for her in getting a job and finding what kinds of things she would be good at doing. **[69:00]** What’s an appropriate work environment for her, what does she need to ask for as accommodations, all those kind of things, I don’t even know how to navigate that at this point, so I feel like that would be very helpful.

**Interviewer:** Absolutely, yeah. Do you think there are gaps in the available services or interventions for young adults like your child?

**Interviewee:** Again, a little on the ignorant side, I don’t know, because I don’t know what’s out there. I think some of it is just actual literal awareness of how do you even get connected to all these resources and figure out what’s out there. I’m starting to realize like oh, people at the OT place, they probably know about stuff like this, you know, people that do speech therapy, people who do therapy of whatever kind, they actually do know about all these services and I just probably need to ask. So some of it is I think a lot of parents just feel a little lost, like you just don’t even know what you don’t know, sometimes. You don’t know what’s out there, you didn’t realize that there’s all things available, I didn’t even know about that. I think maybe particularly people who are in those fields, any kind of therapist, it’s just like, man, just have a running list of all the things that are available out there, whether you think that kid needs it or not, and making the parent aware, like hey, if you ever feeling like you’re struggling with certain things and you just don’t know what to do, I have a whole list of available resources or even just handing them the list, like, here’s a list of all the kinds of things that are out there, in case you ever need it. That would be so helpful because a lot of times you just don’t even know that that stuff exists. And it doesn’t have to be exhaustive or have every bit of detail, but just knowing, like, did you know that there are job services, did you know that there is occupational therapy? Who knew? I didn’t know there was such a thing. I didn’t know what occupational therapy even was until very recently. In my mind it seemed like helping people with job skills, that’s what it sounded like, well, that’s a terrible name, why do we call it that? We could call it something a little more descriptive here.

**Interviewer:** It’s like the daily occupation, I think.

**Interviewee:** Yeah, but even just like, for me, realizing oh, what they mostly do is all this sensory stuff, ooh, yeah, coping with daily life, but a lot of it is sensory, dealing with sensory stuff, I was like, who knew? I didn’t even know there was therapy for stuff like that. So I think just being aware, like, hey here’s all these kinds of things that are out there, there’s speech therapy, there’s sensory processing stuff, there’s dealing with depression and Alex, and there’s dealing with medical problems, so many things, **[72:00]** it’s like all these things are out there, they’re available, and if you need help figuring out how to get these services let me know, I’d be happy to connect you with someone that can get you help with that. That’s probably the biggest piece, is just feeling like you’re always, I think probably every parent feels like they’re reinventing the wheel because you don’t know what’s out there and you have to find all this stuff for yourself, and that’s just the nature of the beast, probably, to some degree. But I think anybody that can help you along the way and say hey, did you know, blah, blah, blah, blah, blah. Most of the things that I’ve come across and learned about has been because someone told me. Her speech therapist said hey, did you know there’s a camp for this and there’s a social skills group? Now I know, but I didn’t before. I think that’s a big one. The other thing is, and I realize that there’s all kinds of ethical issues involved in connecting people together, but knowing that you’re not alone is so important and I don’t know, there’s got to be a better way to make it possible for people to connect to one another in support groups, not only for parents or caregivers, but for the kids themselves. For my kid, just knowing that there are other people that also struggle with these things, and they’re nice people and they’re fun, and they’re interesting. It’s just very reassuring that you’re not the only person. And when you are, you’re like, am I weird, or is this normal? Just people to ask questions to. I feel like that’s a piece, that you just feel like you’re alone a lot of times when you’re struggling with things. I think kids feel like they’re alone and parents and caregivers feel like they’re alone, because they don’t know how to connect, there is no obvious hey, here is a directory of all the people in the world that have a problem with this. And I get that it can’t be that way, but finding ways to make social groups or support groups available and letting people know, if you want some support, you want to meet some other parents, here’s a support group, you can join it. That would be super helpful.

**Interviewer:** Yeah, absolutely. Thinking a little more broadly, how have your child’s sensory sensitivities impacted your goals, hopes, and expectations for them as they navigate adulthood?

**Interviewee:** I feel like, and maybe some of this is because I feel like many of these things came to light when my kid was older. It wasn’t like, oh my gosh there’s something very different about my kid from the time they were little, I think that’s a very different experience from I thought everything was great **[75:00]** and then all of a sudden it wasn’t so great. They’re just different experiences. I think if your child is born with obvious disabilities, that’s a different experience from my kid suddenly has these things, or I just discovered my kid has these things when they’re older. Because my expectations are kind of average, you know, my kid is going to grow up and they’re going to go to college, you know, all the sort of normal whatever things. It’s like I think most of those expectations have been thoroughly derailed at this point. It’s like, you know what, my kid isn’t going to graduate on time, my kid doesn’t want to go to college, my kid is not thinking about moving out of the house anytime soon, wow, okay. Just having to readjust expectations and what you thought they were going to be like when they grew up and realizing my kid is going to be on a very different path from what I imagined they would be on. And it’s not necessarily a bad path, it’s just different. And that’s a big thing I think for me, at least, is coming to grips with like, oh, my kid isn’t going to do all the typical whatever on the normal timeframe. They might eventually do most of those things, but not on the timeframe. And a little bit like, not only coming to grips with my own expectations and my husband, like us together coming to grips, hey, this is what we’re dealing with, but also larger expectations like your friends and family, when your friends who have kids that are your kid’s age, and they’re all talking about they’re going to take the SATs, we’re looking at colleges, and I’m thinking, yeah, I’m not doing that. You feel a little bit like the oddball and like, oh, I’m not like everyone else, I’m not keeping up with my friends and all their things and what they’re doing, so kind of having to let those things go, die to those expectations and feelings, and explaining to family, sometimes family has expectations, like, so when is little Johnny going to go off to college? Whey aren’t they leaving home? Why aren’t they getting a job? Whatever, it’s like, well, you know, they might be on a different path. Here’s the grandparents busy saving up money in the 529 account for them to go to college and you’re like, hmm, yeah, I don’t know if that’s going to happen or not, and them being like, why wouldn’t it happen? Because they don’t live with this, they don’t see it every day, so I feel like overall I feel like friends and family have been very accepting of it, but yeah, there’s that, I’m different, oh no, everyone **[78:00]** is doing something I’m not doing, there’s that feeling that comes along.

**Interviewer:** And this feeling of different expectations, is that related more broadly to your child’s general diagnoses, or more specifically to their sensory sensitivities?

**Interviewee:** Hold on just a second, my child is knocking on the door, hold on.

**Interviewer:** Oh no worries.

**Interviewee:** Okay, sorry.

**Interviewer:** We’re almost done.

**Interviewee:** Okay, totally forgot what you said now.

**Interviewer:** That’s okay, I was clarifying, so you talked a lot about different expectations, and I was asking is that because of their general diagnoses that cropped up later in life, or is that also to do with the sensory sensitivities that have become more apparent over time?

**Interviewee:** Yeah, really, both. To some degree, yes, there are general diagnoses that make me think my kid is going to go in a different direction. But a lot of it is related to the sensory things. If you are permanently really not able to cope in a noisy environment, this has long-term implications of what you may or may not do in life. So, yeah, and I think as much as anything, the sensory issues are most often the things that are really in your face in the moment. Like when you’re having a panic attack because you’re feeling overwhelmed by whatever, in the moment that feels like wow, I’m trying to picture you working at a job somewhere and doing this, and then losing your job because you can’t function and you can’t come to work, those things crop up I think most often in my kind of oh no, what’s going to happen mentality related to the sensory issues, less so for some of the other things. But I feel like it’s the sensory things that are front and center in many situations and kind of a bigger obstacle than being on the spectrum. Being on the spectrum is like, okay, but you, it’s not causing a big scene in the moment very often. So yes, it might be socially awkward at times and people might be like, what? But it’s not going to make you be unable to go to your job one day because you’re having a panic attack, if that makes sense.

**Interviewer:** It does, that’s perfect, thank you.

**Interviewee:** So yes, sensory issues definitely seem more *“oh my goodness,”* **[81:00]** than some of the other diagnoses, but the whole package deal also makes you go, hmm.

**Interviewer:** We’re going to our last chunk of questions, it’s the fastest one, it also might be a little repetitive, so my apologies. Finally, as a caregiver, as a mom, as a parent of someone with ASD but also some sensory sensitivities, what does transitioning to adulthood mean to you specifically?

**Interviewee:** I think transitioning to adulthood means having built up the personal resources abilities and strengths to be able to take care of your basic adult living needs. That you can function on your own for the most part, and that doesn’t mean you never ask for help, because we all do, but it means knowing when to ask for help, when to get appropriate support, and basically be able to live on your own or with roommates or with a spouse, whatever, but to be able to do that and not have everything just fall apart because you can’t pay the bills or you can’t figure out what to do where you are just in emotional turmoil all the time and can’t cope with daily life. So I think it’s the ability to do you daily living tasks pretty consistently, and do them and be able to function.

**Interviewer:** Yeah, totally. And has this perspective changed over time for you?

**Interviewee:** It’s definitely become more of a goal. I never even thought that needed to be a goal until I had a child that looked like it was going to be more challenging to get to that goal. I think most of the time when you have typical expectations in kids and whatever, they sort of naturally grow into these things and figure this stuff out, and when you launch them out there, they mostly survive, and you don’t really think about how is that going to happen. You might worry occasionally about your kid getting their laundry done or whatever, but you don’t wonder if they’re going to be able to do it. I don’t have that concern for my other kid. My other kid, I’m like, he’ll be fine, I am not worried about him, but yeah, for this kid, it’s like wow, this is actually a project to take on, you have to be more deliberate about getting all those things in place so that they can do them. So yeah, my expectations have definitely changed over time.

**Interviewer:** Yeah, yeah, thank you. What do you see happening in your child’s future?

**Interviewee:** I think that there’s sort of a longer, you know, like the plane taking off the runway, it’s sort of a really, really long runway to get liftoff, but I do see liftoff happening eventually.**[84:00]** I do think that she will ultimately be able to launch into being able to take care of herself, have a job, live on her own, I just think the runway is a lot longer than it would be for most people.

**Interviewer:** Yeah, do you see them finishing school?

**Interviewee:** I see her for sure finishing high school. I do think she started more recently talking about going to college eventually, so it’s like, oh, okay, that’s on the radar now. So I feel like the more confidence and skills she gains, the more ability she has to see farther into the future and to think that things are possible, like oh, maybe I could do that, I could get a job, I could live on my own, I could go to college. So I think she is starting to see that a little more, so it gives me hope, like, oh, well if you can see it, then I can see it, too.

**Interviewer:** Absolutely. Do you see them having a family of sorts?

**Interviewee:** I don’t know, that’s a different issue, and for completely different reasons. I don’t know how that will pan out. But not necessarily because of sensory issues or autism, but for some other reasons.

**Interviewer:** Okay. And then last formal question, how has your child’s sensory sensitivities impacted this current perspective you described about what it means to transition to adulthood for them?

**Interviewee:** I think just living with the dailyness of it and seeing how it impacts someone’s daily life really reforms your expectations about how do we even learn, how did we grow up into adults, how do we become capable. Sometimes a bit of the rollercoaster, sometimes things seem to be going well and I’m like yay, things are going to work out, then there are times something happens, and I’m just like, oh my goodness, how is this ever going to work out. So, yeah, just living with it on a daily basis, it definitely gives you a different perspective of what it means to become a functional adult and how that happens, and just that not everyone is on the same pathway to get somewhere. There can be many pathways to the sort of the ultimate same goal, if you will, but it doesn’t always look the same for everybody. And so I think I have different expectations not only for my own particular child, but I think I definitely have a lot more grace with other people in what the might be experiencing, and when things are not going well for whatever reason in their family, whether it’s because of disabilities or problems that are just sheer butting heads, whatever, it’s like you know what, everyone is on their own pathway **[87:00]** to get somewhere and what works best for one person may not be the best thing for somebody else and that’s okay, and we should all be a lot more supportive and cheerleading of everyone else’s efforts to try to get there. So I don’t know, in some ways it’s been really good for me, because it’s helped me to be, I think, a better person overall, more compassionate and caring and a little more forgiving and gracious toward other people. So, I think it’s a good thing.

**Interviewer:** Yeah, that’s wonderful, very positive. So, that’s all I have for my formal questions. Would you like to add anything else?

**Interviewee:** I don’t think so, I feel like I probably said most of the things that I would want to say. I think if I were talking to other parents that are at the beginning of this journey, where they’re just discovering a bunch of things, especially if it comes later, like it’s not an early obvious thing, it’s something that kind of creeps up on you later when your kids hit puberty or something, is to, helping parents feel like it’s not something that you did, it’s not your fault, it’s not like oh, if only I had done X Y or Z differently or better, or whatever, it’s like, yeah, probably not, that’s probably not what the issue is. It really is just a lot of these things are just the way that person’s brain works, it’s just the way they’re wired. It’s not your parenting style, it’s not this choice or that choice, usually. Some things make things better or worse, but it’s really not because of something that you did or didn’t do. And to recognize, hey, this is just your kid and they’re going to be okay. You’re going to have to find some new strategies and new ways to deal with things, but they’re going to be okay and you’ll make it, and hopefully you can connect more quickly with other people and help, real sources of help, so that you’re not just sort of floundering and wasting time. If I could go back, my only wish is that I wish would have recognized and realized sooner. Because I think there were some signs and things that were starting to go off the rails earlier, but you just don’t realize it, you just don’t know. If I could have, even just like by two years, two extra years of realizing what was going on so that we could have gotten help a little bit earlier, that would have been great. So, the earlier you figure things out and not only accept things, but if you think something is going wrong or something isn’t right, pursue finding out early and quickly. Don’t shove **[90:00]** it under the rug, oh, they’ll outgrow it, it’s like if your parent gut instinct says something isn’t right, then find out what the problem is so that you can start doing things that will be helpful earlier rather than later. Because when you don’t even get started until they’re in high school, you’re like oh my gosh, but there’s only like three years left and you feel a little panicky. But if you find out a little earlier, even if you just find out in middle school, even two more years is helpful. So, I don’t know, that’s the kind, I would like for parents to be comfortable in finding things out quicker and seeking out help sooner, and finding the support the they need sooner, so that they’re not floundering as long. I think most people probably do flounder for at least a year or two before they really figure out what to do, and I wish that flounder time was shorter.

**Interviewer:** Yeah, thank you for sharing that, that’s very insightful and I appreciate it. Do you know anyone else who might want to participate in this study?

**Interviewee:** I have one friend who has a child that has some diagnoses, and I’m not sure what all their diagnoses are. I don’t know if they have sensory things or not, I’m not 100% sure, but possibly. Is there a link or something that I could pass on to them?

**Interviewer:** Yeah, I can definitely send you some stuff to share with your friend. There is no pressure if they don’t want to participate.

**Interviewee:** Yeah sure, there is one other person that potentially could be interested.

**Interviewer:** That would be wonderful, thank you. But thank you so much it has been such a pleasure to talk with you, I have learned so much and I really appreciate all your time and insight.

**Interviewee:** Thank you, well, honestly sometimes it really nice to just talk to someone who is interested, because it’s like, oh my gosh, who wants to hear all this stuff? Most of the time nobody really wants to hear all that, so it’s kind of nice to just be able to let it all out.

**Interviewer:** Aw, thanks, well, I’m glad you feel that way. Is there anything that I can do to help you? You mentioned that you read that report and that was helpful for you. Do you want the reports that you filled out? I can send them to you.

**Interviewee:** Yeah, those are always helpful, just because honestly the paperwork trail for things like this, I feel like the more you have and the more papers that you can offer, like every time we go to someone new, and I’m like, here’s my sheaf of stuff, all the testing the results and thing, and they’re like, oh, it’s like a goldmine for them, because it’s so helpful for them to be able to see all the other things that have been happening and all the different testing and diagnoses and things that have gone on. It cuts down on a lot of **[93:00]** endless questions, like, okay, just read this report and then you’ll kind of know everything that I know.

**Interviewer:** Yes, then I’ll definitely send that to you. Can I help with anything else? Anything else I could do?

**Interviewee:** No, I think what you’re doing is great. I’m very excited that there are people that are interested the caregiver perspective, because I think, and rightly so, most of the emphasis is on the person themselves, where it should be, but there is also collateral people involved in anybody’s life.

**Interviewer:** It’s a system.

**Interviewee:** It is a system, yeah, and to recognize them like, hey, the caregivers need help too, and they need to know what they don’t know, and all those kind of things is always good. So, I always feel like anybody that’s doing something that helps is a good thing.

**Interviewer:** Well, we couldn’t do it without you so we appreciate parents like you and you, yourself. As soon as the audio and video from this is done rendering, I will send you a thank you email and that will include a big gift card as a compensation for your time and effort.

**Interviewee:** Thank you.

**Interviewer:** If you need anything else in the future, you know where to find me, feel free to call, text, email, whatever you need.

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

**Interviewer:** Awesome, have a lovely day.

**Interviewer:** Alright, bye bye.

**Interviewee:** Bye.

**[End of transcript]**