**[Start of transcript]**

**Interviewer:** We’re recording. And during the interview I will be asking you questions about your perspective about your child's transition to adulthood in relation to her sensory sensitivities. And I'll be doing something called a semi-structured interview, which means I have a set of planned questions, but I'll be adapting the questions to follow our conversation. Do you have any questions before I begin?

**Interviewee:** No, it sounds good.

**Interviewer:** Okay, great. And if there are any questions that you don't want to answer or make you uncomfortable, you don't have to answer them. It's totally okay.

**Interviewee:** Okay.

**Interviewer:** Okay, awesome. Could you please start off by telling me about your daughter’s sensory sensitivities and interests?

**Interviewee:** In terms of her sensory sensitivities is that she's…I may have noted in the questionnaire specifically her light sensitivity, but then I thought about it probably after, and now after I did the questionnaire…and she also sensitive to sound. For some reason she hates dad's whistling. Oh, I don't…I whistle to but I don't whistle as much as my husband does. So that just drives her up to the wall. And also vacuum cleaning, if she can hear probably a high pitch sound which she pointed out. And with…and I guess these are the two things I kind of come to my mind right now. So the light and the sound…oh and also, I remember there one question about her…I'm not sure if, you know, rein me and if I'm kind of going off track.

**Interviewer:** No, you're doing great.

**Interviewee:** The other thing is she hates absolutely…she will freak out on one tiny little spider. She is not…with insects…she’ll just…tiny little ant, she would be…she would just be hitting the roof. I'm not sure if that's part of sensory, but…and what's the question?

**Interviewer:** Yeah.

**Interviewee:** How is her transition to adult life?

**Interviewer:** I'll get over…get to that **[chuckles]**.

**Interviewee:** Oh that's a call, one moment.

**Interviewer:** No worries.

**[silence]**

**Interviewee:** Sorry, I left the door open. It’s so hot.

**Interviewer:** Oh no, no, no. I totally understand, I have no AC on right now so I can hear you and I'm toasty too **[laughing]**. So you talked about light sensitivity, what does that look like for her **[03:00]**? Like what type of light and how did she react?

**Interviewee:** It could be light at home, it could be light on her…on my phone and then she would turn it down, on my iPad that she would turn it down, or the television or you know, of course daylight. And if it’s on a very sunny day she will have a problem. And so early on we had…she wears glasses. So we had it so that she have these transitional lens, so whenever she goes out, it just automatically is much easier for her to manage than to have to put a clip on or whatever. It's a big issue when she drives, she drives now. She's 20 and I don't know how she does it, but during the day…I mean she drives now, not as much…I mean as I would say her peers, but I think she…probably in her own words she would just say, “*Well, I just have to deal with it.”* **[04:08 inaudible]**

**Interviewer:** Absolutely. And then how does she react when she is faced with the lights that she dislikes or the sounds that she dislikes?

**Interviewee:** I don't know if averse is the word but…or word that I'm thinking about, but she just basically…she just like, “*Oh, it's so bright!* *Why do you…why you know, how can you…”* and I'm like, “*I'm not bright.”* Yeah, it's not bright to me. And of course I have other issues right, I have the opposite where my eyes [*are]* aging and so, you know, so I need more light. And she would be like very, I don't know what's the word …ow to describe the word but she would just be so strongly opposed to it.

**Interviewer:** Yeah totally.

**Interviewee:** She does…as I mentioned earlier that she would just say go around and dim everything.

**Interviewer:** Yeah absolutely.

**Interviewee:** Turn out the lights or whatever.

**Interviewer:** Yeah.

**Interviewee:** *“Don't you need the lights?”* And she’ll say, *“No, I don't need the lights”, “What? It’s so dark in your room.”* and she's like, *“I'm fine mom.”* and then she'll be watching a video on her laptop or something and then it's…she's in her room, it’s dark and the screen is dark. So hmm, anyway.

**Interviewer:** Yeah. And so how else does she manage these sensitivities? So you talked about kind of just dealing with it when she drives. What about for sounds?

**Interviewee:** She's plugged in, not all the time, but you know, that if she's playing a game, watching a game, she's watching a movie or something, then she will have a headset and she has ear buds and stuff like that **[06:00]**. So she’ll deal with that and she controls in that way. But I think…I remember one time we were cooking in our church and we were cooking for a hundred people. And we weren't using the pots and pans that we have at home, of course, that was too small. So then we have a metal…a huge metal pot to stir-fry some vegetable and we have a metal spoon. And I realized that you know when I stir-fry I scrape the bottom of the pot and then she was…she was helping me, and she was standing next to me and she’s just like…it's almost like nails scratching on the blackboard, that kind of sound it.

**Interviewer:** Mm-hmm.

**Interviewee:** That's her reaction was like she was just…she was there because she wanted to help – and she's a very good cook also…and it’s something that we both enjoy doing together, but I didn't realize that, that you know, I don't make that kind of sound when we cook but it didn't *stop* her because she wanted to do it. She really wanted to do it, but then I saw her physical reaction. She was kind of like **[sigh]**, and then I know she was dealing with it. And then there were other people talking in the background and she couldn't hear my instructions. So it was the noise right there.

**Interviewer:** Yeah.

**Interviewee:** I guess she does deal with it in that sense, even though she has a sort of a physical response to it.

**Interviewer:** And before you…oh, sorry.

**Interviewee:** Yeah I meant…I was going to say that she didn't put the…she didn’t put her hands on her ears because she couldn't, because she's wearing mittens or whatever, the pot was very hot. And she used to do that when she was young.

**Interviewer:** She used to cover her ears?

**Interviewee:** Oh, yeah. Oh, yeah. Yeah.

**Interviewer:** But not anymore?

**Interviewee:** No, no. I think that she takes advantage of the headset, whether it's plugged in or not, maybe that helped to filter the sound. But she doesn't do that in public, unless she's listening to...she doesn't plug in just for the sake of plug-in so that she can avoid social interaction. One of my daughters does, but she does it only because she needs it, she's listening to music or something.

**Interviewer:** Okay, so she doesn't wear headphones unless she's like doing it for a different purpose.

**Interviewee:** Yeah. Yeah.

**Interviewer:** Got you.

**Interviewee:** But I wonder though, I do wonder if she's like, *“Oh, I'm listening to music but I want to filter other sounds.”* you know.

**Interviewer:** Absolutely. And then has she received any particular therapies or interventions to help her manage or overcome the sensitivities?

**Interviewee:** No, no.

**Interviewer:** No? Got you. And then how have these changed over time? How have her sensitivities changed over time? If at all.

**Interviewee:** **[08:59]** If at all, I would say it's a little bit more.

**Interviewer:** Yeah, how so?

**Interviewee:** She complains more. No, she complains more about it and…but I would say just slightly.

**Interviewer:** And are her reactions different?

**Interviewee:** Besides not covering her ears with her hands, she hasn't done that. But I think vacuuming now, she puts on the headset. I guess she is kind of managing herself.

**Interviewer:** Yeah, absolutely. And then these changes that you're talking about or the slight changes at least, do you think they're related at all to any independence that she's gained over time?

**Interviewee:** What do you mean by that?

**Interviewer:** So we're trying to connect independence and change, and sensory sensitivities. And some parents are reporting that their kids have…as they’ve gotten older and achieved some more independence, their gaining more communication skills or they're gaining advocacy skills and that's helping them manage their sensory sensitivities over time because of the skills they've gained. So may not be the case for your family at all and that's okay.

**Interviewee:** I don't think so for Melody because it's not like she'll wear…at least this is how I understood your question. At least she's not wearing that in say, to go…she just went to her friend's house and it was I don't know, probably six or eight people. That's a pretty good size for her. I don't think that she would have worn her headset just to filter the sound. Or she would definitely wear…if it's outdoor, she would definitely...well, her lenses are transition so there you go, she got her protection. So, in that sense, I don't think they have made any changes in that. But having said that, because I might have alluded too early at that, maybe if she goes to a mall or something and then it’s just really noisy or…she might put on her head set without turning it on. I don't know because I never asked her. It’s not that loud, if she turns on the music that I can hear, that would be pretty loud **[chuckles]**. She hasn't done that as far as, yeah, wearing it to a party that I…say a family party or something that I would have…be there as well. So in that sense. And…she's not…oh, I warned her about wearing her ear-buds while she's driving because then it sort of diminishes her response time to…

**Interviewer:** Totally.

**Interviewee:** Yeah, the entire driving **[12:00]** experience.

**Interviewer:** And how is driving for her? Because I mean sometimes cars are noisy or something or there's a lot of auditory stimulus when you drive.

**Interviewee:** She unfortunately, in her own words, that she drives an old car which does not have a good sound buffering and all that. So she would say it's noisy but after a while, you know, it becomes a white noise. I mean if she wants to go from A to B, right? So…and definitely I think she would turn on her own music to make it worthwhile, I guess.

**Interviewer:** Yeah, totally. And then do her sensitivities cause or increase anxiety?

**Interviewee:** I think it does, but I couldn't think of…because she keeps everything…she just…she keeps everything sort of very together. She didn't…I mean she does freak out, I mean she does, she will say I'm just…this is then she would tell me and that's a good thing. But sometimes she would just hold it to a point where she just couldn't do it anymore, then I will see. So I believe it does bother her, they do bother her, but I don't see it right away. It's not like a total reaction, you know, where she’s just like, *“Oh!”* **[screams]** she'll just go…or when she was young, she’d just cover her ears, with hands and things like that.

**Interviewer:** Yeah. This might be a little bit hard to answer given what you just said, but do you think she manages that anxiety?

**Interviewee:** I think…I'm not sure if it's a management. I think she basically copes, that…sleep, I had to ask her before, she sleeps a lot. Well, I mean she's not working, right? So…but she does take care of her cat and she does help me with the housework, or sometimes cook. And so…but majority of, minus those times I listed, she will sleep if she's very overwhelmed or she would watch maybe a video, I believe. I think sleep was primarily something that will relax her.

**Interviewer:** Got you.

**Interviewee:** The second thing is probably she sketches, you know **[15:00]**.

**Interviewer:** Got you. Do you think the anxiety has changed over time at all?

**Interviewee:** No, I think they have been there. They just have been there, and now she's in college, you know, her schedule looks very different than high school, right? High school is very structured and everything. And so I didn't see it until COVID hit and then she has to finish her spring semester home back in March. So I see a lot of that sleeping too. Well, I mean she doesn’t have to go anywhere right, she just has…she just gets online and attends the lecture and whatnot.

**Interviewer:** Yeah.

**Interviewee:** So yeah.

**Interviewer:** Was she at school previously?

**Interviewee:** Yeah. She was on campus. She was a living on campus, yeah.

**Interviewer:** Got you. Got you, that makes sense. And then what are your goals and hopes for her, in terms of her sensory sensitivities?

**Interviewer:** I think self-awareness is a big thing. I heard of this word years and years ago, and I didn't really realize it myself what it means. And I think that not only about her sensory but I think her response to things in life, in general. So be it a vacuum cleaner, be it a noisy car, be it somebody talking really loud and things like that. I think if she's aware what triggers what…what is the word? I don't know what's the word.

**Interviewer:** Triggers, elicits?

**Interviewee:** Yeah, whatever makes her tick, right? Then I think that's a step of…that's a big step of recovery*...*

**Interviewer:** Totally.

**Interviewee:** …or you know working with that issue. So that's I think my over-arching desire for her, is to really know herself. And then I think she can, not just manage but then she will be saying, *“okay, I'm anxious and it's okay. It’s right now when I'm angry, and it's not like this forever.”* or over every little thing. Because we all have it.

**Interviewer:** Totally. Awesome, thank you. Now shifting gears slightly to our next chunk of questions. As she's grown up an aged, how has her and your community reacted to her sensory sensitivities?

**Interviewee:** I don't know about her friends, her school friends. Whether it's high school or college friends, or whether **[18:00]** she even let…give them any, what's the word? Hint or ideas that she actually struggles with noise or lights? I mean, around the people that…family friends or something like that, you know, people would take note and say, “*oh whoa! Your glasses are dark,”* and you know*,* and whatever. And she goes on and just say, “*well, she's sensitive to lights*,” in that sense. They don't…I’m sure if they…I don't think that they make fun of her per se but I think I remember one of my friends…family friends’ daughter said…they grew up together and then she said, *“oh! Melody is so cool, her glasses.”,* and then, they would joke about it. But they are pretty…what do you call it? Like not malicious.

**Interviewer:** Yeah, kind-hearted commenting maybe?

**Interviewee:** Yeah, it was just kind of like they're just joking, she's not maliciously…she’s not, yeah.

**Interviewer:** Absolutely. And then, was the community more or less accepting and accommodating when she was younger?

**Interviewee:** I don't think so. When she was in the school system, she had a *really* hard time…oh, yeah, she's also sensitive to…I may have said that in the in the questionnaire. She's also sensitive to texture clothing.

**Interviewer:** Yeah? What type of texture?

**Interviewee:** She refused to actually wear anything but fleece in the winter time. Now, it's not in the background, but we…all my children were born in a tropical country. And then we came back about 12 years ago. So Melody was around seven, eight, now she’s twenty. And we came back in April, end of April, we were wearing winter coat.

**Interviewer:** Yeah, it was cold. It's cold here in April sometimes.

**Interviewee:** Well, it was not a cold day by Boston **[20:26 inaudible]** standard and it…but it was very cool and she would just refused to wear a jacket because it was just so stiff and heavy and rough. And until my sister had some old clothes for her daughter, they were completely fleece and I was like, “*thank God for someone who…amen to that.”* So, when she was younger and I think even now she has a choice of choosing what kind of clothes she wants to wear, I don't think that she would choose linen, you know. Yeah, things like that.

**Interviewer:** So its **[21:03 crosstalk].**

**Interviewee:** Not necessarily scratchy but…or wool in the wintertime, she's not going to choose those.

**Interviewer:** So, is it kind of the restrictive fabrics that that’s she dislikes?

**Interviewee:** Scratchy, yeah.

**Interviewer:** Got you. And what about now, is she able to wear a coat if you need to or will she find the right type of coat that fits her needs?

**Interviewee:** Yeah, she will wear coats. I mean, of course we have acclimated to the leather and also she goes to school in Western Massachusetts, so it's much colder there.

**Interviewer:** It is **[chuckles]**.

**Interviewee:** She's really, really a New Englander now.

**Interviewer:** Yes. She's able to...yeah, she will wear acoat and she’s able to find something that is suitable for her.

**Interviewer:** Are there any texture that she particularly likes for clothes?

**Interviewee:** I'm trying to think what coat does she have? She actually would wear some wool that is very soft. Soft wool as a jacket, of course living in New England we have to wear it waterproof **[laughing]**.

**Interviewer:** Yes, we do.

**Interviewee:** Yeah. I don't know what other material there are that she…I couldn't think of any off the top of my head.

**Interviewer:** No, that's okay, thank you. So, going back to our other question about her when she was younger, was the community more accepting of her and accommodating?

**Interviewee:** No, because…yes, that’s along the line I was thinking why I brought up about the clothing. Because she refused to wear jeans, right because it was rough, unless it's been worn, I guess. Or she doesn't wear it, often enough it’s not going to be worn. So then she would just be going around wearing, you know, fleece, right? When you're in elementary school it’s okay, I think in middle school is not so cool. I don't think she was wearing that much fleece in middle school per se, but because she's so different that…and also we didn't know that she has autism, so she was just having a hard time and…oh, yeah by then she was already wearing glasses with transition lens and that's kind of different, you know for kids in elementary school.

**Interviewer:** For sure.

**Interviewee:** So I don't think that the community was very kind to her really, and for those reasons…aside from her diagnosis which we didn't know at the time, she was actually bullied. So I think all the kids in the bus…yes the noise, I didn't…I wasn't aware of it **[24:00].** And she didn't know how to cope with that, I don't think that she was treated very well. And she wasn't one of those kids who would just like, would just, *“Hey, let's hang out. Let's wander in our neighbourhood.”* which is very safe. And because she's not like that, so she was actually kind of yeah, bullied.

**Interviewer:** I'm sorry to hear that, thank you for sharing that. So you just talked about school versus family, friends, but which aspects of the community or which spaces and places were more or less accommodating of her?

**Interviewee:** I would say that people outside of the school district here.

**Interviewer:** Were more accommodating?

**Interviewee:** Yes.

**Interviewer:** Got you. And you talked about your church. What about your religious group?

**Interviewee:** That's a religious group.

**Interviewer:** No, no, I'm sorry. Were they accepting of her?

**Interviewee:** Oh, yeah. Uh-huh, yeah.

**Interviewer:** And then what are your worries or hopes or goals for her in terms of how the community will react in the future?

**Interviewee:** My worries are that she's not able to advocate for herself and say, *“hey, this is really loud”* oi…Iwonder how this is going to play out, because she has an off-campus housing that she's going to be moving in in a couple of weeks, and I don't think the girls are necessarily noisy or party type of girls, but you just don't know. I mean if they have a bunch of friends come over they might be noisy, right?

**Interviewer:** Totally.

**Interviewee:** So, we don't know how that's going to be, I mean me, I don't think knows either. And one of the things that I have been talking to her about is really how to…it's not mean to say what you need, but to be able to say your needs, yeah. That would be my concern, my primary concern. And back to the self-awareness, it’s like not sure of herself, not sure of what she thinks and what she feels. And what is appropriate and what is not appropriate. Does she feel like, “Oh is it too mean to tell…because she's sharing a room with one of the girls, and she's like…is it*…“I really don't want her to move my furniture.”* because she’s already…we already moved some furniture in the room already and then her roommate is from out of state and then she's going to be moving in a few days before she’s actually going to move the rest of the stuff in, plus her cat…yeah, which makes…things could be a little bit complicated but they already know he's coming. And so…and she's like, *“well,* *I think it's going to be mean for* ***[27:00]*** *me to tell her not to move your furniture”* and I'm like*, “no it's not. There are a number of considerations why you already put your bed that way, it's not that she had less space.”* She was…I said, *“no.”* I said *“being assertive is not being mean.”* So those are the things that I worry about. Of course, like I said, you know, my goals and my dreams are…she's really a lovely person in that she doesn’t…she's really a lovely girl and that if people would know beyond all her, she doesn't like noise, she doesn't like bright lights and that kind of stuff then I think she's pretty cool.

**Interviewer:** Yeah **[laughing]**

**Interviewee:** Yeah.

**Interviewer:** I'm sure she is. And now kind of shifting gears. In the transition to adulthood, where do you see her?

**Interviewee:** I'm not sure, because…I actually have some apprehension because of all the things I mentioned, not being able to be…sort of advocate for herself, and not really being aware of herself, what she needs. But also, she changed her major and she's going to be a junior and into a field that is…we're not even sure if she can get a job.

**Interviewer:** Sure. If I may ask, what did she change her major to?

**Interviewee:** She started off with Animal Science. And as I mentioned that she's…sketching is one of the things that she loves to do, and she wants to change it. She actually did change it to illustration, scientific illustration. So, I don't know aside from major, major publisher, who's going to employ someone full time to do illustration…scientific illustration Yeah, so yeah. And whether this is something that she will enjoy doing because she's done it as a hobby, and is it something that she would want to do for the rest of her life? Because then the joy will not be there anymore and there’ll be a lot of pressure. So, in that sense, I'm very apprehensive, yeah.

**Interviewer:** Absolutely. And then thinking about her independence, in what stage of independence is she? So you talked about how she used to live on her own in the dorm and she's going to move off campus, things kind of like that.

**Interviewee:** I'm actually not worried because she can cook, she can drive.

**Interviewer:** Yeah, that's great **[chuckles]**.

**Interviewee:** And she **[30:00]** lives in a very convenient location where she doesn't have to drive no more than 5 minutes. She can even walk to a supermarket if she wants to. And just how to live with people, I am concerned about…I think she tends to be more accommodating on her own expense…

**Interviewer:** Got you.

**Interviewee:** …than…I think she’d want to make it work where everybody would be, *“yes, this is our apartment, it's not so and so apartment.”*

**Interviewer:** Mm-hmm.

**Interviewee:** Who supplied a lot of brand-new stuff in the house, in the apartment, which is I think is a little bit excessive but they can afford it. But it’s just kind of like, then she almost has most of the ownership, almost. It’s that part I am concerned about, I have been working with her on that but as far as like being able to live on her own she can take care of the cat. She loves the cat very much. She takes…she's very responsible for him. Yeah, my concern is really that she would be too accommodating on to the fault.

**Interviewer:** Yeah like not to stand up for herself.

**Interviewee:** Yeah, yeah, and then she would end up not being happy. And then I say, “*well what's the point of living off-campus, right?”* *“To save money.”* *“Okay well, but by saving money and then you are not able to have the space that you need to study…”* which they’re going to spend a lot of time in the apartment because most of the classes she's taking is online.

**Interviewer:** Yeah, absolutely. And is she able to manage money to a degree?

**Interviewee:** I think she can. I think she can. And of course, she…I mean she actually got into a very interesting study that paid her really well.

**Interviewer:** Yeah **[laughing]**.

**Interviewee:** So that kind of took care of one year of her expense.

**Interviewer:** Wow.

**Interviewee:** Yeah, yeah.

**Interviewer:** It must have been a big study.

**Interviewee:** It was, it's like a two year study and…but I think that, yeah, I don't think that she would just go and spend, buying everything off Amazon, something like that.

**Interviewer:** Absolutely.

**Interviewee:** I think she'll be okay, yeah.

**Interviewer:** Has she had a job before? I know you said she doesn't have one now.

**Interviewee:** Yes. She had a job, she had jobs before.

**Interviewer:** Yeah, and then she would spend…because she's in the fencing club, so sometimes she has to buy equipment or certain apparel and then she would just pay it off herself.

**Interviewee:** That’s awesome!

**Interviewer:** Yeah, as much as possible, she wants to pay the expenses for her cat but she did adopt him on our own expenses. So, **[33:00]** but cat stuff is very expensive. So we’re like, *“yeah I know, we love him too, so.”* Yeah, I mean he's a blessing to us, while he's living in the house. So, he’s such a joy.

**Interviewer:** *Yeah*, it’s good to have the love right now.

**Interviewee:** **[laughing]** Yes, cat time is good for me.

**Interviewer:** Absolutely, absolutely.

**Interviewee:** I think he's going to need therapy after this but.

**Interviewer:** The cat? **[laughing]**

**Interviewee:** Yeah. Because so much…he doesn't have his space. We’re always like, *“Where is he? Where is he?”*

**Interviewer:** Yeah **[laughing].** It's going be happy when you all leave and have some like cat time to roam around the house. Is she able to manage her own social life?

**Interviewee:** I think so. But also, I feel that she might have some time management issue, where she cannot say no.

**Interviewer:** Yeah, where’s she's like, *“oh, yeah, I think I should be there.”* when she doesn't want to be there or she's anxious because she has all these things, she thinks that they lined up and then she might not have enough time to do, and that kind of thing. And I said, *“well, if you feel bad of doing it just say no. I mean you know, what do you have to lose?”* And then right…I guess she thinks that she has a lot to lose.

**Interviewer:** Absolutely. And then is she able to take care of herself physically day-to-day?

**Interviewee:** Oh, yeah, yeah. She…personal hygiene, she's good. She even cleaned my kitchen and…you know that kind of stuff.

**Interviewer:** That’s nice.

**Interviewee:** So yeah, she will shower, she would, yeah, she would do her laundry as long as she does mine. I mean, hey.

**Interviewer:** That’s nice.

**Interviewee:** Yeah **[chuckles]**. So I mean, yeah.

**Interviewer:** Awesome. And then, do you think she'll be able to achieve more independence in the future?

**Interviewee:** I think she can, it’s just that I'm concerned about her occupation. I’m concerned about her occupation and how much pressure she can take and how she can manage her anxiety, right?

**Interviewer:** By pressure do you mean you're worried about…can you talk a bit more about that?

**Interviewee:** Work load. Even now, like if she has an assignment, she hates to write and that's pretty difficult for her. She gets anxious and she doesn't get feedback from a TA or professor. She doesn't get email report. *“What should I do? What should I do if I don't hear back from the apartment office.”* right? She doesn't have the thought to go into the building and I said, *“well have you contacted them?”* that kind of thing. Those are the things that I'm concerned about. If she knows what she has to do, she would do it, but it's the things that she doesn't know that she has to do, or how she can do it, that's the thing I worry about [**36:00].**

**Interviewer:** Got you. And what do you think will help move her into adulthood a little bit more?

**Interviewee:** I think if she would have a life coach or a work coach, job coach. I think that will help her. So far she has allowed me to speak into her life, in other words, she’ll ask me and she will take my advice. And yeah…and if she doesn't like it, she would tell me to back off and I'm like, *“yeah sure, I'll back off.”* and it's fine. And we have we have a good understanding, we have a good relationship in the sense that I know that you know, I back off, it’s not like…so we're very secure in that sense. It’s just that, yeah. She actually talked about getting medication for her anxiety.

**Interviewer:** Mm-hmm.

**Interviewee:** Yeah.

**Interviewer:** Do you think that will…sorry.

**Interviewee:** I think it will, but I think it will temporarily like, when the chemical is in effect and all that but I don't think it's a long-term solution.

**Interviewer:** Mm-hmm, absolutely.

**Interviewee:** Where you have to depend on medication to sort of calm yourself. I think it's…that could be one of the plan, part of the plan, but I don't think that should be *the* solution.

**Interviewer:** Totally.

**Interviewee:** Yeah. I mentioned that to her and yeah. Because I mean it's not just about…I think you know, it's not just about dealing with the apartment or it's just your roommate or school work, because then there will be other stuff that she has to deal with, right?

**Interviewer:** Yeah.

**Interviewee:** And, it may be in a relationship, I mean I know that she wants to have a boyfriend eventually, and then what? It's not going to…always feel that rely on medication. It's not, yeah.

**Interviewer:** Mm-hmm, no, absolutely. Do you think there any particular services our interventions that might help?

**Interviewee:** I…it has worked for her sister. I have…there's a program…there is a program called LifeMAP by A…from AANE. Is it called LifeMAP coach or something? I always call it life coach. Yeah, yeah, I think that might help her.

**Interviewer:** And now putting these two things together, sensory sensitivities and transition to adulthood. How do they intersect for your daughter? **[39:00]**

**Interviewee:** Well, if she ever owns ahouse, she needs to be able to mow the lawn. If she can't go outside because it's too hot, it’s too bright, it’s too loud, then she can't live in the house that requires that kind of outdoor work. I guess it won't a driving a truck, although she talked about she would love to ride on a motorbike.

**Interviewer:** It's noisy **[chuckles].**

**Interviewee:** A big one, like a Harley-Davidson which my…there’s someone in the family whohas one. So that's pretty loud too, I think. I can't think of anything right now.

**Interviewer:** No, that's okay. I've got other prompted questions, so maybe that will spark some thoughts. And if not, this is…that's perfectly excellent answer as well. Do you think her sensitivities are an obstacle a vehicle or bit of both towards her independence?

**Interviewee:** I think it's an obstacle.

**Interviewer:** How so?

**Interviewee:** Because it keeps her from doing things, it keeps her from…there's always that fear or anxiety or the feeling of that scratchy fabric or the feeling of…it's almost like you're traumatized, right?

**Interviewer:** Yeah.

**Interviewee:** PTSD or something, right?

**Interviewer:** Absolutely.

**Interviewee:** And yeah.

**Interviewer:** And then what do you anticipate as being challenging for her as she does gain more independence in relation to these sensory sensitivities.

**Interviewee:** I missed the first few words.

**Interviewer:** Yeah.

**Interviewee:** Can you repeat the question?

**Interviewer:** Absolutely. What do you anticipate as being challenging for her as she gains more independence in relation to her sensory sensitivities?

**Interviewee:** I'm not sure **[laughing]**.

**Interviewer:** Perfect, great answer **[laughing].** That's totally fine, totally fine. And what do you think might help her in this intersection of sensory sensitivities and transitioning to adulthood?

**Interviewee:** Not sure if I understand the question.

**Interviewer:** So like you talked about how mowing a lawn might be hard for her if she owned a house because of the bright lights and perhaps the noise, and that would make it hard for her to be a homeowner. So what do you think might help her overcome something like that?

**Interviewee:** To have the proper tools. I mean like there's such a thing as what, noise cancellation for mowing the lawn and doing this kind of machine, having machinery noise **[42:00]**. And you know, along with the physical tool or mechanical tools or whatever you call them, the…I think that other tools that she can have is like strategies, to have I don't know what they are, I don't know what could be. But again I think that if she can have a mind set to say, *“yes, I have anxiety because of this.”* And there's…*“number one there's nothing wrong with me.”*

**Interviewer:** Totally.

**Interviewee:** *“And number two, there is a way or there are ways for me to overcome them, or to cope with them or to manage them”,* right? In ways that I can still enjoy my friends or necessarily that she…if she ever want to go to a bar, that she’d know how noisy it is and to enjoy the things that she wants to do.

**Interviewer:** Yeah, absolutely.

**Interviewee:** Or even own a bike, right?

**Interviewer:** Yeah or a lawn mower.

**Interviewee:** Yeah **[laughing]**.

**Interviewer:** Do you think there are particular services or interventions that would help give her those tools?

**Interviewee:** I think at this point in her life yeah, the job coach and the life coach, I think it's…it’d be really good. I think the other thing is, Oh I forgot to mention it, I think *therapy*. I think that's a therapist or counsellor would be good for her.

**Interviewer:** Mm-hmm.

**Interviewee:** Yeah.

**Interviewer:** Absolutely. And then thinking about her and kids or young adults like her, do you think there are gaps in the available services and interventions for them?

**Interviewee:** Her age group you mean, the teens, late teens and the 20s?

**Interviewer:** Yeah.

**Interviewee:** Yes! Absolutely.

**Interviewer:** Yeah go ahead.

**Interviewee:** No, no. You keep on going. I feel like...well, you know, well autism…the diagnosis of autism has been around and it is good that we have, oh, I forgot there are two, remediation and is it intervention? Intervention is when you start young, right? And so there's a lot of intervention programs for children and then they see very good outcome. But what about those…well my kids belong into this group where they don't…they never had intervention and so it's remediation for them. Melody, she was diagnosed when she was in high school **[45:00]**, I think or the summer before high school, so she was 14. And what saved her life is that she went to an agriculture high school, which she has to go through…she has to take two tests and she has to go through an interview. So it's a big step for a 14 year old. But she did that because of the kids who bully her in the school district, she didn't want to go to school with them in high school. And she's the youngest so she knows what it's like and I know what it's like because I have two older sons who’ve gone through that school, and I've seen the kids, and they live in our neighbourhood. **[45:45 chuckles]** Anyway, so I think that the gap…and I forgot your question really.

**Interviewer:** No you answered it or you were answering it. The question was do you think there are gaps for kids like your daughter?

**Interviewee:** Yes, and I think that they don't understand what they're facing right now, because everything is changing, it's not just COVID, for them that they have to face right now. And it's almost like a world that the therapist or professional never tread, and they don't really understand how intelligent these kids are. And yet they are physically growing up chronic logically, they are growing up. But they're not catching up. The IQs might be okay, but the things are not mashing together, and because of that, the obstacles…nobody's helping them to remove those obstacles that they…with all those obstacles, they are just, they are on par with no problem. But, yeah.

**Interviewer:** Awesome, thank you. That was great. That was a really lovely answer. And then, how have your daughter’s sensitivities impacted your goals, hopes and expectations for her as she does navigate adulthood? I can repeat the question, it's kind of a mouthful.

**Interviewee:** Yeah.

**Interviewer:** Yeah **[laughing].**

**Interviewee:** Please.

**Interviewer:** How has your daughter’s sensory sensitivities impacted your goals, hopes and expectations for her, as she navigates adulthood? Kind of like, how do her sensory sensitivities impact how you view her as an adult or in becoming an adult?

**Interviewee:** Well, I suppose that she's not the only one who has…okay…it’s just…diagnosis **[48:00]** or no diagnosis, alright? Whether it's ABC, whatever CDF whatever, I call them ABCs but it's a joke in this house. So, because it doesn't matter what it's called, it doesn't matter whether there's a diagnosis. To have a sensory sensitivity just such as light, sound or texture or…I don't think it's specifically related to an autism diagnosis or any diagnosis for that matter. I think anybody could have it.

**Interviewer:** Absolutely.

**Interviewee:** So it's how she views it and how…yeah, it's really her mind set. If she thinks that, *“oh, that's going to stop me from riding my bike, it’s going to stop me from driving a car.”* That's a big deal. It hasn't stopped, only except we don't have a bike. She would love to have a bike, right? So it's not stopping her. It's not like she's not going out, she's not going to go picnic with us, or with her friends, that kind of stuff. Or she's not going to go…or she's like…she definitely won't enjoy…it was a wedding years ago. She was younger and I think she was in elementary school. She was…she didn't enjoy it because it was loud music and all that stuff, but she has a place to kind of go outside and just chill and talk, and besides having to dance or whatever. So I think that it's not uncommon, but I think it's just how when she realized, *“oh, yeah, I have this and I have other ways to handle that and there are other options there…I'm not weird.”* So as long as she knows that, then it's fine.

**Interviewer:** Yeah, absolutely. And then moving into our final chunk of questions, we’re almost there. As a caregiver, as a parent, as a mom of someone who has ASD and also some sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee:** It means to me a lot of worries **[chuckles]**.

**Interviewer:** Yeah, fair, absolutely fair.

**Interviewee:** It means to me that, I'm not sure if I should have any dreams, which is kind of scary. It's almost like, *“oh, I want her to be like so and so.”* I think I sort of gave up. I don't know if I gave up but I mean to say, *“well this may not be her.”* So, I studied computer science. So it's not…I already said, okay, she never liked math, right? So I'm like, I'm not going to make her like math, I'm not going to ever make her like computer science study and to have the degree. I'm not ever going to make her. But she needs to be able to use a computer, right? She needs to be able to do basic math so that she won't get cheated, right? And to say math is your friend because when you cook it's going to make a difference **[laughing],** a quarter teaspoon of baking powder and so on so forth.

**Interviewer:** ***[51:35]*** It's a big difference **[chuckles]**.

**Interviewee:** If you make instead of a quarter teaspoon, you made a quarter tablespoon, it's going to make a big difference, so those kinds of things. That's what I mean by not to dream, I guess my dream for her to give that up. But to be able to see that whether it's sensory, weather it’s her anxiety from the sensory sensitivity, or any other fears that she has, that she would be able to overcome them, but.

**Interviewer:** Mm-hmm, absolutely.

**Interviewee:** And also what it means to me is that, how do I say? That she's not going to launch as early as say her peers, because of her ASD, and that is okay, even though it pains me to see that.

**Interviewer:** Pains you how?

**Interviewee:** Well that she's not, she's…it's not like she's oblivious because she's not. She's not one of those, *“well, I don't care what other people say.”* she does. She has it…so I have two children who have ASD. So the other one she's like, *“I don't care,”* but Melody is different. She's almost like she doesn't have ASD. If you don't look at her profile, her profile is very different and…and I forgot what I was going to say.

**Interviewer:** You said she’s…you were talking about how she might launch a little bit later than her peers.

**Interviewee:** And it pains me…is that she will realize that, *“oh, I'm not doing the same thing as my buddy.”*

**Interviewer:** Got you.

**Interviewee:** And…or her cousin or whatever.

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

**Interviewee:** My perspective?

**Interviewer:** Mm-hmm, about what it means to transition to adulthood.

**Interviewee:** For her?

**Interviewer:** For her, Mm-hmm.

**Interviewee:** I don't think so. I don't think so, because her oldest sister has ASD. So she's still at home, she's 26 and as every year goes by it pains me. Again her profile is a little bit different. I feel like she's a little bit more severe, I mean relatively speaking, but.

**Interviewer:** Sure.

**Interviewee:** But then again, I also see challenges that Melody has. She holds everything in, which concerns me, it concerns me. I mean if you see it then…if I see it then it's like oh it's easier to handle. But if she just sort of tries to camouflage it and I see that with girls, because she has…she definitely hasfriends that have ASD. Whether or not they're diagnosed or their parents acknowledge it and so there, I don't know what's the word but the presentation is different than guys and then everybody's different, everyone who has Asperger is different.

**Interviewer:** **[55:19]** Absolutely. And then what do you see specifically happening in your child's future?

**Interviewee:** Besides that she will launch much later?

**Interviewer:** Like job, live by herself, have a partner, things like that.

**Interviewee:** Yeah, I see that, but I see that as it will happen much later than her peers. Because I don't see her as mature as her peers, although she...I’m thankful that she has great friends. She has great friends, which my eldest don't have. I think she will make a fine Mom.

**Interviewer:** Yeah.

**Interviewee:** I think she will.

**Interviewer:** That's great, that's really great. So I have one final question for you. How did her sensory sensitivities impact this current perspective that you have? If at all **[56:37 crosstalk]**

**Interviewee:** In her living on her own and stuff? Like independence?

**Interviewer:** Yeah, in terms of what is it means to transition to adulthood? What…how….what role did her sensory sensitivities play in the perspective that you've been describing?

**Interviewee:** Whether they would be an obstacle, whether they are an obstacle?

**Interviewer:** So you talked about how transition to adulthood means uncertainty, it means a little bit **[57:00]** of more a delayed trajectory. it means worries for you. How much of her sensory sensitivities are a cause for that perspective?

**Interviewee:** How much, how do I measure it?

**Interviewer:** Great question. I mean sometimes they **[57:23 crosstalk]**

**Interviewee:** Like one up to five or something.

**Interviewer:** Sure, you can give me a number **[laughing].** Qualitative might be a little easier, but I'll take a number too.

**Interviewee:** How much.

**Interviewer:** Or did they?

**Interviewee:** I think she's a package.

**Interviewer:** Yeah.

**Interviewee:** I think she's a package, along with not knowing who she is, from the ASD diagnosis. I would say yes, it will have an impact, how much? I wouldn't say it's...five is high. I would say a two.

**Interviewer:** Absolutely.

**Interviewee:** I would say somewhere, like I said, she's a package.

**Interviewer:** Yeah.

**Interviewee:** So how do I foresee it can impact her? I'm not sure.

**Interviewer:** And that is okay. So it’s actually all we have for the formal questions. Thank you so much. Would you like to add anything else?

**Interviewee:** I'm not…I don't think so **[58:28 crosstalk]**

**Interviewer:** No, that's totally fine. No, it's totally fine. It’s worth an ask at the end. No, but this is it, thank you. It's been really wonderful to hear what you have to say and to learn from you.

**Interviewee:** It’s actually very interesting the questions you asked because I actually like never thought about that. Although yeah, I do worry, but I just never link the two together, this aspect of her life together.

**Interviewer:** Well, it's interesting because there's a lot…there's a good amount of research about parent perspectives, but none of it's about sensory sensitivities. But there's also all this research about sensory sensitivity, so it's been really interesting to talk to parents and hear about it, because I haven't been able to learn about it in other ways, so.

**Interviewee:** Right. So, what are some of the things that was interesting that you have heard so far? I don't know if you can share, but.

**[End of transcript].**