**[Start of transcript]**

**Interviewer:** Okay, we are recording and I will be asking you questions. I am asking questions about your perspective regarding your daughters’ transition to adulthood in relation to her sensory sensitivities.

**Interviewee:** Okay.

**Interviewer:** And this will be a semi-structured interview, which means I have my planned questions but I’ll be adapting them to follow our conversation so it actually fits for us. Any questions?

**Interviewee:** No, questions.

**Interviewer:** Okay, if there are any questions that you don’t want to answer that’s okay, don’t feel pressured and if you think of something later, go for it, it doesn’t have to be a linear conversation.

**Interviewee:** Okay, thank you.

**Interviewer:** Ready?

**Interviewee:** Yep.

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

**Interviewee:** Okay, so it’s evolved. She is 18 but…I’m so sorry, they’re calling, give me one minute.

**Interviewer:** I’m going to pause the recording.

**Interviewee:** …her sensory and I’m going to try to explain it and do the best I can. She had serious sensory issues before she was diagnosed with Celiac Disease and she didn’t have a good sense of space, she ran around in our backyard, she was like only two and a half. She has a twin brother so she was doing things differently then Bryce, it was very different. I always looked at, she’s just independently different. Anyways, and then they did a lot of sensory, she liked to jump, she liked to sit for doing her speech at that time, because she was early intervention. It wasn’t so much she didn’t like people touching her, she just needed…like a trampoline was helpful in those days, we had a little trampoline. She always had OT, she had OT a lot at the beginning but nevertheless, her coordination is really good, her hand eye coordination is phenomenal. She can be crying and upset and throw a basketball right in or kick a ball into a net or twirl around in circles and then kick the ball right into the soccer net. From being upset. She’s very coordinated, it’s too bad. I think she has some good athletic tendencies that she’s not going to peruse. At any right, but that’s okay, that’s no big deal. My point is, as she got more OT and as she had speech, she’s had speech seven days a week for…through high school, K through 11th grade and then in 11th grade they start changing it to less speech, less OT and I have to say, she didn’t need the same kind of sensory input she needed when she was in K through five and in middle school **[0:3:00]** it started decreasing in terms of what she needed for the sensory and the OT turned into more functional issues like writing, she writing was pretty sloppy. But she now has OT really only once or twice a week. Never the less, when she does have behaviours, the sensory room, they have sensory rooms in programs, in her private school, she goes to a beanbag, she sits in the sensory room and she decompresses and it really helps her a lot. It also helps and I don’t do this right but there are people who know how to squeeze hands in a way that she likes, it helps her when she’s upset, otherwise she doesn’t need it. It’s probably high anxiety. As long as Kayla knows exactly what’s going to happen and when it’s going to happen, she’s in charge of the schedule at school, she puts up the calendar everyday, she plans for the month, she likes to know everyday of her life. She’s asking me questions for May, what will her life will look like. Normally we go to Florida to visit her grandparents every December but because she won’t…she has an issue with wearing the mask all the time, she can wear it for periods but it’s very hard for her to wear it continually so she can’t go on plan right now. Whenever we go to the airport, I always try…she can’t go through TSA fast because I haven’t taken to her…to get the TSA pre-check you have to go to Newark and I don’t think that’s a good waiting place, waiting is also a big issue for her. She doesn’t know what it looks like and what it’s going to feel like and what’s going to happen, her anxiety goes sky high., she doesn’t tolerate a situation. I would say her anxiety is very tied, gets quickly tied to her sensory input because she has certain movements she goes into when she has high anxiety and she’s upset, she squeezes her hands and shakes and so she gets a lot of stimulus clearly, even when she’s happy she’ll sometimes shake. I know that’s a sensory issue. I also know that she even has head movements sometimes when she’s doing things and I tell her, *“Don’t do that Kayla.”* He brother thinks its OCD, I think it’s…I think there is some kind of reward in her mind that she’s getting when she goes through certain movements. I think it’s all tied to anxiety, sensory and to probably this OCD issue.

**Interviewer:** For sure.

**Interviewee:** Long answer to your question.

**Interviewer:** That’s okay. So, I just want to confirm. Are you saying that she like seeks out sensory input **[0:06:00]** when she is anxious and it’s like a sensory seeking behavior?

**Interviewee:** She has a sensory…you can see that she’s looking for a sensory input when she’s upset.

**Interviewer:** Gotcha, perfect, thank you. You talk a lot about movements, does she seek out certain smells, textures, noises, other things like that?

**Interviewee:** No, it’s really about her own movement and she tries not to…I know before it escalates …it doesn’t happen a lot, but before it escalates, she puts her hands in fists and shakes and puts her arms straight and then it can escalate and she’ll grab. Her therapist for the home program thinks she’s trying to get sensory input from grabbing shirts, she’s ripped a lot of people’s shirts, a lot of people. She’ll grab and she’ll pull, she’s very strong, she’s small and petite but she’s very strong when anxiety goes high. I think that’s sensory, it’s all sensory…it reduces her anxiety or she needs it and she’s not really…it’s very hard to connect with her when this happens.

**Interviewer:** Does it cause anxiety at all or just reduce anxiety?

**Interviewee:** I think it probably is a reaction to the anxiety and it’s her way of coping and so her therapist is even trying to distract her when this starts to happen with different distractions, *“Oh Kayla, put your hand on your head.”* Just stop thinking about whatever she’s upset about. I don’t know, I wasn’t there when that happened recently. I have to be honest, it happens sometimes a week before her period, when her hormones go fluctuation.

**Interviewer:** Yeah, that’s real. Then, how does this anxiety come back down? Does she just keep on seeking out these sensory experiences? What happens after?

**Interviewee:** Well, and I have to say that she goes through spirts. We haven’t had problems for like six months and before that or even longer, we just recently started having a little bit of a problem but we really didn’t have problems till she left her last school, which was about a year and a half ago, she was in the public school system and it wasn’t working, so we went to a private school and it’s been a fantastic place, fantastic. It’s very infrequent, it’s hard to really gauge a lot about this situation, other than everybody wants to collect data and everybody wants to kind of figure it out. Help me out, where do you want me to go with this again, I’m sorry? **[0:09:00]**

**Interviewer:** No, no, no, it’s fine. You’ve described how she uses sensory input and sensory seeking to cope with anxiety and I’m wondering what it looks like when she is coping and coming back down?

**Interviewee:** So, when she’s coping, that’s when at school they brought her into the sensory room and then she also had a little bit to eat because she doesn’t eat a lot at any one time, she’s not a big eater, she never eats junk food. Sometimes I worry if she gets enough calories. She eats, has a snack at school, then lunch, then she comes home and has another lunch because she never eats a big mean. They have a sensory room that helps, she told me a little bit of a snack helped, her teacher told me when it happened this week and at home, when it starts to escalate, I don’t want you to get the wrong idea but we have…this usually happens down stairs and we have an open concept house, there’s a bathroom and I implemented this, I created this, I say, *“Kayla, you’re going to go into the bathroom to calm down,”* because I don’t want her to…she has attacked people, she’s actually bite her caretaker, not break the skin but it’s sufficient that it causes swelling, she goes into the bathroom, I don’t shut the door, so she’s not locked but I keep the door a sliver open and we’re looking at each other eye to eye and I say, *“Okay, I need you to calm down, as soon as you’re calmed down you’re out of her.”* We just look at each other, she’s not locked in the room, I don’t hold her in, she’s not crying, I don’t want you to think I’ve ever put her in a room.

**Interviewer:** I don’t.

**Interviewee:** I don’t, it just keeps her safe, it keeps us safe because if she’s started to attack and someone accidently heard her, god forbid, it just keeps a distance, the whole thing is about just keeping a distance if she get’s that upset. It’s very infrequent, but this is my approach and it calms her down, like within a minute, she doesn’t have to be separate from us, she hates that, so she calms down and I say, *“Are you going to be okay now?” “Yes,”* and she comes out and she’s done.

**Interviewer:** Perfect.

**Interviewee:** But I don’t really like anyone do it because if they shut the door all the way, I’m afraid she’s going to flip out, she doesn’t want to be locked in a room and I don’t ever…I don’t ever want to lock her in a room. I’ve showed my husband what to do. One time I was at work because I go into work most days, he’s working at home during the pandemic and it happened once and he implemented it but he said, *“But I kept the door open like you told me and everything was fine and she came down quickly and left the room.”* I know this is being recorded and I don’t want it in anyway look like we’re…this is any harm to her. This is safety number one and the door is open.

**Interviewer:** Yes, that is very clear. I’m not worried.

**Interviewee:** And it’s a pretty bathroom. There’s a mirror there, she likes that bathroom, everything is…there is nothing bad, it’s like a minute of her life, you know. I have a hard time saying this because I don’t want it recorded that **[0:12:00]** I don’t want this misconstrued.

**Interviewer:** I’m not concerned. I’m not going to report this, don’t worry.

**Interviewee:** I don’t want you to share this part actually because I don’t want people to misunderstand this. This is all about her safety. When you’re an adult and if you…quite frankly if you go to bite someone, I’m afraid…that’s why she left the public schools because they were holding her arms and she came home with bruises on her arms and I was like, *“This is not going to work for me, she’s going to get hurt and it’s going to cause PTSD,”* which I think it did. She has to be a place where they know how to do positive reinforcement and keep her safe and I’d never lock her in a room, never, never.

**Interviewer:** Absolutely. Thank you for sharing that.

**Interviewee:** I just want you to know, we adore Kayla and we want her safe.

**Interviewer:** Yes, I can tell. I can tell it’s all about her safety and everyone’s safety, all for positive things, don’t worry. Thinking about her sensory…seeking her sensory preferences, has this changed over time?

**Interviewee:** Yes, definitely she’s matured. This bout, even though I’m describing because it’s painful for all of us, these bouts are very infrequent, they are extremely infrequent. In fact, from the time she was four years old till she went to middle school she really didn’t have any serious issues. She just may barely grab someone’s arm, she used to grab a lot to distract from doing the work, she was in an ABA classroom. She didn’t do anything for years and years and then in middle school she can’t have casein, it’s neurologically impacts her and in middle school…our nanny bought rice cheese thinking it was rice but it case casein as the second ingredient, on the weekend I came down and my husband her they’re devouring the rice cheese and I’m like what, anyways she went boom, way out there and neurologist said it takes a long time for that leave her system. Whatever happens there is a…it is a terrible reaction in her body. That took a while, took months for that to come out of her body, it was really bad. But anyways, she’s matured, she doesn’t eat any cheese with casein, casein is not part of her diet, gluten, she has celiac disease but it also causes neurological impacts, soy causes neurological impacts and then she has allergies. There is a lot of great food today, it’s not like it use to be when I was young, she has a very healthy diet.

**Interviewer:** Excellent. You mentioned that you’re seeing changes in her, like sensory behaviours, do you think any of those changes are related to any independence that she’s gained over time?

**Interviewee: [0:15:00]** I think her anxiety comes from not wanting to do something, not feeling safe and not wanting to do it and so as long as she gets her way, she’s the happiest human being in the world, I guess like all of us. She had a three-day weekend because of Columbus Day and she had a couple of days where she was grabbing in school, Tuesday and Wednesday and they were trying to figure it out, we talked on the phone, we were going to have the behaviours in our home program, talk with them and then yesterday, she had a beautiful day. I actually think she had a three-day weekend and she was very happy being on her iPad, going to the park and then watching her Disney Junior TV station, that’s what she likes to do.

**Interviewer:** Yeah, for sure. We all like to do leisure.

**Interviewee:** That’s her independence, she wants to do what she wants to do.

**Interviewer:** Absolutely. Has her anxiety changed over time as well? You talked about her behaviours as infrequent, is her anxiety also infrequent?

**Interviewee:** Yeah, I think if Kayla knows what’s going to happen and she has a schedule and she knows what it looks like…we’ve always done social stories when we went on a plane or we go to a new hotel or anything like that or if we stayed at a house for a summer vacation because we always have to bring the stuff to cook her food, so we always had to stay at a house or have a kitchen, I’ve always had to show her exactly what it’s going to look like, *“This is where you and I are going to sleep, this is where we’re going to have our food, this is where we’re going to sit,”* and I show her were everybody’s bedroom is going to be and as long as she finds it esthetically pleasing, it’s all good. She just has to know what’s going to happen and when it’s going to happen. There is still things that she doesn’t like. She was supposed to have her pediatrician, her physical, she was due about four months ago and she has a real problem with the exam room at the pediatrician, he has a lot of exam rooms but they look a like and she will not go in there, she goes in to a panic. I don’t even know, maybe she had a bad dream because no one has ever hurt her, no one has left her alone, she’s never been in harms way, he always lets her wear the stethoscope, I don’t understand but for whatever reason. Our new approach is that she’s going to go in the weight room, the room where she gets weighed because she apparently tolerates that and he’ll do the exam in there. We just have to brainstorm how to make things work for her.

**Interviewer:** Absolutely, sounds like a good solution. You talked about how she’ll go into a sensory room at school, how she can decompress, how else does she or how else do you help her manage and cope with her sensory seeking and sensory input behaviors?

**Interviewee:** I have to be honest, I don’t see that she has a lot of sensory seeking behaviors other than when she gets upset but I know **[0:18:00]**…like I said, it’s enough for her when she’s on the iPad and she likes something a lot or she’s watching TV and she likes something, to shake, puts her arms straight and shakes, she’s excited and she shakes, that’s her sensory input. So, it’s changed, it looked very different when she was younger and this is more of what it looks like. She’s matured. She still has motor planning issues. When she was in grade school we started doing sign language with speech because it helps using everything to get the…to improve the…when you have apraxia but then we did kind of a lull on doing sign and all the speech therapist often has to do is touch their mouth or go like this and the Kayla is already improving her articulation or getting it out. We’ve gone back to sign now, expanding her vocabulary and working on always using sentences and she’s really smart with that, she just picks it up really quickly.

**Interviewer:** Good.

**Interviewee:** And it improves her motor planning, that’s most important. I think that’s a sensory issue, the motor planning. It’s something we all have to work on her, to improve our…expand out sign language here in the house so that we’re helping her.

**Interviewer:** Absolutely. You said that it looks different now than when she was younger, you talked about her doing those shaking movements, what did it look like when she was younger?

**Interviewee:** She needed to jump a lot and run. When she was real young, she would have these little puppets, finger puppets, she had the whole Sesame Street Gang of finger puppets and she would carry them and it almost looked like they were interacting with each other. We thought, *“Oh my gosh, she’s so brilliant,”* there was a lot of stimulation. She had to carry all the time, when we were on the plane, wherever we went, she had her little Sesame Street characters.

**Interviewer:** Got you. And you talked about occupational therapy for her sensory things, can you talk a little bit about that?

**Interviewee:** Her occupational therapy?

**Interviewer:** Yeah, like what do they do with her? Do you think it helped her?

**Interviewee:** You know, they had a trampoline in the classroom, little round one so she could jump on that. She always loved to play with balls. She always like those, I don’t know, there are some sensory places you can go to, she liked all that kind of stuff. **[0:21:00]** Like I said, as soon as she went to middle school, I think they stopped working on all…providing all the input and tried to have more of a workout, doing more gym activities and then when she got to high school, they actually went to a field house and worked on all the different equipment. Kayla is not big into the equipment although she is a good walker. There is nothing wrong with her ability to run, she just doesn’t…getting her to run is like…she can never do a two wheeled bike, she’s on a three wheeled bike, with a basket, it doesn’t look a tricycle but it has the two wheels with the basket so it’s a nice bike. She goes slow, she goes slow on the bike, she’s never going to have the momentum to go on a two wheeled bike. No, they don’t really…now, the sensory being in the school is going to this sensory room where they have some reduced lighting, with a beanbag where she decompresses. I think it’s just about getting her a little bit grounded as opposed to her needing the feedback so much but then when she gets upset, she does seek for feedback.

**Interviewer:** Absolutely. Thinking a little more broadly and towards the future, what goals or hopes do you have for your daughter in terms of her sensory habits?

**Interviewee:** So, I want Kayla to…like I said, I think her sensory is tied to her security and her anxiety. I don’t mind her shaking, to me it makes no difference, if it makes her happy to do that because she’s not going to say, *“Oh, I love this show.”* She’s going to shake a little bit, that’s good. We all want to express when we’re happy but that doesn’t phase me and it never has. For the future I want her…so what they do in the home program is she writes her schedule, she types it into the iPad, she’s in charge of the schedule at school and I think that has a huge impact in her sensory management and her anxiety and therefore her sensory needs. I think the goal for Kayla is to always…to have a schedule, to know how to set up her schedule, to plan but not…the biggest problem is that it’s very narrow, the things of interest. By going to the school she’s at prior to the pandemic, they were…this school offered so many things for her in terms of extra curricular activities, in terms of electives, in terms of community **[0:24:00]** and Kayla loved it, she loves it. She use to go to…before she go into the school, every summer instead of doing extended year through the district because there were no girls I had her go to a summer camp, it was for special needs kids but pretty, how people would call it, very neurotypical to kids but kids who might have a slight learning disability and things like that. Kayla was the only probably who had an aid with her there, she loved it. She was with a girl group every year, for five years she went there, she was with a girl group, they went to all the places teenagers…they’d have different events and go different places and she loved it, loved going there. What I was so happy about her moving to the ECLC is that it had very similar flavor of having the electives, having the extra curricular activities, hopefully she gets there, going out into the community, by doing all these things I hope to expand her interests and understand that there is a wide array of things that she can do without saying no. This is my goal to make her part of the world and not to keep her in her little world.

**Interviewer:** Yeah, absolutely.

**Interviewee:** That will reduce her sensory.

**Interviewer:** Yeah, because then she can plan for things she likes more and have more things she likes.

**Interviewee:** Yeah.

**Interviewer:** That was an awesome segue, thank you. We’re going to go into our next chunk of questions which are all about community, so well done. As your daughter has grown up and aged, how has her and your community reacted to her sensory habits and sensory needs?

**Interviewee:** The community? You know, I think she’s different, period. I haven’t really talked with anyone in the community so much about that. I think when she goes into the community, she just loved to go to Whole Foods, since she was four years old, Whole Foods was her store and it’s my store. I can’t shop at other stores because I just can’t stand the odor of a grocery store since I probably worked in high school, I just don’t like the odor of a grocery store, it’s probably I have some sensory issues myself. Anyways. We were in the Berkshires this summer and we stayed at…I forget the name of it, it’s like Big Y or something, we called it ShopRite, made the big mistake of calling it ShopRite so now, the only store she’ll go to and I won’t go with her, I can’t go to ShopRite, you don’t have in Massachusetts, it’s like a chain **[0:27:00]** but the Big Y I guess was better but I liked more of this…starts with a G place. My point is, we use to go to the Whole Foods all the time, everybody in the store knows here. It’s not so much a sensory, they know how to interact with Kayla, *“Hey Kayla, how you’re doing? It’s so good to see you. Oh, you’re not in school today? What are you doing today?”* I loved it. And now, she doesn’t go there, so she doesn’t have that connection. She goes up town in her home program. They have a soccer for special needs kids but she hasn’t gone to that, she’s a little…what she loves to do…they don’t really know about her sensory. She goes to the park everyday for about a mile walk. She loves to watch young kids. Loves to watch the young kids and loves to look at babies now. Our nanny said when she sees babies she just stops and stares at them, I don’t know what’s going on.

**Interviewer:** It happens sometimes. Was the community more or less accepting of her when she was younger?

**Interviewee:** You know, I think so, I think people were…one reason we moved…we live in Monte Claire, I wanted her to be in a school where it was diverse and have inclusion. There was only two public schools that had in Northern New Jersey, it was Monte Claire or Morris Town. We moved to Monte Claire, it’s very close to my work and we’ve lived here now for a long time, we’re lived here for over 13 years. Monte Claire is known for diversity, very urban suburban kind of living but it could improve, I’ll be honest with you. It could be much better. There could more…it could be more welcoming, provide more opportunities. When she was younger, I ran into the mayor once and I started…such a waste of my time, I said, *“You’re not really hitting on this, this and this,”* now I have to be honest, I don’t remember all the things that I should be doing. I think there is more communities could do, absolutely. I think Kayla is too isolated and think there are ways she could be more integrated and more inclusive world and it’s not fair, without a doubt. Accepting how she moves or what she needs for input would be part of that. I know and the reality of the big picture things have improved but I think it could be better, much, much better, that’s across the board, right? It’s a big issue across this country.

**Interviewer:** Yeah, absolutely. **[0:30:00]** So, are you saying there were less accepting when she was younger but they still have way more to go in the future?

**Interviewee:** I’m saying as a parent, I always notice when people are not accepting. You kind of forget all that stuff. She’s 18 and we do our thing. Yeah, I’m just trying to think. I’ve always just been so focused in on my children’s happiness but I don’t pay a lot of attention to problems around me but I think about what opportunities that could be better. I’m not really good at answering this question, I’m sorry.

**Interviewer:** You did great, not at a problem at all. Thank you. Are there certain aspects of the community that are more or less accepting or again, is it not kind of relevant because you kind of tune it out?

**Interviewee:** I think people who have someone in their life that has this kind of…has Autism or something related, extremely kind, there are really kind people. I remember Kayla, when she was in middle school, she didn’t like the…it was a postman but didn’t like the person parking in our area, I have no idea what was going in her head, she’d see the truck and that’s when she started darting from the house. She went to look for him to get him to leave the neighbourhood. I don’t know what was going on. Chris had to run after her and when they found him, it turns out he had a son with Autism, he was very understanding. He was very kind. There was a little danger in her running and darting but now, she’s very cautious and she wouldn’t do that. You know, there’s a range of people. I think most people if they’ve been exposed and they have anyone in their life, they’re very understanding and if you don’t, it’s hard but hopefully people can’t start to become empathetic but there is a lot of very kind people.

**Interviewer:** That’s good, I’m glad you think that. Again, thinking more broadly, what hopes or worries do you have for your daughter in terms of how the community will react to her and sensory needs in the future?

**Interviewee:** I’m very overall worried and I think for Kayla, she’ll always have someone with her, always because of her verbal, her lack of being able to express everything. But she will always have someone with her. Whoever that person is or whatever that looks like at one point, if I’m not around, I just want to make sure everyone understands who she is and what her needs are when she can’t explain it and about her life. That’s more of my worry, is making sure long term. Even for my husband, I feel there’s a lot of learning there he has to do. I feel like I need to start writing a book about this **[0:33:00]** because sooner than later is always a good thing, to just start documenting, as a parent, that’s what I think about.

**Interviewer:** That makes sense, absolutely. Thank you for sharing that. Again, you’re giving me nice Segway, we’re going to move onto our next chunk of questions but they’re related to what you just said. In the transition to adulthood, where do you see your daughter?

**Interviewee:** So, right now, I see her with us. She’s in a school that transitions into I think it’s one of the only ones in Norther New Jersey that actually have academics as part of the adult program.

**Interviewer:** Oh, that’s great.

**Interviewee:** I always want her to have academics. I don’t see her working eight hours a day in some position. I want her to do some work, I would love for her to work at pre-k place where she can help with the kids. I want her to be happy. I want her to be in a positive environment. I’d like her to be able to go the Y everyday with someone to train her, to work on equipment. I’d like her to still go to the part everyday and I’d love for her to be in a program that offers all these different things with academics and I think the school she’s in, assuming everything goes well and this is where we’re at, I’d like to see that longer term. Yes, I’d like her to have a place where she feels like she’s part of a community, I don’t know what that looks like. I would like it to be where she has her own bedroom but she has 24-hour people there for her, she’s not responsible for cooking all her meals, she’s not going to be able to shop and get all her food. A place possibly that provides like farm products, because I’d like her to be with animals, I’d like her to be with people, I’d like it to be very functional, I don’t want it to be institutional, I want it to just be a really healthy environment, like we want everyone to live in a healthy environment. I’d like her to be in a very healthy environment like that, where she lives somewhere like that. Is able to go to the school everyday for all her different activities, go back, be part of another community and be able to see her family as much as she’d like.

**Interviewer:** Excellent.

**Interviewee:** I don’t know if that’ll happen but that’s what I’d like.

**Interviewer:** You’ll figure it out, I’m sure. Thinking about what skills she can do independently and what skills she needs support on, could you describe that a little bit?

**Interviewee:** When she want’s too, she’s really smart. They do all the pre-vocational work with her and she can do it all but it’s whether she really wants to do it with Kayla, she may not want to do it. That’s why I don’t want her to do anything that she finds very… she’s not happy, skills wise. **[0:36:00]** Again, I think she a lot of interest in little people, so if there is a way, she can be an assistant at a pre-k place or help with the animals, feed the animals, as long as it’s not gluten or any other foods she allergic, have any contaminants for her. I want it to be a healthy way to apply what she does and to continue to grow in her reading, writing and math, problem solving, art, I want her to continue doing art. I’d like her to have music in her life. I really want her to have everything because she enjoys music and she enjoys a lot of things but she’s going to need a schedule.

**Interviewer:** For sure. Can you talk a little bit about the skills that she does have right now in terms of independence and where she also needs some support? Can she prepare simple meals, things like that? Can she take care of her body?

**Interviewee:** Everyday she wakes up, she does all her own hygiene, she makes sure her clothes are clean. She makes sure her clothes are in the right drawer. She takes care of her bed, makes her bed, her dad may help a little. She get’s herself ready for school. I pack her bag for school, which I really could have her do that, she unpacks it everyday, she could pack it, that’s something I could do to help make her more independent. In terms or making meals, she does not want to make her meals, so part of her home program right now is to work on her making meals. She can do it. In high school, throughout high school she…she eats a lot of eggs because she needs the protein and she’s not a real big meat eater, she had meat every night for dinner or chicken or fish but just to have protein at lunch when she’s home she’ll have eggs in the morning, she has French toast and eggs. She was making the eggs at school and every time I ask her to do it at home she says no. I say, *“How about making your pear?”* because she likes to eat a lot of pears and you have to skin it and cut it and she’s like, *“No,”* that’s going to be part of her home program, to prepare her food. Not necessarily chicken yet or fish or the different meat that she eats but we’re going to start getting so she can definitely make her eggs, make her French toast if she wants it. Make her pears like she likes to eat and eventually we’ll get to dinner but that’s the plan.

**Interviewer:** That’s great. You talked about pre-vocational skills, what are those?

**Interviewee:** I never really get into this but I know they include sorting **[0:39:00]** and classifying. I know in high school they had this whole set and they’re doing it now too and she has a skills class even at school, so they have a whole range of things that they focus on, from shredding paper to putting things in different…I know she does all that and I think she can do all of that. In high school she used to make copies and then she was doing things like that. I don’t know what the other skills are that they work.

**Interviewer:** That’s fine. Does she ever express interest in her own way of wanting to have a job or do something like?

**Interviewee:** No.

**Interviewer:** That’s fine.

**Interviewee:** It’s a big no.

**Interviewer:** Then before we were recording you mentioned that she likes school and has friends through school, does she manage some type of social life through that to some degree?

**Interviewee:** Well, so no she doesn’t but she likes…she didn’t have girls in her class for a long time. There was a girl who was her peer mentor in middle school, Catrina and they stayed friends and they stayed friends because in high school whenever Kayla had a free day or on the weekends periodically we have lunch at a gluten free restaurant…we haven’t been able to do it with pandemic, it was closed for a while, Catrina is now in college and she’s adorable, she wrote to Kayla or text her, *“Let’s get together to talk.”* She’s so funny, Kayla doesn’t really converse. We’ll be talking with Catrina and Kayla will probably pop in and Neal and I will carry on the conversation with Catrina but she’s a very nice young woman. She’s had Catrina in her life but in terms of more peers that are in her class, when she moved to the ECLC there was two girls, Jamie and Julia and Jamie is extremely verbal and Jamie, they put her right next to her before the pandemic and Jamie would be like, *“Kayla is watching Barney, isn’t that great.”* She would be the mouth for Kayla, whatever she’s doing. Whenever there was a photo of the class, I can tell Kayla really liked, she would put her hand on her shoulder, she liked Jamie a lot. She liked Julie. When I would go to the school Jamie would say, *“Oh, are you Kayla’s mom?”* They’re just so adorable. Unfortunately, Jamie’s not in her class and I don’t know why but she’s not in her class this year, that’s disappointing. Julia is in her class and there is another girl Alexa in her class. **[0:42:00]** Her teacher said that with the mask, it affects Kayla because Kayla likes to see everybody smiling and this has kind of affected her connections in class.

**Interviewer:** Totally, it’s affected everyone. Our face is such a big part of communication. Some of these vocational classes are prevocational skills have they gone over money management or money as concept?

**Interviewee:** Big time, money has been a big thing, she’s been working on money since she’s been high school. I think she knows all the money; they do the round up for paying for things. Yeah, so they’re doing when you go to a restaurant you add it up, Kayla is very good with calculators, she does all that, she’s very fast. They have to keep the work really moving in her class because Kayla doesn’t like to chit chat, there’s a lot of kids in her class that like to chit chat. I notice this in the pandemic when she remote, they’d be between math and reading or social studies there are a couple kids that love to just talk, talk, talk and Kayla is up, leaving, gone, she doesn’t want to be part of it. Her teacher recognizes there can’t be such a lag with Kayla, she doesn’t want to sit there and listen to the chit chat.

**Interviewer:** Yeah, for sure. Thinking about her money management skills, does she understand saving and things like that?

**Interviewee:** No, she just knows you have to pay for it.

**Interviewer:** That’s a good first step.

**Interviewee:** Actually, I think the better alternative to money is a credit card. She has a credit card in her purse, in her bag where she puts her phone and as far as I’m concerned, she just used the credit card. I understand the issue with money, I’m glad they’re working with it, I know she has to work with it, how she can round up, round down, I think these are good skill sets, how you pay for something but in the end, I think it will be a credit card.

**Interviewer:** Absolutely. In her own does she ever express interest in wanting to live more independently?

**Interviewee:** No, she addicted and loves her home. She could be…her favorite thing to say when things don’t really…whenever she goes, home, home. We can be in Florida, home.

**Interviewer:** Do you think she’ll be able to achieve more independence in the future?

**Interviewee:** Yeah, I think that there will be more independence. I want her to be independent with her cooking, her management of her life. I want her to be independent with her schedule and knowing her day and hopefully even communicating one day if she’s not living with us, communicating with us.

**Interviewer:** What do you think will help move her into adulthood, move her into this independence? **[0:45:00]**

**Interviewee:** Being in her program she’s in. I think being in the program she’s in, with a strong home program, we’re going to grow the home program. Right now, she needs a transition, so we’re only going to do it twice a week but I think she can have it over the weekend, have at least a couple of hours on a Saturday because she doesn’t do a lot. All of that, I think will be very helpful.

**Interviewer:** Absolutely. Thank you. Now, we’re going to put these two concepts together. Her sensory habits and her transitioning to adulthood, how to they intersect for her or how do they not?

**Interviewee:** I think she’ll always get excited the way she gets excited but I would hope she can deal with the frustration by being more exposed to the world, things won’t be annoying her schedule, she won’t be as anxious knowing that the schedule can broaden to include a lot more things, a lot more places, a lot more opportunities, that’s my hope.

**Interviewer:** Do you view her sensory habits as an obstacle, a vehicle, neither or a bit of both towards her independence?

**Interviewee:** I think she’s got to manage it with her sensory, when to use it to help her. I think she uses for happiness and it comes on with frustration and something we’ve never really talked about but now that it’s cropped up at the school, I think what we want to do is have it in between the happiness and frustration point before frustration happens. I don’t know what that looks like but I think that would be very helpful if she feels like she’s getting anxious, doesn’t like the fact they’re doing what they’re doing in school or wants to go home or is scared about something, to have some place in between how she can deal with it and I don’t know what that looks like but she’s going to have something to deal with that if she’s not living with me.

**Interviewer:** Gotcha, that makes sense. Thank you. Then similarly, what do anticipate as being challenging for her as she does gain more independence in regards to her sensory needs and sensory habits?

**Interviewee:** What is the question?

**Interviewer:** Yeah, I’ll repeat. It’s a long one. What to do anticipate as being challenging for your daughter as she gains more independence in regards to her sensory needs?

**Interviewee:** Really understanding that transition point, it’s going to take some work. You know, talking with you has made me realize this. It’s a direction we need to work on, I don’t know what it looks like but thankfully there is experts who hopefully can help on this. Really, this transition point is going to be very key to how the future…it’s going to be important for her future. **[0:48:00]**

**Interviewer:** And just to clarify, when you’re saying transition point, you mean the transition from happiness to anxiety verses her independence?

**Interviewee:** I think the happiness to anxiety will determine how independent she can be because you can’t have high anxiety and be independent, with her kind of communication skills.

**Interviewer:** Gotcha, thank you, that is very clarifying, I appreciate that. Do you know what could help her or kids like your daughter?

**Interviewee:** What can help her?

**Interviewer:** Help her in this transition, in this intersection?

**Interviewee:** That’s a good…no, I don’t. I don’t have a picture of how to set that up to prepare her, how to train her, I don’t know what that looks like.

**Interviewer:** Gotcha, absolutely.

**Interviewee:** Maybe your work will help me.

**Interviewer:** I hope so, I hope so, that would be the goal, that is the goal. Do you feel like there are gaps in the available services for people like your daughter?

**Interviewee:** Yeah, I think there is a lack of opportunity without a doubt. A lot more opportunities…you have to seek it out. I like her to have music in her life like I said, I’d like her to have yoga in her life, with the pandemic all of this is impossible, it’s all been put on hold.

**Interviewer:** The pandemic didn’t do good for anymore.

**Interviewee:** Pardon?

**Interviewer:** The pandemic wasn’t good for anymore.

**Interviewee:** No, no.

**Interviewer:** Thinking again a little more globally, how have your daughter’s sensory needs impacted your goals, hopes or expectations for her as she navigates adulthood?

**Interviewee:** I can’t separate them; I’ll be honest with you. I look at Kayla as a whole thing and at this point, we’re pretty much taking day by day. Do the guardianship and we did do…we started working with social security, we’ll take all the steps we need to take. For New Jersey I don’t know what the options will be, there are not a lot of options, people say there are waiting lists to even get into a place for 10 years and I’m not even sure if I would like that place. There is a lot of things to think about.

**Interviewer:** Absolutely. Thank you for sharing that. We’re going to go into our last chunk of questions, we’re almost done. As a caregiver, as a mom, as a parent of someone with Autism but also some sensory needs, what does transitioning to adulthood look like for you and what does it mean to you?

**Interviewee:** Making her as independent as possible and being happy, healthy and safe and ease of life. I don’t want her life to be hard, I really don’t.

**Interviewer:** Has this perspective changed over time?

**Interviewee:** Yeah, I guess when she was in elementary school, I really pictured her going to college. One of those special needs type of college, so I started looking at them but being away from home wouldn’t be an option for her. She’s in the perfect program for her.

**Interviewer:** That’s great. That’s what matters right, it’s all about fit.

**Interviewee:** Everybody has a different path.

**Interviewer:** Exactly. What do you see happening in your daughter’s future? **[0:52:00]**

**Interviewee:** Well, like I said, right now she’s in a good program till she’s 21 and then she can go to the adult program after 21. We don’t have any intention to move at this point, so I foresee that she’ll continue to be with the ECLC. I will look at different options for…if she moves away from us, what that would like but right now we don’t see that, right now we see with us for a while.

**Interviewer:** Absolutely. Then, how have your daughter’s sensory habits and sensory needs impacted this perspective that you just articulated?

**Interviewee:** It’s just part of who she is, it’s part of the big picture.

**Interviewer:** Yeah, absolutely, it’s what I thought you were going to say. So, that’s it, that’s it for all my formal questions. Would you like to add anything else?

**Interviewee:** It’s been a pleasure.

**Interviewer:** Thanks.

**Interviewee:** You know it’s really nice. It’s actually been nice to reflect with your about a lot of these things because often you live…dealing with everything everyday and most of the time you have to focus on problems, going to work or whatever you’re doing but the good thing about this is that it just kind of made me reflect about some things about to make her life better. I look forward to learning more from you about your results and how it can help inform us as we go forward. I’m very serious, keep in touch with me about what the results are, what some direction, some recommendations, if you hear of fantastic opportunities, places, experiences along your way, creating some type of resource for parents like me would be so fantastic because it’s always good to know because you never know where you’ll move to. I would move if it was the right place for Kayla.

**Interviewer:** I’m doing that actually. These interviews are transcribed and then as I review the transcripts, I’m taking out everything parents say that is relevant for resources and I actually just finished a transcript from a mom from New Jersey, so I will send you all the resources she mentioned. She’s lovely, she actually started a non-profit, so I’ll send you her information, the non-profits information, she has a son who is obvious on the spectrum, that’s why she’s in the study, hopefully that can also be a helpful connection for you.

**Interviewee:** Thank you so much, I really appreciate it.

**Interviewer:** No problem, happy to help in whatever way we can. Do you know anyone else who might want to participate in the study? It’s okay if you don’t, completely fine.

**Interviewee:** I don’t want to necessarily give out…what I could recommend is now that Kayla is at the ECLC I could recommend a reaching out to Alisson Clemens, I hope she doesn’t mind. She’s the assistant principle at Kayla’s school and she’s just a really nice person.

**Interviewer:** I’ll reach out.

**Interviewee:** She’s at the ECLC of New Jersey and if you want to reach out. Is there something you want me to do?

**Interviewer:** No, that’s perfectly fine. You’re good. I can take if from here. Don’t do anything else, you do enough.

**Interviewee:** I think it’s appropriate right, that you reach out to school, private school like this.

**Interviewer:** I reach out to everyone. I cold call, I’ll just ask.

**Interviewee:** Yeah, that you’re doing research. I mean, you know how to explain your own work. That’s great.

**Interviewer:** Perfect, thank you. Can I do anything else for you? Do you need anything else? Can I clarify anything?

**Interviewee:** No, no. Like I said, I don’t really want you to share some of the more…I don’t want people to misconstrue that one part I told you about but other than that, I wish you the best in your research and your career.

**Interviewer:** Thank you. I appreciate that. I hope your appointment goes well. Thank you for making time for use, we so appreciate it. We learn so much from people like you. We couldn’t do it without you.

**Interviewee:** It was nice talking with you Rachel.

**Interviewer:** You too. Bye.

**Interviewee:** Bye.

**[End of transcript]**