**[Start of transcript]**

**Interviewer**: We’re recording, ok great. So just kind of as a recap from yesterday, we talked a lot about Taylor’s sensory sensitivities. You talked about how she’s sensitive to some things, like brushing her top teeth, she doesn’t like being cleaned, but then she does like certain things like paper towels and water. You also talked about, in terms of her independence, about how she needs help with a good number of daily skills but that ABA [applied behavior analysis] is helping her and you hope that it will continue to help her in gaining more independence. Do you feel like that’s an accurate summary of yesterday?

**Interviewee**: Yes.

**Interviewer**: Ok, awesome. So now putting these two things together – sensory sensitivities and the transition to adulthood – how do they intersect for Taylor?

[0:52]

**Interviewee**: I think for Taylor it intersects in the sense that she’s always going to need direct support. She’s always going to need that one-on-one feedback in the community about what is socially acceptable behavior and what is appropriate behavior out in public. So I think it’s always going to be … we work a lot on continuous feedback. Like, you know, every time we’re out we’re in the moment, we’re redirecting, we’re correcting kind of throughout the whole trip. I think for her with the sensory especially … like we talked about certain stores that are too overwhelming or too loud, I don’t think we’ve ever taken her to an Ikea, but I think that those kinds of stores would almost be just overwhelming. Although, she does do good in the mall, I think because it’s more open and you know you have the big walkway. So I think for her a lot of her needs are going to rely on what stores are acceptable for her in the sense that they can accommodate wider walkways, maybe the lights aren’t as bright, maybe there a lot of people but it doesn’t feel crowded because it’s not a small space, so things like that. I think for her too the transportation would be a big thing. I mean, realistically, I think that her dad and I will always transport her. But from a community perspective, I think finding some sort of reliable community transportation, whether it’s people that drive their own vehicles and they take people, or whether it’s you know maybe handicapped vans or something like that. Just some kind of alternative to a public transportation bus that has a lot of typical people that also ride it who may not be understanding or aware of people with special needs.

[3:13]

**Interviewer**: Absolutely. Hi … [*laughs*]

**Interviewee**: [*inaudible … speaking to Taylor?*]

**Interviewer**: Would you say that her sensitivities are an obstacle, a vehicle, a bit of both, or neither towards her independence?

**Interviewee**: I would say behaviorally in some ways they’re an obstacle. Especially because she’s not very verbal. It’s hard for her to say, like she couldn’t say, “*It’s too crowded here I want to go home*” or, you know, “*This store is too cold, I can’t shop here*.” So it’s an obstacle in that sense because it just turns into a guessing game. If it’s a new store for us and there’s something about it from a sensory perspective that she doesn’t like, we have to figure that out. So that would be an obstacle, especially if she was out shopping with someone who doesn’t know her as well as we do, who may not be picking up with all of her nonverbal cues. I think it would be an obstacle for sure because they wouldn’t be able to recognize and respond to it in the same way or right away. In some ways I feel like it doesn’t affect her because in some ways her sensory issues … she’s not bothered by a lot of things. So I guess it’s a little bit of a blend, but I think in general it’s more of an obstacle, just because of the verbal communication being limited.

[4:56]

**Interviewer**: Yeah, absolutely, that makes sense, thank you. Similarly, what do you anticipate as being challenging for her as she does gain some more independent skills, in regards to her sensory sensitivities?

**Interviewee**: From an independence perspective the thing that does worry us is safety, because she thinks, “*Oh, well I can do this now*,” so you know, it’s almost like … At one point her therapists were working on trying to get her to work on putting things away in the sink when she was done eating, and we were trialing that at home as well when they weren’t there, and then one day she thew her plate in the sink and it happened to hit a cup just so and it was a glass cup and it exploded in the sink. She has no safety awareness in the sense that it’s glass, it’s broken, it’s going to cut me. So she was trying to help clean up but then she’s almost getting hurt in the process, so I think from a safety perspective it worries me. She’ll try to use the water dispenser on the fridge and she’ll get water all over the floor and then she slips on the floor because she doesn’t watch where she’s going really, she kind of just, you know, walks without looking at the floor. So there are some things from a safety perspective that worry me in that sense, because she understands the concept of like, this needs to go here or this needs to be here, this gets put away here, but if it’s not done safely she doesn’t understand that.

[6:38]

**Interviewer**: Absolutely. Are there any things related to her sensory sensitivities that you think about in regards to her future independence in terms of challenges, similarly?

**Interviewee**: I think, yeah. I feel like she doesn’t sense pain the same way most people do. And hot or cold, like if it’s freezing outside she’ll put her hands or fingers in her mouth to try to kind of warm them up but she will *not* wear gloves *at all*. We have tried, I mean I’ve thought about sewing them on to her shirt [*inaudible* …] but she will *not* wear gloves. She will *absolutely* not wear a hat. From the perspective of COVID, there is *no chance* she will put a mask on her face. She’ll put it on for a second and look at herself in the mirror and then snatch it right off. It doesn’t matter if it ties at the back, it doesn’t matter if it’s a scarf, it does *not* matter. She doesn’t like anything on her face, she doesn’t like anything on her head, she doesn’t like anything on her hands. So from a climate perspective, that is scary because we have to be really really quick. We basically get her dressed, wrap a scarf around her, and zip up her coat really really quick and tuck it all in so that way she can’t really get to it, and even then a couple of minutes later she’s trying to take it all off.

**Interviewer**: Totally.

**Interviewee**: Same thing with heat. She’ll go outside and it’s a hundred degrees outside and you know she doesn’t understand that she needs to be careful out in the sun or things like that. So definitely I think hot and cold, pain, things like that, she’s almost not sensitive *enough* to recognize, “*I’m cold, I need to put more layers on*” or “*I’m hot, I need to go inside for a little while*.” It just doesn’t bother her. It doesn’t bother her until it’s too late.

[8:41]

**Interviewer**: Could you give an example with pain, like has she cut herself and not realized it?

**Interviewee**: She will scratch, like if she has a bug bite or a scratch or anything like that she will tear it apart until it bleeds. If she stubs her toe she’ll stop and say, “*Ow*!” But usually her sign for “*Ow*” is rubbing her head and saying the word “*Ow.*” But she won’t point at her toe or she won’t hold her belly, she’ll just say, “*Ow*!” But we don’t know is it her gall bladder, is it her appendix, does she have a headache? We have no clue as to where the pain may be. So she’s not reliable in that sense, you know, she’s telling us she has pain but she can’t tell us where or why or what happened.

**Interviewer**: Yeah, absolutely.

**Interviewee**: So definitely the sensory thing I think with that would be a big thing with pain and recognizing dangerous situations.

[9:48]

**Interviewer**: Yeah, for sure, that makes sense. Then again, thinking about sensory perception and adulthood, or transitioning to adulthood, what do you think would help her perhaps overcome these obstacles that you’ve articulated or just kind of bolster her to be better prepared for them?

**Interviewee**: I mean for us the biggest thing and really the only thing that we can do is practice, practice, practice, getting her to feel like she wants to do it. So giving her options, letting her pick things at the store, letting her see us wear it, which I think is why she’ll put a mask on for a second because she sees us wearing them and she’s sees her therapists wear them when they come to the house. But the problem is that she may put it on for a second, but her reasoning skills are behind. So if we tell her, “*Taylor, you have to wear a mask on to be safe out in public*,” that doesn’t mean anything to her. So she doesn’t grasp the concept of coronavirus and why you need to wear a mask out in public. Even if we said, “*It’s the rule, they said you have to wear it*,” for her she’s like, “*I never had to do this before, I’ve been here several times before*.” It’s not something that she would have put on her face before the pandemic and it’s certainly not going to happen now.

**Interviewer**: Got you.

**Interviewee**: You know, it’s frustrating in today’s world because you know if she could wear a hat that had a peak shield or something like that, that may be kind of another alternative that we could do. We do have a little wagon that she can fit in that comes with a canopy, but the problem is the canopy is kind of built for smaller kids, even though she’s still right under the weight limit. It comes down so close to her head that she wants to kind of push it off. So we have not found a good solution for getting her out in public right now, so pretty much she’s just been at home and then one of us will go to the store while the other one is home, things like that. But it’s been very difficult because so much of her therapy is based on those social skills and we can’t practice that right now.

[12:16]

**Interviewer**: Yeah, no, I’m sure that’s really hard.

**Interviewee**: And that’s where the sensory impacts her right now with the pandemic because she won’t wear those things that make her safe and so we’re severely limited in what we can do kind of out in public during the pandemic. And who knows how long the mask wearing is going to be in effect.

[12:39]

**Interviewer**: Yeah, absolutely, that makes sense. Do you think there are any types of services or interventions that would be able to help her?

**Interviewee**: So far with the ABA therapy coming to the house Monday to Friday is kind of the best we can do right now. We’re waiting on official word from her school with what we’re going to do for school starting in a couple of weeks. They have said that it’s going to be all virtual starting off, for everybody. But they’ve also sent us a couple … they’ve emailed us a couple of packets for her to keep her skills up throughout the summer and it’s stuff that I couldn’t even do! It’s like algebra and line intercept forms and all these crazy things. I’m like, “*She’s never learned this*!” They sent her reading lists and they’re all chapter books and none of it is geared towards Taylor at all. And then the other issue is that when she goes to the ninth grade these teachers have never met her, so they don’t know where she’s at, they don’t know what she’s been working on. They’re just sending her whatever they think is the curriculum, but it certainly is not geared towards her needs at all. So I don’t know if it really counts as sensory, but as far as attention and things like that, she’s not able to sit really in front of a computer. I mean the amount of time she was over here is about the longest you’re ever going to get. You know, a couple of minutes here, a couple of minutes there, a couple minutes upstairs. So, you know, I don’t know how she’s going to attend to online learning. But you know so much of her progress is based on social cues and how to act around other people and how other people act around her, and life skills like holding a fork and using a spoon and all those sorts of things, so those are all the sorts of things that you can’t really teach online.

[14:50]

**Interviewer**: No, they’re much harder to teach without that in-person component. Yeah, it’s a bummer and hopefully they can find a solution to fit everyone’s safety but also genuine needs.

**Interviewee**: Yeah, it’s difficult, and even if they do go in school for certain kids, do we want her to be in school since she won’t wear a mask and she doesn’t really social distance? Then we have the issue there because she doesn’t understand, you know it’s like, “*I hug everybody now I can’t*.” She thinks that … she’s such a social butterfly in that regard, which is interesting with the autism because it’s a little bit opposite of what you normally see, whereas to her everybody is a friend and so she wants to hug people, she wants to high five people, she likes to shake their hand. She loves all that kind of stuff and she gets a lot of input from that and that’s how we do a lot of positive reinforcement because she loves high fives, she loves hugs, she loves to hold hands and dance, things like that. And those are all things that they couldn’t do in school right now. Then going back to the sensory, let’s say she does get coronavirus and she ends up in the hospital, we would have to fight to have one of us stay there with her, she would *not* want to stay in that bed. There is *no chance* she’s putting oxygen on. So it’s like, you know, getting her [vital signs?] at the doctor’s office is hard enough when we’re there for any other kind of visit, let alone getting blood pressure every couple of hours, getting an oxygen on her finger, I mean I cannot … I’ve thought about what hospitalization would look like for Taylor and they would have to sedate her the entire time. Because I mean we can’t even take her to the dentist, we have to go to the hospital and have her put under general anesthesia for them to do even a basic cleaning. There is *no way* you’re getting a dentist anywhere near her. That’s a sensory thing too because you know those are general things that people need to do – they go to the doctor, they go to the dentist, they get these appointments done, and they are something we have to plan for. You know, a dentist visit is *so much* simpler when you can just go to the dentist, get your cleaning and come home and get your toothbrush to come home with, versus getting the appointment and waiting months for the doctor to be available and there’s only dentist in the whole area that does the OR [operating room] dental visit and it’s like one day, so if we’re not available that day we have to make ourselves available. Then with the sensory thing too, she hates having the IV, she hates having to wait, and then it’s like you’re waiting to go back. Then once she’s back and she’s under anesthesia she’s fine but then coming out of it she’s always nauseous then gagging and she doesn’t like that feeling of not being able to walk because she *wants* to be independent. So she wants to like jump up and run around, but she’s still out of it from the anesthesia, so we have to hold her in the bed until we’re ready to go and then we have to *wait* for the doctor and *wait* for the nurse and it’s just all … a long process.

[18:12]

**Interviewer**: Yeah, it sounds like it. It sounds like a lot. Thinking about kids like Taylor and young adults like her, do you think there are gaps in the available services and interventions that could help them in this intersection?

**Interviewee**: Oh yeah.

**Interviewer**: What do you think they are?

**Interviewee**: Well I think that they exist, but the availability of them is difficult. Her … right now, her dad being retired, we automatically are placed at the clinic [on base?] and it’s frustrating because every time we make an appointment it’s a new doctor. So she’s never really had a pediatrician or even just a constant, which I think would be so helpful because every time we’re explaining her *whole* life story to this new person and then we make an appointment a few months later and it’s like, “*Oh well that doctor got deployed somewhere else, so now you have this doctor*.” She takes a while to warm up to people, but once she warms up to them she’s familiar with them and she’s comfortable with them, so I think it would be *such* a benefit for her to have a stable pediatrician that could take care of her, but with the military we don’t qualify for that. They said that the clinic is available to us and that’s what we have to use. So she doesn’t have a stable health care provider. Psychiatry services in this area are horrible. We have basically one outpatient clinic, but they mostly focus on mental illnesses like schizophrenia, bipolar, things like that. We made one appointment with them and the guy told us that he had never heard of Taylor’s condition and he didn’t know anything about it and he only had one medication that he would prescribe her and that was the medication she had already been on. We told him, “*Well we’re here because that medication isn’t working*.” So he basically said, “*Ok, well bye*!” [*laughs*]

**Interviewer**: That’s not helpful.

[20:22]

**Interviewee**: No it really wasn’t, and it’s all telehealth, which I think for a lot of people is fine, but again, he’s not there with her kind of seeing those little nuances that you may see in person. You know, like we talked about how transportation is lacking, in-home caregiver support does not exist here other than the one clinic that we use. But yeah, I mean there’s really not much. We don’t have any special needs daycare. Well, we only have one day program but they have to be over eighteen and they have to be enrolled. They don’t do any sort of drop-in care or events or anything like that, it’s only for the people that are enrolled full-time Monday to Friday. There’s really nowhere that we could go to do an event or anything like that. They did have at one point like a sensory kids concert. They had a band that came to the library and they had little sensory things for kids to play with. They gave out fidget spinners and toys and balls and they didn’t hook up their microphones or anything so they just played the instruments and sang, but it wasn’t very loud and they interacted with all the kids and it was *amazing*. We *loved* it. Taylor had *so* much fun, she did *so* good. She saw some of her friends from school because a lot of the parents took their kids. It was *so* great and we asked them, “*Oh, when are these guys doing this again, is it a regular event*?” and they said, “*No, that was a one-time thing*.” We looked up the band and the band travels the country, so they’re never coming back. So it was like … it was such a fun thing for her and it was fun for us as parents to watch her kind of have fun and be kind of more relaxed, and that was, you know, a fluke that we caught that event. We’ve tried the indoor trampoline parks, but they’re so crowded, there’s kids everywhere, they jump all around, and they don’t recognize initially that Taylor has special needs, so it’s a little bit difficult and I think that was kind of overwhelming for her. We didn’t have a whole lot of success with that, even though she loves the trampoline. So as far as events out in the community or places that are available to her, they’re severely lacking.

[23:02]

**Interviewer**: Absolutely. Thank you for sharing that. Kind of thinking a bit more broadly now, how have Taylor’s sensory sensitivities impacted your goals, hopes, and expectations for her as she does navigate adulthood?

**Interviewee**: It’s hard, I mean I think every day we kind of – I don’t want to say necessarily dream – but there are times where it’s like, we’ll walk by and we’ll see parents with their kids on their bikes going down a bike trail and it’s like, man what would that be like to be able to just say, “*Hey kids, get in the car*.” So I think that there’s a lot of things, like going to the fair. We can take her to the fair if she has her wagon and she has her toys and we stay kind of on the outskirts. But, you know, I like carnival rides, I like rollercoasters, so I think for me it’s a little bit difficult because I grew up with my mom doing things like that and so it’s like now as a parent I want to be able to share that and we can’t with her. There’s a lot of things that developmentally she may kind of fit, like the infant and toddler programs, but they don’t even allow her in. Like story time at the library and things like that, they said, “*Oh, she’s too big, these are for toddlers only*.” They have a little water park nearby that has a splash area for kids and they told us that we cannot go in. We’ve explained the situation but they said that there’s no exception because the other parents of small kids go there, expecting to be surrounded by small kids, and they think that for whatever reason that she’s a threat. So there’s a lot of things that developmentally and chronologically like her age is so … there is such a gap, and as she gets older and bigger the gap is widening. It wasn’t as noticeable when she was so so small because she was … at age eight she could still almost pass for a five-year-old. But then she hit puberty and she shot up like her dad. She gained a couple of feet and now it’s like she’s probably five three, almost five foot four, she’s a hundred pounds, so she can’t interact with kids that are her developmental age because she doesn’t realize how big she is – she’s like a Great Dane but she thinks she’s a lap dog.

[28:47]

**Interviewer**: [*laughs*] Yeah, that makes sense. Thank you for sharing that. So kind of like putting it all together, as a caregiver and as a parent of a child who has ASD [autism spectrum disorder] but also sensory sensitivities, what does transition to adulthood mean to you?

**Interviewee**: It doesn’t mean much to us because she’s still going to live with us, she’s still going to be cared for by us, she’s still going to have all the same needs. So we’re going to have to get guardianship of her, we’re going to have to get medical power of attorney, things like that, because apparently when she’s eighteen she has the age of consent and things like that, but she doesn’t medically, so we have to be her decision makers. We have to be responsible for all those things and we have to go through the courts and fight to get that. So for us transitioning to adulthood basically means going to the court and proving that she is not functionally an adult, even though her age may be, and then kind of finding resources to keep her at home and safe with us and get as many supports as we can and things like that, and kind of just, you know, stimulate her mind and whatever milestone we can make with her we celebrate and whatever she can do we’re cool with it. I mean I don’t know that we have true specific goals for her because I don’t want to focus too much on one thing and then not be minding other things that she’s good at, so basically it’s just a learning process every day. Just seeing what she can figure out and what she can do and keeping her routine, keeping her schedule, things like that I think are all helpful for her.

[27:54]

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

**Interviewee**: I think we’ve always kind of been on that track. I think once we got her potty trained it was kind of a big thing. Getting her to tell … I mean we didn’t think she was ever going to be able to tell us that she had to go to the bathroom. Even though she needs help with toileting and help going, you know getting her out of diapers full-time was such a big step. So I think we’ve adjusted her goals a little bit but we’ve always known that she’s going to need an in-home level of support for her lifespan.

[28:38]

**Interviewer**: Absolutely. That’s a good segue to my next question. What do you see happening in her future?

**Interviewee**: So I think for her right now we’re planning on the day program, trying to find like a workspace that she could go to with a one-to-one aid. Whether it’s working at, you know, they have like a thrift store where she could like stand by the door and greet people. There’s a couple of restaurants nearby where I think she would definitely like to open the door for people and say hi to everybody. That’s her place! So I think for her it’s just finding some meaningful sense of community with a trusted support person. She definitely likes to be out of the house. She likes to be in the clinic where she kind of knows what to expect and she knows what’s expected of her. So I think definitely getting some kind of environment out of the house where she goes to receive services and then just basically staying safe at home and staying with us is kind of our goal for her.

[30:02]

**Interviewer**: Absolutely. I have one final question. How have her sensory sensitivities impacted this perspective?

**Interviewee**: I think it impacts it because it kind of helps us justify why those things are needed. With the safety awareness and stranger danger, she doesn’t have any of that. Knowing what to wear for what climate and knowing what’s a safe behavior and what’s an unsafe behavior, things like that, those are all impacted. So I think basically for us it would be mostly safety awareness and kind of learning what’s appropriate in a social setting. I mean for us just safety is just such a big thing.

**Interviewer**: Totally. That makes complete sense. That’s actually all I have for my questions. Would you like to add anything?

**Interviewee**: I think we’ve touched on everything.

**Interviewer**: Awesome. Well this was so great, thank you for making time and thank you for letting me learn from you, it’s been really helpful. Do you know anyone else who might want to participate?

**Interviewee**: I’d have to think on it. It’s hard, with COVID we haven’t really kept in contact with anybody from school, but if I do I’ll send them your way.

**Interviewer**: Yeah, that would be wonderful, thank you. You mentioned briefly just recently that you’re going to have to justify why you need to have guardianship over her, would it be helpful if I sent some of the reports from the surveys that you filled out, would that be helpful in any way?

**Interviewee**: Yeah, whatever you can, yeah.

**Interviewer**: Yeah, I’ll send you all the reports, easy-peasy. Awesome. Can I like help you or do you have any questions for me?

**Interviewee**: No, I don’t think so.

**Interviewer**: Ok awesome. Well I will send you a gift card very shortly as a thank you for all of your time and all of your effort and your help, so that will be in your inbox very very soon, but if you need anything from me in the future you know where to find me, please just reach out.

**Interviewee**: Yeah and if you need anything more from me or if you need any more information or anything just let me know.

**Interviewer**: Thank you, I will, I appreciate that. Good luck with your master’s and I hope you have a nice weekend even though you’re working.

**Interviewee**: Thanks, you too.

**Interviewer**: Ok, take care. Bye

**Interviewee**: Bye.

**[End of transcript]**