**[Start of transcript]**

**Interviewer:** Okay, we are recording. I will be asking you questions about your perspective regarding your child's transition to adulthood in relation to his sensory sensitivities.

**Interviewee:** Sure.

**Interviewer:** And I’ll be doing something called a semi-structured interview, which means I have my planned questions on my script, but I will be adapting them to follow our conversation so they actually make sense for us.

**Interviewee:** Okay.

**Interviewer:** And if there are any questions that you don’t want to answer for whatever reason, that is perfectly okay, you don’t have to.

**Interviewee:** Okay.

**Interviewer:** Perfect. And if there are things that come to mind later, you’re welcome to bring them up, it doesn’t have to be like a linear conversation.

**Interviewee:** Sure.

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

**Interviewee:** You want to know what my interests are? Or my son’s? I don’t know, I don’t know what the question was.

**Interviewer:** Sorry, about your son’s sensory interests or sensory sensitivities.

**Interviewee:** I would say that he has trouble with, he has hyperacusis, loud noises, where if you talk or shout, it’s actually painful for him auditorily. And then he needs to have so much distance away from people or he feels threatened, like he misinterprets that as he might get attacked. So he needs a lot of physical space around him to keep him, it kind of self isolates himself.

**Interviewer:** Do you mean that he perceives the auditory input as attacking?

**Interviewee:** No, I think that’s just more painful for him. He’s really just comfortable with loud sounds, loud noises, shouting, yelling. If you raised your voice like that, that would be aversive, that’s literally painful for him in his ears.

**Interviewer:** Got you. What about touch? I think in our last conversation you talked about sensitivity to clothing.

**Interviewee:** Yeah, he won’t wear any long-sleeve shirts, he doesn’t want anything to touch his forearms, his lower arms. He will wear pants, but he prefers shorts. But we live where there’s cold weather, eastern Washington, so he will wear pants, but he prefers shorts.

**Interviewer:** Will he wear long sleeves if he has to, or is that a definite no?

**Interviewee:** No, no, he’ll wear, because where we live it snows, he’ll wear a vest, he’ll wear a hat, he’ll wear gloves, but between his elbows and the gloves he has an open arm. So that kind of negates him taking long walks in the snow. **[03:00]**We can’t really go skiing or teach him skiing, because he would be too cold.

**Interviewer:** Yeah, absolutely. Does he have any other sensory sensitivities regarding vision, taste, smell?

**Interviewee:** No, just touch. He doesn’t want to be touched. If you give him a handshake or a hug, he probably would just get verbally defensive about a handshake, but if you hugged him, he might assault you.

**Interviewer:** Do you know what about physical touch he doesn’t like?

**Interviewee:** He just tells me he doesn’t want to be touched.

**Interviewer:** Okay.

**Interviewee:** So, I don’t know, I have never really found out.

**Interviewer:** Mm-hmm, that makes sense. And is that it for sensory sensitivities?

**Interviewee:** Yeah, I’d say mostly just auditory, sensitivity with the clothing and no touch, I think that’s mostly it.

**Interviewer:** Have these sensitivities changed over time?

**Interviewee:** To what time?

**Interviewer:** Have they changed over time, his sensitivities?

**Interviewee:** I think the hyperacusis is getting worse.

**Interviewer:** Oh yeah? How so, or like in what way?

**Interviewee:** Well, I mean, it never used to bother him that much if someone talked and *enunciated their language like this*, but now he’s very sensitive to that. I’m quite worried how that will translate in a job.

**Interviewer:** Yeah, absolutely.

**Interviewee:** And he’s sensitive to the TV, like he will tell us, you know how the TV has a number attached to the sound dial, 10, 12, 15, he’ll say, *“Mom, it can’t go past 10, or leave it at 7. ”*

**Interviewer:** Got you. You said that it has increased and been a little bit more acute. Do you know what marked that change for him?

**Interviewee:** I think maybe it has to do with not being in school, like he’s not as exposed to sound anymore. He’s at home now, so I wonder if he’s kind of lost his exposure, so by having less exposure, I mean, this is just my hypothesis, that he’s more sensitive, because he hasn’t built up his exposure anymore.

**Interviewer:** Yeah, that makes perfect sense to me. Is this related to COVID or just related to transitioning out of high school.

**Interviewee:** I think it’s just related to graduating out of high school. Yeah, **[06:00]** I would say that’s mom’s hypothesis, that’s mom’s educated guess, yeah.

**Interviewer:** It’s a good one. What about his sensitive to things on his forearm, has that been consistent over time?

**Interviewee:** Consistent, yeah, since he was little.

**Interviewer:** And what about the lack of physical touch, like a hug?

**Interviewee:** That’s pretty consistent since maybe age 5 or 6. When he was under 5 he would allow to be touched, but it might be because he didn’t know, he didn’t have the language to say he didn’t want to be, so maybe it was because he allowed it because he was little, and that’s what parents do, and then once he was verbal, he told us no. It might have to do with his verbal ability but I would answer the question from age 5 on, he’s been consistent.

**Interviewer:** Do you think any of the sensory changes that you’ve noticed, do you think they’re related to any independence that he has gained over time?

**Interviewee:** Independent studies did you say?

**Interviewer:** These changes, are they related to independence that he has gained?

**Interviewee:** Oh, you mean being independent?

**Interviewer:** Yeah.

**Interviewee:** I think the touch is, because he knows when you get older people don’t give you baby hugs and high fives. I think for touch, that has to be with being more independent, the other two, no.

**Interviewer:** What do you mean, touch? Do you mean because he can say no? Is that what you mean?

**Interviewee:** Right, exactly, and he also feels that as people get older they don’t give people high fives, pats on the head, that socially some of that goes away.

**Interviewer:** Yeah, that makes sense. And how does he manage or cope with his sensory sensitivities?

**Interviewee:** How does he manage what with his sensory sensitivities?

**Interviewer:** Manage or cope.

**Interviewee:** Oh, well, I would say he’s doing better. Because of home ABA which we started again in 2018, we’ve been teaching him self advocacy skills. So, with instruction, he’s learning to say, *“Please turn down the sound,”* or *“It hurts my ears,”* or *“You’re too close. ”*Because of ABA intervention since 2018, he’s learning self advocacy skills **[09:00]** and by learning those skills, he can appropriate advocate for modification, you know, keep the sound down, don’t get too close. So I would say they’re improving since 2018, but that’s because of ABA instructions.

**Interviewer:** Got you, that’s awesome. What strategies has ABA taught him, like you said, turn down the volume as an example, anything else they have taught him?

**Interviewee:** I think they taught him appropriate behavior, like, hey, don’t scream about that, say blank. Kind of like deflect and redirect. So you know, instead of hitting, they don’t come close. Instead of yelling, they keep the sound down. We’re not to keep the sound down please, yet, but we’re at keep the sound down.

**Interviewer:** That’s good, though.

**Interviewee:** Right, we’re trending in a positive direction. I think they’re teaching kind of deflect and redirection with his verbal language.

**Interviewer:** Did you reflect and redirect?

**Interviewee:** Yeah, like I think in ABA they say deflect and redirect, like if you were going to hit me and I’m an ABA therapist I might block your hit, and then I give you a high five, because I try to show you, you’d be getting just as much or more attention from me with a high five good behavior. So I think what’s different about him with ABA is because one, he’s so old, so it’s not tabletop exercises, and two, they’re teaching more verbal language skills to advocate, just like, hey, I’m blind, I need braille. So I would say it’s a little different in that they’re notreally tabletop exercises, it’s more about coaching him on appropriate language.

**Interviewer:** Mm-hmm, absolutely, thank you for sharing that. Has he received other therapies or interventions to help him with his sensory sensitivities?

**Interviewee:** He did do AIT when he was little. He did, I think you do it twice a day for a week, and it really helped.

**Interviewer:** Yeah? How so?

**Interviewee:** Well, he kind of got to a point where he was having so much verbal stim, like talking and humming so much, and holding his ears, that we really, I didn’t feel he would be able to receive any education because he was spending most of his day with his hands over his ears and like humming, kind of what I would say, **[12:00]** producing white noise. I know there’s not good data on that, but I really felt stuck on doing something because I thought this AIT, and I had his home program and I just felt like none of the input was going to be able to get in if he’s holding his ears and humming. I would say it lasted for about a year, it helped for about a year. He had it twice a day for, I don’t know, weeks, is how you do it, and it helps for about a year, then it kind of wore off. But he was never bad again, he never had as much white noise, he still produces some, but he doesn’t hold his ears and produce as much vocal stimming has he used to. He does some, but I’d say it’s down 50% from where it was when he was 6.

**Interviewer:** Got you, that’s great.

**Interviewee:** So, that’s something we did, and then I think that we did give some B12 shots, and I think those helped.

**Interviewer:** Helped in what way?

**Interviewee:** The auditory stim like with the humming and holding is ears, that’s just my guess. We did both the treatments at the same time, so it’s hard to say which did what, but maybe it was a combination of the B12 shots and AIT.

**Interviewer:** Yeah, absolutely.

**Interviewee:** That’s my guess.

**Interviewer:** I’m sure it’s a good one. When your son is in an environment where there are sensory sensitivities like loud noises, or there is something on his forearm, or someone does hug him, does it cause more increased anxiety for him?

**Interviewee:** I think so, yeah. I don’t know if I would say it’s anxiety as much as it will increase, it will increase behavior and the example would be the behavior could result in either assaultive behavior or verbal defensiveness with like swearing.

**Interviewer:** Mm-hmm, got you.

**Interviewee:** So, that’s how I would answer it, I would say I’m not sure it’s anxiety but definitely it’s going to be adverse behavior.

**Interviewer:** Got you. Has that always been the case?

**Interviewee:** Yes.

**Interviewer:** Has it increased or decreased at all?

**Interviewee:** I’d say that the auditory hyperacusis is increased **[15:00]** since he’s been out of high school. He graduated high school in June of 2015.

**Interviewer:** Sorry, I should have been more clear in my question. Do you think his challenging behaviors have increased or decreased in time in response to adverse sensory experiences?

**Interviewee:** Increased.

**Interviewer:** Okay, awesome, thank you. And the thinking towards the future, what are your hopes or goals for your son in terms of his sensory sensitivities?

**Interviewee:** My hopes and fears? Is that what you said?

**Interviewer:** Hopes and goals, but fears if you’d like to talk about that is also okay.

**Interviewee:** Okay, I think my hopes are that he can continue to trend forward with using his verbal skills for self advocacy, for example saying turn down the sound, or please don’t stand too close to me. And my goals are that he will be able to do it without a one-to-one support, just on his own.

**Interviewer:** Mm-hmm, that’s excellent, thank you. So, we’re going to move on to our next chunk of questions, we have a total of five chunks, we just did the first one. Thinking about community, as your son has grown up and aged, how has his and your community reacted to his sensory sensitivities?

**Interviewee:** I think they’ve been pretty accommodating.

**Interviewer:** That’s great.

**Interviewee:** But I would say that as his mother and legal guardian I’ve put a little bit effort into pre-teaching people in the community that he interacts with on a daily basis, so they have had some pre-teaching.

**Interviewer:** When you say *pre-teaching*, what does that look like?

**Interviewee:** Like, for example, he likes to go into the video game store, like, hey, how are you doing, my son and I buy video games here, I wasn’t sure if you’re aware, but he has a disability, but he likes to shop on his own now. You could talk slower, or ask him kindly, don’t touch him or give him a high five, thanks so much. Or the bank, you know, so, I haven’t done it with all but I’ve done it with I’d say 70% of the community he interacts with.

**Interviewer:** Are people receptive to your pre-teaching?

**Interviewee:** Yes, I try to make it with people that we actually do business with, I’m not going out of my way to do it with **[18:00]** people we don’t have a relationship or spend money. So I think they know it’s good customer service and I make it kind of humorous, I make it very short and concise, and I don’t ask for more time than maybe 5 minutes. So managers, store owners, employees, pretty sharp and to the point, and occasionally I write a note and take it there.

**Interviewer:** I’m sure they appreciate that too, because they can do better at their job, too.

**Interviewee:** Right and you have a store with a lot of employees, they rotate around, so if you tell one person, that doesn’t mean that everybody in the store knows.

**Interviewer:** Absolutely. What about when he was younger, was the community as accepting and accommodating?

**Interviewee:** Maybe not, but I also feel that I didn’t put as much effort by building that bridge with the community, but now that he’s an adult, that’s all I do.

**Interviewer:** Mm-hmm, absolutely. What part of the community? You just talked about businesses you attend, what about family, school when he was in school, a religious group if you’re part of one?

**Interviewee:** Well, we kind of dropped out of church. Well, I was doing pretty good, **[19:54 inaudible]** and then with COVID, no one was going. And with the family, I’d say some of the inclusions dropped off because he’s bigger now, and there’s little grandchildren, so no one tells us they’re frightened, but I think some of the family members maybe on purpose try to keep him away from the little kids, but I’m not sure.

**Interviewer:** Okay, thank you for sharing that. Thinking again to the future, what are your hopes or worries for how his community will continue to react?

**Interviewee:** My hopes and worries on how he will react in the community? I missed the first part of the question.

**Interviewer:** Oh no, it’s okay, hopes or worries about how the community will react to his sensory needs in the future.

**Interviewee:** Well, my hope is that they be patient, give him a chance or two to **[21:00]** explain himself, or even apologize. Sometimes he will raise his voice, my fear is that he will get arrested.

**Interviewer:** Yeah, thank you for sharing that. We’re going to move on to our next chunk of questions. In the *“transition to adulthood,”* where do you see your son?

**Interviewee:** Well, I see him living with minimal supervision in his living environment, it might be with his parents, in like a mother-in-law setup or a duplex next door and his goal is to go to a four-year special needs college program that has a residential component. That’s his goal.

**Interviewer:** That’s great.

**Interviewee:** Yeah, it’s 50/50, he has enough life skills and just about high enough IQ to go, but what’s holding him back is behavior and his need for one-to-one behavioral intervention.

**Interviewer:** Do you think he will be able to meet that goal with some more supports, like in scaffolding?

**Interviewee:** Well, I’ve got him enrolled in an adult program where we live, but he doesn’t want to go, and so we’re in the process of trying to explain to him, you have to try to attend the adult program, you need to try to attend, getting another job or internship job, because these are steps you need when you apply to a program. The exact program he wants is the UCLA one for admission, and progress, you know, he is resistant to a lot of language so I’m trying to lean on my ABA company to help me explain this to him. Because he is at the age, we can’t really force him to do anything anymore. So, he’s either got to engage and do it, or he does it and does poorly, then that will decrease his overall goal of getting to one of those four year colleges.

**Interviewer:** Mm-hmm, absolutely. So, you mentioned that he does have a lot of good life skills. Could you talk a little bit about what he is able to do independently?

**Interviewee:** Yeah, if you’re familiar with, a lot of research people know about the ABLLS for Autism. There is another one called AFLS, which is Adult Functioning Life Skills. So it’s kind of like ABLLS for adults because they actually have, it’s very taxing, **[24:00]** like the ABLLS, it’s like 240 questions and then they do categories, **[24:08 inaudible]** household, community knowledge. . .

**Interviewer:** Like what, sorry?

**Interviewee:** There are different categories for the AFLS, functional life skills, for instance a category for banking, money, and so except for leisure and some community knowledge and social awareness, he’s almost topped out in all of them. For example, the banking one has maybe 20 questions and so he has them all filled in except for the last two. He doesn’t have a banking app on his phone yet to check his balance and he is asking for is 21st birthday for a checking account. So, that’s an example, his money skills. **[25:09 inaudible]**

**Interviewer:** Sorry, you cut out for a second, can you repeat that please?

**Interviewee:** Yeah, so, or I can even send it to you, I have it on my desktop at home. So, out of the 25 categories, they’re almost all completed except for like 3 of them.

**Interviewer:** Got you. So, you mentioned banking, he is almost there, and I heard you say two other ones, I just didn’t catch them.

**Interviewee:** Yeah, I’d say community knowledge maybe 60% completed, mechanics 60% completed. Household chores is at 90%, social awareness 60%, mobility is 90%, transportation is probably 60, so out of those categories the categories that he’s got really deficit in are leisure and maybe social knowledge, which makes sense with his disability.

**Interviewer:** Yeah for sure, absolutely. And then do you think he will be able to achieve more independence in the future and be able to ceiling out on all these categories?

**Interviewee:** So far he hasn’t shown that he tapped out, so that’s why we’re kind of still pushing for his goals, so they’re a little high for him, he has not tapped out. He can learn now without direct instruction.

**Interviewer:** That’s awesome. And what do you think will **[27:00]** help move him into adulthood more?

**Interviewee:** I think he needs motivation with money and he really wants a girlfriend, he really wants a relationship, I think that would help him move to adulthood. He really wants the ability to drive, which doesn’t look like he can do, he’s tapped out on that, he’s not been able to pass the test. And maybe living on his own would help him, but I don’t know, we’re concerned that’s a double edge sword because then that will further isolate him. So, that one is a question mark, we don’t know, it could be good, it could be bad.

**Interviewer:** Why do you think a relationship will help move him into adulthood more?

**Interviewee:** Because he kind of knows, that’s like a life passage, and he does advocate, once we taught him the definition of loneliness and boredom, it took a while to teach him that around 19, 20, he does say he’s lonely, he said he wants a girlfriend, he wants to feel loved, so I think that would help him feel more complete.

**Interviewer:** Mm-hmm, absolutely. Do you think there are any services or interventions that could help him in these arenas?

**Interviewee:** Oh gee, if I knew of it I would drive to take him there. I do think there is an adult program in our area that’s just for social gatherings and hanging out, and I’ve tried to introduce him to that, but now it’s all shut due to COVID. I do think the college programs, there aren’t many, but there’s about, I don’t know, 12 in the United States now. I think they really do work on social gathering, social emotional opportunities. So, I think if he could obtain admission to one of those colleges like UCLA, Pathways is what it’s called, or WSU Project Roar, he would have a good opportunity to expand into those arenas. Because it’s more set up for him, he doesn’t have to do it on his own, it’s more set up. I mean, they can’t get him a girlfriend but they’re going to give him a lot more opportunities to meet girls.

**Interviewer:** Yeah, which is what we all want, right, no one can force us. . .

**Interviewee:** Right, like a dating app, they’re going to help him. **[laughter]**

**Interviewer:** Now, putting these two ideas together, his sensitivities and his transition to adulthood, **[30:00]** how do they intersect for your son?

**Interviewee:** Well, I think they are inhibiting him from some of his goals.

**Interviewer:** Mm-hmm, how so?

**Interviewee:** They are intersecting adversely. You know, like, with not being touched, there is often day to day activities you used to do before COVID where people would shake your hand. He had a job interview or job practice and someone shook his hand, and that just really set him off. So, he’s not going to make it through the first 10 minutes of a job interview pre COVID because of the shaking of the hand. So, that would affect him adversely. Now, if he remains living with us in Spokane, half the year it’s cold, 20 degrees. Even though he can rely on walking, he’s going to be adversely disproportionately affected because he won’t wear a coat and he won’t cover up his arms, so that sensory is going to be an issue, and then the noise, so you know, when you have low job skills, you might have to take varied types of job situations. Some might be like assembly line, or they might be in a store, and that, you can’t always control the noise volume. So there’s three examples of how those sensory sensitivities are adversely affecting his transition to adulthood.

**Interviewer:** Mm-hmm, absolutely, thank you, that was very clear and very helpful. You have basically answered this, but it’s part of my script, would you say his sensitivities are an obstacle, a vehicle, or neither, towards his independence, or a bit of both?

**Interviewee:** I’d say two of them are an obstacle and one a vehicle.

**Interviewer:** Which two are an obstacle, which one is the vehicle?

**Interviewee:** I would say the not wanting to be touched and not wearing the clothing are an obstacle. I guess the hyperacusis could be both an obstacle and a vehicle. I’d just say he’s really learning quickly just to advocate verbally for less sound. So, in a way, now that he has the ABA contact again, it’s like he’s just using the hyperacusis as a vehicle **[33:00]** to self advocate and he really doesn’t know that he’s autistic yet, so I’m thinking that this is going to be a vehicle pretty soon to teach him he’s autistic.

**Interviewer:** Mm-hmm, absolutely. Small side bar, but I also feel like not wanting to be touched during COVID, not a bad thing.

**Interviewee:** Yeah, right.

**Interviewer:** What do you anticipate as being challenging for him as he does gain more independence in regards to his sensory sensitivities?

**Interviewee:** That situations are going to come up, well, not right now, due to COVID, but after COVID, where people, because it’s a Western way to greet people with a handshake or a pat on the shoulder or a hug, I think that’s going to continue to come up and he’s going to react adversely, so that’s going to be a challenge. He’s going to have to continue to advocate about sound, that’s going to be a challenge, because that cannot be controlled when you go out in the community. I think the clothing, the other reason he wants to go to California is he just doesn’t like the weather and so if he remains in eastern Washington, then that will be a challenge because he will be cold any time he’s trying to ambulate outside.

**Interviewer:** Mm-hmm, absolutely. What do you think could help your son in this intersection?

**Interviewee:** I’m sorry, I didn’t hear that. How can I help him? Is that what you said?

**Interviewer:** What do you think would help him in this intersection?

**Interviewee:** More ABA. We don’t have any community waivers for him. Because he had early intervention 25 to 30 hours for 3-1/2 years age 3 to 6, he tested out of the need for state services. Also his nonverbal IQ is 89, so he is testing out for a lot of services. He needs those services because he needs to work on his behavioral intervention, otherwise he’s at risk to be labeled a threat and if the state labels you a threat **[audio break]**

**Interviewer:** Could you say that again please? **[36:00]**

**Interviewee:** Sorry, I was just saying, if he reacts violently in the community then he is at risk to be labeled a threat, then he would get what’s called a community service waiver in the state of Washington, which means he can’t go out without someone else.

**Interviewer:** Oh, yeah, that would not be good at all.

**Interviewee:** No, so it’s kind of like, for example, you might have a young man that likes to go to the playground because he likes children, but he might be on the autism spectrum, well, he may not realize socially he’s an older man and he’s talking to young kids, and that might be misconstrued. That person would also be at risk for community service. My son doesn’t do that, but he may hit someone if they shake his hand **[audio break]**

**Interviewer:** Sorry, I didn’t catch that last thing you just said.

**Interviewee:** . . . senses, even though it’s not real assault, he could label this a threat to society.

**Interviewer:** Got you, you cut out for a second, I just want to make sure I heard what you said. I heard you say that he could be at risk for being labeled as a threat, and therefore have this community waiver and someone could misconstrue his actions as assault. Is that correct? Did I hear you? Sorry, you’re cutting out.

**Interviewee:** Sorry, can you hear me now?

**Interviewer:** Yes, beautiful, I heard that, that was clear.

**Interviewee:** Okay, there are five types of waiver in the state of Washington through CHFS or DDD**[audio break]**

**Interviewer:** Ooh, I’m sorry, you cut out. I’m so sorry, you keep on cutting out when you’re describing the five different types.

**Interviewee:** Oh, sorry, okay.

**Interviewer:** No, it’s okay, it’s okay, this is what happens sometimes, this is life, not a problem. I think I heard you say there are five different types of behavior, predator, something else, is that correct?

**Interviewee:** Yeah, so you don’t want to be labeled **[39:00]**a predator or have behavior, because the state may intervene and say that a person with this disability can only access the public with health, and then they wouldn’t have any freedom.

**Interviewer:** Mm-hmm, yeah, absolutely. That would not be good. Do you feel like there are gaps in the available services and interventions for young adults like your son?

**Interviewee:** Yes.

**Interviewer:** What’s missing for you?

**Interviewee:** The biggest gap was between the school district and DVR.

**Interviewer:** In what way?

**Interviewee:** When I went to DVR which stands for the Department of Vocational Rehab, and I asked for help with behavior for my son, they said due to his age being 20, that they could not provide any behavioral support. So then I asked, well, my son has an IEP with the school district which does provide behavioral support, could we merge the two? Could we merge the school district behavior support person with the DVR job coach and job placement? And the answer was, *“We don’t usually do that.”* And I said, *“Could you?”*And they said, *“We rarely do it, we could.”* And then they did not.

**Interviewer:** That’s such a shame, I’m sure that was very frustrating.

**Interviewee:** Well, it was because we had nine meetings, **[audio break]**I found my son the job he wanted, I got them to sign on, all myself, without the DVR, and then he was terminated from his job in 1. 5 hours because he had behavior. But the point was is that I had told them in the beginning that he will need behavioral support, and that is different than a job coach, that’s different. And so as I said earlier, he got set up for failure.

**Interviewer:** Yeah, absolutely, I’m sorry you experienced that, I’m sorry your son experienced that.

**Interviewee:** And DVR apologized and I was like well you should have accepted the idea that when I came to you in the beginning what I said was what I needed to say, which was that my son will need behavioral support. So, they made him fail first, and now that he’s over 21, they can consider behavioral support.

**Interviewer:** They cannot consider that?

**Interviewee:** They can over 21, but they won’t do it at 20. **[42:00]**

**Interviewer:** Oh, that seems kind of silly.

**Interviewee:** So, it’s kind of a loophole because they’re so young, they want the school to maximize stuff, but they don’t want to merge with the school, they want the school to finish and then they’ll take over. There is no merging, there is no bridging.

**Interviewer:** Mm-hmm, absolutely. And then thinking a bit more broadly, how have your son’s sensory sensitivities impacted your goals, hopes, and expectations for him as he navigates adulthood?

**Interviewee:** Well, I tread lightly in my family’s gatherings and any kind of social gathering with friends, because I have to think about how many people will be at the gathering, oh, I forgot to say, my son does not like animals, so we don’t usually go anywhere, yeah, well, he doesn’t like dogs particularly because they bark. So we have to consider, can we take him to the social gathering at our family’s house or our friends’ house, because they have a dog. And then if they’re really good family and friends, we may ask for a modification before he goes, could you put the dog outside **[audio break]**It limits how many places we can go.

**Interviewer:** Yeah, I’m sure it does, absolutely. Does his sensitivities impact your hopes for his adulthood and what he can achieve?

**Interviewee:** For my home, you mean?

**Interviewer:** For him as your son.

**Interviewee:** Oh, What was the question?

**Interviewer:** Yeah, yeah, no worries. How does his sensory sensitivities impact your goals, hopes and expectations for him, for your son, as he navigates adulthood?

**Interviewee:** It puts more pressure on me as a parent and a legal guardian, because I feel the need to clear a path, pre-teach any public place he’s going to, advocate stronger for behavioral support or him, work with alternative medicine and traditional medicine to get him access to treatment that will help with his behavior and sensitivities, because they’re impacting him with full inclusion.

**Interviewer:** Absolutely, **[45:00]**that makes sense, I’m sure it’s a lot of effort on your part.

**Interviewee:** It takes me about 6 to 10 hours a week working directly with people, medical and educational and behavioral, just to help him access support or services, even though he’s home.

**Interviewer:** That’s a lot. We’re going to move into our final chunk of questions, we’re almost done, you doing great. As a caregiver, as a mom, as a parent of a child with autism but also some sensory sensitivities, what does *“the transition to adulthood”* mean to you?

**Interviewee:** It means starting all over, I liken it to the initial diagnosis which was, there was a lot of grief and sadness and madness, there was also busywork, get started with treatment, to get him verbal, to get his IQ going, just like a full court push. It’s more like that in adulthood, if you don’t push hard you’re just going to fall off the cliff. So I liken it to you’ve got to get going all over again, with the same amount of money, the same amount of intensity, the same amount of advocacy, or your son or daughter is going nowhere and they have no place, and no one.

**Interviewer:** That makes sense. Has this perspective changed over time?

**Interviewee:** Yes, when my son was younger, I didn’t really believe adulthood would be so difficult, I felt like he had pretty good skills from really intense early intervention, so I thought he would fit in and do better. So, I didn’t see it coming until he graduated from high school. But, you know, I really did keep pushing and he has good skills, but it’s not enough, it’s still a huge deficit.

**Interviewer:** Got you, that makes sense. What do you see happening in your son’s future?

**Interviewee:** Well, I feel it’s yet to be determined. I feel that his goals are a little bit slipping away from him, but they’re not unattainable **[48:00]**so I’m literally **[inaudible]** for things so I can help just like I did when he had earlier intervention to push forward, to give him the best opportunity to see if he can get to that four year residential college. And by the way, they’re not cheap, they’re private, the residential programs for the disabled at the colleges are not cheap, you know, they’re expensive.

**Interviewer:** Yeah, I can’t imagine they would be cheap, nothing is, unfortunately.

**Interviewee:** Yeah, you know, since he can learn and he does have so many life skills, it’s not clear to me that he can’t reach it, but he definitely needs an advocate like myself or a specialist in autism because of his sensitivities and because of his behavior, it makes the path much harder.

**Interviewer:** Mm-hmm, in terms of his goals, you talked about wanting a girlfriend, you talked about attending this four year program, what other goals does he have or does he tell you about?

**Interviewee:** He’d like to drive.

**Interviewer:** Oh yes, sorry, you mentioned that.

**Interviewee:** I did let him attempt to go to the driving school and take the test. He took it online and he took it in person and he took it with accommodations at the Washington State Drivers DMV and he can’t pass. So felt that it was my due diligence to make sure he could pass the written. I think he could learn to drive, but I also feel that would be irresponsible of me as his guardian if he can’t pass the written. So, I made him try to pass the written, and he reads at about a 4th grade level. He did try to read the book, the Washington State book, it’s 79 pages, I don’t think he got a lot out of it. But he did attempt and read every page. He really would like to drive.

**Interviewer:** Yeah, makes sense, it sounds like he put in a really big effort, though, so, maybe.

**Interviewee:** Yeah, because as his parent I’m trying to teach him that it’s not up to me, there are other people in the world that are going to say yes or no to him, and it’s a tough lesson but, you know, typical people, I’m sure you’ve had people at colleges tell you yes and no, or you might have got in one college and not another, and I don’t feel it should be any different for the disabled, so I’m trying to transfer that power to other people, even if it’s bad news, I want him to get him to get it, but not always from me.

**Interviewer:** Yeah, it’s a critical lesson in that transition. **[51:00]**Does he have any goals in terms of like a job or a career?

**Interviewee:** He would like to get a job, something with computers. His skills seem to be better with disabling the hardware in a computer than programming, that might be a little above his skill set at this time. But he’s pretty good on a computer and I think he likes it because the computer doesn’t talk usually, it’s quiet, and also, it’s very dependable. When it prompts you, it prompts you a certain amount of time, there’s not as much variability, and he likes stock, I could see him stocking, he likes game, and he likesmanufacturers of video games, what year they came out, so he could be pretty good at SKUs and expiration dates and things like that. He doesn’t say that’s what he wants to do, but he does have some skill there. And he can hand sew a little bit. He can do hand stitching.

**Interviewer:** Oh, nice, that’s a very important skill.

**Interviewee:** Well, I’d love to teach him to sew, but again, this is a great example for your study. A sewing machine makes a lot of noise, so he probably could learn the skill, because hand sewing is harder than a machine, but if you have hyperacusis or hearing sensitivity, what about the sewing machine? That’s going to be a problem.

**Interviewer:** Yeah, a lot of sensory things intersect lots of things that we do on a daily basis that we just don’t think about if we done have the sensitivity, so that is a perfect example. So, final question, actually, this perspective you described of this transition being kind of like a *starting over,* how did your son’s sensory sensitivities impact that perspective?

**Interviewee:** It creates more barriers because the path to adulthood for people on the spectrum is very arduous and difficult as it is, but then if you have an adult with behavioral irritability, hyperacusis, and skin sensitivity, you have to take those deficits into your plan and depending if you’re a layperson like me, I’m not a specialist so I don’t have access to speech audiology tests and games, you know there are certain speech tests you can even do to help with hyperacusis, like Fast Forward, well, I’m not a speech therapist, I don’t have access to that. **[54:00]**So then that puts more onus on the advocate or the parent, or even the school district to try to access that, and if you’re not in, you know, eastern Washington, I don’t have access to an academic institution like UDub or WSU, so that decreases my access to really highly skilled personnel. I did attempt to go to the WSU Speech and Language place, and they have exercises for auditory processes, they have a program for auditory processing difficulties, but they won’t accept anyone with autism, because they said that’s part of the disability, that’s part of the definition, therefore they can’t tease out what’s part of the autism and what’s part of something different. So, he can even access their auditory processing program.

**Interviewer:** That’s a shame, that’s a real shame.

**Interviewee:** And that seems discriminatory to me.

**Interviewer:** Yeah, I honestly don’t think it’s correct, personally.

**Interviewee:** And when he was young we did pay big money, we paid I think $1800 for an auditory processing program and it was run through LA, and we had our ABA company was licensed to administer it, but they were not licensed to take the data, figure out the plot points and that, but that was all our doing. We had to pay for it, it was all private. But it was a brand that’s called Fast Forward. And so it actually slows the speech down until you can understand the word or the sound and then it speeds up. So if I said the word, *chair,* it might be *chhaaiirrr*, and then every week when you’re looking at my data, if it looks better, then the programmer will set the computer and then the next week it will be *chhairr* [shorter] and then the next week it will *chair* [shorter]. Yeah, so, which is super helpful. I can’t get that from the university, I can’t get it from the school, you know, **[57:00]**I have to go to highly trained people in a different state.

**Interviewer:** Yeah, that’s really frustrating, that’s really hard. So, he did use that Fast Forward program when he went to LA, is that correct?

**Interviewee:** We used it in Spokane, but the programmers were in LA.

**Interviewer:** Oh, I see. Did it help him?

**Interviewee:** He gained 12 months of speech in 6 weeks.

**Interviewer:** Wow! That’s awesome! That’s amazing.

**Interviewee:** It’s crazy, yeah, and you would think, I mean, you know, so many with autism are excellent at the computer and they’re on the computer all the time, what a shame that you can’t use this program more. I mean, maybe there are other programs, I’m not trying to say this program is everything, but it’s pretty amazing. Even the speech therapist who didn’t believe it, we had people take speech tests pre and post the program, and he gained almost a year of speech.

**Interviewer:** That’s awesome, I’m so glad that happened for you.

**Interviewee:** Yeah, thank you.

**Interviewer:** Yeah, so that’s actually it for all my formal questions. Is there anything else that you would like to add?

**Interviewee:** No, just it’s just been great hanging out with you, Rachel, and thanks for your flexibility.

**Interviewer:** Oh yeah, my pleasure, this was great, I’m glad it worked out for us.

**Interviewee:** And I think I still have three questionnaires to do, I did three last night.

**Interviewer:** Yeah, I was going to ask, did you have trouble with them or was it just like a time thing?

**Interviewee:** Just a time thing, I did three of them, I did the ABC and, well, the first three and then, yeah, and then when you complete them, do you get your cash card or your Amazon card?

**Interviewer:** Yeah, so as soon as you finish those other three, I’ll send you an email with a gift card, it’s an Amazon gift card.

**Interviewee:** Oh, thank you.

**Interviewer:** Yeah, thank you, this has been wonderful, your insight, is so helpful and every parent has a unique perspective and it’s such an honor and a pleasure to hear from every parent.

**Interviewee:** Aw, thanks. Yeah, you might tell your professors, I used to be the president of the Washington State Autism Society, not that that’s a big deal, but you know, it did give me a chance to work at the legislature, I was on the governor’s task force for autism, I got to work with the Department of Health on a grant back in 2010 to develop a website, show resources and training. So, I feel, compared to a lot of families, I had **[60:00]** more income, more access, and look how terrible it has been for me? So I really have a heavy heart for single families or families where English is a second language, or single parents, or people with autism in the foster system, because I just think that there isn’t anybody looking out for them as much, you know? They fall in traps, like incarceration or the court system, and I worry about that.

**Interviewer:** Yeah, it’s a real worry.

**Interviewee:** Yeah, or even just restraints and seclusions at the hospital. . .

**Interviewer:** Absolutely. And a lot of parents I’m talking to say they don’t know what’s out there, and there is this massive lack of centralization. There could be lots of services out there to help these families who need help, but they just don’t know about it.

**Interviewee:** Even there aren’t a lot of services, that’s good to know that, because then you need to know, well, maybe my family wants to raise money to send Johnny to WSU, maybe we should buy a duplex and try to get a waiver through DDD, and then we have 25 hours of help a week, I mean, even knowing there’s only four resources, it’s helpful, even though it’s not good news, because it puts families in the driver’s seat to take action. It’s kind like I mentioned, you don’t want to lose a lot of pressure time right now, because if your loved one sits at home too long, that’s what they’re going to do, they’re going to sit at home. And then I think the last thing I’d like to share before we say goodbye is that I took it upon myself to get legal guardianship in the court for my son and some people would not do that because, like, my son has pretty good skills. I did it to help protect him legally, in case he ever gets booked for assault or anything like that. And I think, especially with COVID right now, I think families need to think about that because, you know, if Johnny goes to the hospital and you can’t take Johnny because he’s 18 and over, and Johnny wants to leave because he’s a full fledged adult and no one has guardianship, I mean, it’s going to be pretty hard to commit Johnny. And so these are new problems with COVID and I’m concerned about how that’s going to go down. I think we need more advocacy at the universities **[63:00]**telling parents. Hey, I do telemedicine now with a psychiatrist and a doctor for my son. But you kind of want to set that up now in case you have more issues with COVID, I would just **[audio break]**take someone with autism that is nonverbal with behavior to the ER, and you can’t stay. I guess the person could stay, but if they get admitted, they’re probably not going to be able to be their family, it’s going to be a disaster. What is going to happen? Are they going to get booked for assault? Well, they could. But if you have legal guardianship, they probably wouldn’t. So I think it’s an extra layer of protection and some might say, well that’s decreasing their access to being an individual, but I think right now with the police brutality, did you see that thing about the boy that got shot in Utah?

**Interviewer:** Yeah.

**Interviewee:** Did you read that? Yeah. I mean, the Washington Post reported that 22% of people with disabilities were shot by the police least year.

**Interviewer:** That’s a way high number.

**Interviewee:** Yeah, disabled lives matter. So, same thing. But of the thank you for your time, I’ll get off my soapbox now.

**Interviewer:** Oh, no, no, this is the place for your soapbox, I appreciate it.

**Interviewee:** Oh good, there you go. Okay, Rachel.

**Interviewer:** One final question, do you know anyone else who might want to participate?

**Interviewee:** You know, what I was thinking is if you can write up a little for us, we might be able to put it in our email newsletter and it goes out to about I don’t know, a couple hundred people, and then I can give you the email to the ARC of Washington, or the ARC of Spokane. I think if you put something kind of catchy in there, like, *Hey, help us help you,* you know, buy yourself a Halloween treat for you and your family, I think people would do it. I think going through the ARC of Washington would also be good, they have a newsletter. But if you just email like tomorrow, I could try to put the email in the letter further below, and then you can decide how you want to do it. If you write me a little paragraph, I can introduce you to my email people, because we have a newsletter that comes out every month and so you missed October, but it could some for November 1st.

**Interviewer:** That would be awesome, we so appreciate that.

**Interviewee:** Okay, yeah, how many people do you need for the participants? How many people do you need? **[66:00]**

**Interviewer:** We’re really close, we need a total of 485 and we have like 484, so this might not be the best avenue, because we wouldn’t want to turn away people, but we’re really close.

**Interviewee:** Okay, Yeah, okay, so just three left, okay, cool. And then I helped Thomas Burbacher at UDub do a urine perforin study for children with autism and we got 79 participants and I had to collect urine, so there you go, how does that make you feel?

**Interviewer:** Very confident. **[laughter]**

**Interviewee:** That’s a lot of urine to run around with in the state of Washington. So, anyway, yeah, you can google it, I’m sorry it was James Woods, it’s in the environment health perspective, children with autism. So anyway, a little trivia, a little autism trivia for the day. So, I feel for you.

**Interviewer:** Thank you. Again, thank you so much for making time on your drive and being flexible, this has been so wonderful to talk to you.

**Interviewee:** Thank you. I think this is a good time for me to not be interrupted. Yeah, if you and your professor want to meet Griffin, I can definitely set up a Facetime link if you want to say to say hi to him.

**Interviewer:** Awesome, perfect, excellent, thank you.

**Interviewee:** Okay.

**Interviewer:** Thank you, have a nice rest of your drive.

**Interviewee:** Okay, thank you so much, bye Rachel.

**Interviewer:** Bye.

**[End of transcript]**