**[START OF TRANSCRIPT]**

**Interviewer:** Cool, we’re recording. So, we had just started talking about our new chunk of questions, it was a good transition last time. So, you had just described Parker in terms of his transition into adulthood as doing better than you thought, you talked about how he's in college. And so, now could you describe a little bit about like where he…like his state of independence? What are some things he's able to do independently and what are some things where he needs some support?

**Interviewee:** Yeah, so he can do a lot more independently than we imagined. So, I’ll kind of go through chunks of life; when it comes to taking care of himself, personal hygiene, getting up, managing an alarm clock, just sort of self-management, he's great. He does all that really well. He actually still struggles brushing his teeth. So, the nice thing about having split this up as I was able to really like *watch* him for the past week **[Rachel laughs]** between the two calls, and he said something the other day. He said, *“I just don't like the way toothpaste feels in my mouth,”* and I went, *“ahhh, that's a sensory thing that I had just never even thought about.”* I just bug him and nag him to brush his teeth. So that's a sensory thing that he's got, but I would say better than your average 21-year-old male these days, he's self-managing, takes care of himself.

Academically, he still struggles significantly. So, he did decide over this past week, for example, that he's going to take a break from college classes and he's just not ready, he can't separate out all the cacophony of noise of a teacher's lecture to try and figure out what's really important in that. So, you know, academically he still needs quite a bit of support to just…so much about our education system is designed to get kids to fail, right? Be it questions that say ‘which of these is not true?’ And then the next question is ‘which of these *is* true?’ And if you aren't clearly paying attention to that, you’ll just fail the questions, and yet you still know the material, right? So, he really struggles with a lot of those kinds of things.

**[00:02:35]** Food wise, he really surprises. So, in these conservation corps programs that he did over the last 2 years, we started talking about how as he became older, he needed to be *cautious* and cognizant of who he told that he has a diagnosis of autism. I think I mentioned this in the last call, in the school environment, like all the way up until 12th grade, having a diagnosis is a benefit, it opens doors up, it gives you access, it gives you freedom, it gives you an individual education plan, it gives you all these things. The moment you walk across that stage with your graduation cap, it becomes a label that may or may not prove good for you. So, as an example, in his first Idaho Conservation Corps, he decided to not tell anyone – and he ended up telling them later in the year – but he decided not to. But he couldn't figure out how to grocery shop. He was given $180 to buy 2 weeks’ worth of food, and he was like, he bought a lot of gummy bears and M&Ms and stuff like that, and then didn't have the right foods. And so, I stepped in and *significantly* helped him with shopping plans and grocery lists and that organization and how do you get through a noisy grocery store, 'cause we've never…and so we started to realize, like a lot of the coping mechanisms we did to help him grow up actually became problematic as he was becoming an adult.

So, a grocery store’s very noisy and chaotic, lots of people there, we just wouldn't take him in there! Well, now here he is, an adult over in Idaho, he needs to go grocery shopping, and that's pretty overwhelming, right? So, we taught him things like, even my husband and I when we go grocery shopping, we go at 6:00 in the morning on Sundays.

**Interviewer:** Me too.

**Interviewee:** It's like it's still the stocking clerks at that point, there's no crying babies, there's no families, the noise level is significantly less. So, that's that noise sensitivity that could still be problematic. But I would say that with the exception of tweaks that he needs to make here and there, he's really, really quite independent.

**Interviewer:** That's wonderful. Is he able to prepare his own meals?

**Interviewee:** Yes.

**Interviewer:** And you talked about him being pretty good about self-management in terms of getting up on time, hygiene, things like that. How is he with household chores?

**Interviewee:** Good, very good. If I were to take…I assume you're familiar with the usual tests that parents get when they're going through an autism diagnosis, it's the one that's green – can’t remember the name, it's not Wexler, but it's the one that’s green, always comes on a green card, you know, that one. If I were to fill that out now, it would all be all 2’s for self-management, household chores, and that was not the case early on.

**Interviewer:** Yeah, absolutely. And how is he with like money management and budgeting?

**Interviewee:** If you'd asked me last year, I’d have said zero. And this past summer, something shifted and changed. So, for him a $1.00 in was $1.50 to be spent. Like, *“well, you overdraw your checking account again.”* I mean, you’re standing there with that **[00:06:05 inaudible]** like, *“alright.”* And this past year that he had a sudden shift and change and became quite competent at understanding you have to save today's money for tomorrow's bills.

**Interviewer: [00:06:19]** Awesome. That's a good thing to learn.

**Interviewee:** And I don't know how, I'm dumbfounded how that happened.

**Interviewer:** Yeah, got you. And what about moving out, has he expressed interest in doing that?

**Interviewee:** Permanently, no. But he's very comfortable…so, in 3 weeks he leaves to go to Iowa and he'll be living there for a year.

**Interviewer:** Wow, that’s a long time.

**Interviewee:** Yeah, it's a long time, **[with a sobbing voice]** it’s a really long time **[chuckles]**. And he won't be living solely in Iowa, he's going to be with the National Conservation – National Community Conservation Corps. And so he'll be going to all kinds of different states, he'll be living in different rooms, he'll be living in different environments, different states, sometimes camping, sometimes in hotels, sometimes in cabins, sometimes…all kinds of things. And here was something that really struck me last week as we started thinking about packing, he said, “*I don't think I need to bring my sleeping bag, they're going to issue me a sleeping bag.”* I was like, *“yeah, maybe a government issued sleeping bag, it's not gonna be cozy or comfy, right. You get that?”* He goes, *“no, I think I'm OK with that, it will be itchy, but I think I'm OK with that.”* I was like, *“OK, well can I buy you like one of those REI sleeping sack liners?”* You know, to go in it kind of thing. So, he said, *“OK, OK yeah, we could do that, I can have a sheet to go in it.”* So, I think there are aspects of…he's more recognizing that he's got to do his own coping mechanisms to become as normal as he can become, if that makes sense?

**Interviewer:** No, absolutely. And after this year is over, does he want to come back home with you or is he comfortable kind of going on and off?

**Interviewee:** Yes, yeah.

**Interviewer:** Got you. And does he want to continue doing this conservation work as his job? Like as his career?

**Interviewee:** Well, he can only do it one more year. So, the way the Americorps grant things work, you can do it 4 times. So, let's do it one more time. You know, what he wants to become, actually, is a wildland firefighter and a forestry technician.

**Interviewer:** Got you, that's awesome.

**Interviewee:** So, still outside, he would never be able to do a cube-based job.

**Interviewer:** That's OK, not everyone should **[chuckles],** not very fun.

**Interviewee:** Yeah, I was just looking back at some of his diagnosis papers and there was a lot of discussion around setting up a trust for him, setting up a permanent way to take care of him, and we haven't done any of that because I see enough signs. I guess I would say if my husband and I were to unexpectedly die tomorrow, it would be devastating that he does not have enough skills to become independent yet, he does not have enough of a plan to become independent yet. But I see enough signs that the possibility is there.

**[00:09:22]** Great. And does your son manage a social life to some extent?

**Interviewee:** Yes. Yeah, that's been very, very difficult. Actually, a fellow researcher which I didn't realize was also at Boston U until just as I was clicking your links this morning and went ‘wait a minute, you guys are both at Boston U’.

**Interviewer:** Oh! Who is it?

**Interviewee:** It's called Project Crush.

**Interviewer:** Oh yeah, Crush, they’re at Children's Hospital.

**Interviewee:** Yes, yeah, Boston Children's Hospital. Yep, Yep, in the Lab of Cognitive Neuroscience…

**Interviewer:** I used to work in that lab.

**Interviewee:** OK, excellent. So, they found us, I can't remember the gal’s…Brooke! Brooke is her name.

**Interviewer:** Yep! we've been collaborating for recruitment purposes, she's great.

**Interviewee:** Awesome! Well, she found us. And so, he just got approved for her study, and we’ll be doing the interview today on that. And I really, really wanted him to be comfortable doing this one, because best I understand her topics, this has been a hard area for Parker. Parker has not made friends well, he does not keep friends well, he's never had a girlfriend that he’s been able to connect with. He has one friend who they call each other brother and sister, like they are really good friends, but he picked up the worst of the worst kids when we put him in high school to be his friends, which we didn't quite get was totally going on. So, that social side of life has been *excessively* difficult his whole life. There's an aspect of some of his deficits that gets into an obsessive area, and so…like a lot of autistic kids, singular topic kinds of things. One of the ways we saw that manifest itself when he was younger is we lived in a neighborhood that was full of kids, like if you didn't have a kid, you didn't buy a house in this neighborhood, like you just…like, why would you live there? It’s the cacophony of noise of kids and bikes and all this kind of stuff, right? So, that was great. The downside was there were 2 boys that lived 2 doors down from us that were intermixed age. So, Parker was the oldest and then their boy and then my younger son and then their younger son. So, it was like 4 boys across 6 years of age kind of thing.

And Parker became so obsessed with playing with them that like at 5:00 in the morning in his underwear, he would get up and go sit on their doorstep until it was time to play. And I’d get up at 5:30 for my coffee and I'm like *“frick! Where's Parker?”* And we knew that he was just on their doorstep. And it was like no matter what we did to help him understand that that's not OK, he can't be doing that…and sure enough, the boys and the boys’ mom…like the boys’ mom was understanding about Parker, but the boys started going like, *“this dude’s weird, like he's creepy, he's stalking us, he's weird.”* And then that would devastate Parker because they wouldn’t wanna play with him. But he couldn't understand that the boundaries that he didn't have were boundaries that other kids demanded.

**Interviewer: [00:12:34]** Yep, that makes total sense, thank you. You've alluded to this a bit in your previous responses, but do you think your son will be able to achieve more independence in the future?

**Interviewee:** Yes.

**Interviewer:** In what ways? Or like how do you envision this manifesting?

**Interviewee:** It's an interesting question. I think a lot of it will have to do with if he can get the job of his dreams, which is working for the US Forest Service or Department of Natural Resources, the likelihood that he would be in Olympia is slim. Most of the people that work in Olympia are going to be more the Bachelor degree type, natural resource people, 'cause they're in the state offices doing the planning work. The field work is done in very remote locations. And so, if that can happen, I believe that he will be very successful basically living on his own but in Forest Service camping tents and driving the Forest Service truck. So, it's in a way I would call it…it's almost like supported independence, if that makes sense? Like they have no idea that that’s what they’re doing, but when the truck is provided to you, when the cabin is provided to you, when the bunkhouse where all the forestry technicians live is provided to you, it mitigates some of the challenges of independence.

**Interviewer:** Yeah, absolutely.

**Interviewee:** But when I close my eyes and I think about, OK, so he gets a job here in Olympia and he moves out and has an apartment 2 miles away from us, well, that just doesn't seem to make sense. Like I can't wrap my head around that as being, well, why wouldn't he just stay living with us, until then and if he found a relationship that warranted obviously leaving the house? But like I said, I'm really interested to see what Project Crush does because I don't see a line of sight to Parker having a relationship, a marriage, a family kind of thing.

**Interviewer:** You don't see that?

**Interviewee:** I don't, I don't. I hope I’ll be able to see that, I want to be a grandma, of course **[Rachel laughs]**. But that's a hard part for me to imagine because it's an area in his overall autism that we just have never really cracked the nut on, and seeing the growth of mitigation, the growth of independence like we did in sensory issues, academic issues, general independence issues, things like that.

**Interviewer: [00:15:21]** That makes sense. So, you just mentioned his job as kind of a form of supported independence. Do you think there's anything else that would help him move into adulthood a little bit?

**Interviewee:** Yeah, I mean if I…if I think about programs that Seattle offers, for example, I've done things, I've done everything and anything and then some to give him opportunities, like the Doctor, the Neuroscientist, the Neuropsychologist that we saw for a long time lived up in Mountlake Terrace, which is Timbuktu as far as Olympia is concerned, you may as well drive to Canada. And we would go up there because that was just the right thing to do. Well, over time, that becomes less of a concept and smaller communities just do not have support. He was part of a…at a supported job, so he was a fifth-year high school student, in his fifth year [he] did a program called Project Search, which I believe is a nationally accredited program concept, and it involves supported employment with a support organization and the Department of Vocational Rehab. So, it's like this trifecta; they have private employers, this nonprofit that works with disabled adults, the Project Search curriculum and then the high schools. So, they all work together and they…and Parker did that. He actually ended up graduating after the first semester, so he only did it for 5 months. But that that was about it in our community in terms of adult support for moving forward. So, I think that's what concerns me. And then again, it’s that whole thing of like, a diagnosis in high school is helpful, a diagnosis after school just makes you lost.

**Interviewer:** So, what specific things would you wish were available in your community? Like are there particular services or interventions that you would think could be supportive and helpful for him?

**Interviewee:** Sure, social groups, therapy groups, therapy providers who understand that teaching an autistic person CBT skills isn't going to work, they need …'cause every therapist in America practices Cognitive Behavior Therapy, and I'm like, *“yeah, well that's not helpful.”* Because if you don't understand the autistic *brain*, then you're not gonna teach some of these things. So, I guess it’s too general to say, I just want more, I want more! I want…I want…I guess that kind of wraps it up there **[Rachel chuckles]**. I want social skills groups, I want social skills training, I want…yeah, just stuff like that.

**Interviewer: [00:18:35]** Yeah, absolutely. And now putting these two things together, your son’s sensory sensitivities and his transition to adulthood, how do they explicitly intersect for him?

**Interviewee:** It’s a good one. There is a…so, if I think about like his noise sensitivity, his dad works in a glass manufacturing plant, and they would hire Parker in a heartbeat. In fact, he did get hired there over the winter just to do some basic work, keep himself busy, kind of thing, sort of more as a favor for my husband than anything else. But at the end of it, 2 of the supervisors of the work crews came up to Parker and said, *“hey, if this Iowa forestry thing doesn't work out for you, you come back, I would take you on my crew in a heartbeat.”*

**Interviewer:** That's awesome!

**Interviewee:** Which is great! It's a living wage job, it has health insurance, it has benefits, my brother actually works there too, so it's our whole family, family deal, right? And it's pretty cool, nobody really thinks about how the window that you look out gets made. And in this case, it's actually how the glass gets made, kind of thing, so it's kind of cool, right? He couldn't work there, it's so freaking noisy! **[Sneezes]**

**Interviewer:** Bless you.

**Interviewee:** Oh excuse me.

**Interviewer:** You OK?

**Interviewee:** Yeah. It is noisy, it's dirty, the supervisors yell if you don't meet your quotas, that kind of a demanding sort of environment, it's just like, you've got to be kidding me! And what's interesting, because Dad doesn't really get the autism part like I always have, my husband was like, *“he should just go and work at Cardinal, he could just get a job at Cardinal. What’s this forestry crap? He's never gonna get through school, he should just get a job at Cardinal.”* And I’m like, *“you don't understand, he would last 6 months before he would be…”* And maybe I'm wrong, maybe I'm too protective, Dad is too pushing and I'm too protective, right? So, maybe together we balance out. But I think about things like that, that the kinds of jobs that a high school graduate with deficits can get in our environment these days, or in our society these days, they're not usually great jobs, right? You go back…I mean, you know, it's all over society these days, right? The loss of manufacturing jobs or the loss of low wage jobs and things like that. I think that would just be really…that would be hard.

**Interviewer: [00:21:18]** Yeah, absolutely, that makes sense, thank you. And then do you see his sense of his sensory sensitivities as an obstacle, a vehicle, a bit of both or neither towards his independence?

**Interviewee:** Did you say a vehicle as the second choice?

**Interviewer:** Yeah, as something that would facilitate independence.

**Interviewee:** A little bit of both, I would say. If I were to draw a Venn diagram, I would say he's got obstacles because of some of them, and he's got facilitation because of some of them.

**Interviewer:** How so?

**Interviewee:** It will largely come down to what we've seen in the past year, does he continue on that kind of path? So, a little bit like I described, he said last week, *“I'll take the itchy government issued sleeping bag because I don't want to be different than everyone else, I don't want to have to explain why I have a different sleeping bag than the rest of the crew.”* I was like, *“OK, that's a great, great reason, that's a great decision!”* So, can he make more of those decisions and less of the decisions that emphasize the sensory difficulties, I guess.

**Interviewer:** Got you. So, you see that decision as being a vehicle towards independence and you see…?

**Interviewee:** Right, yeah.

**Interviewer:** Got you.

**Interviewee:** But I see him coming home from Cardinal and having to go take a 2-hour nap at the end of a work shift because he was overwhelmed with all the stimulus and the noise and the forklifts that are beeping when they back up and the people and *“they stand too close to me mom and and and…*” he would…and I’d be like, *“you gotta get your biology done, you gotta get your biology done.”* He's like, *“I just need to go take a nap, I just need 2 hours of silence.”* I was like, *“alright, you're not going to get biology done anyway,”* with how ramped up he is, *“so, go lay down, go take a shower.”* We call them coping cards, *“go use your coping cards, take a long shower, go take a nap and then come down, you gotta get your biology done!”*

**Interviewer:** Got you, that makes total sense, thank you. And then, relatedly, what do you anticipate as being challenging for your son as he does gain more independence in relation to his sensory sensitivities?

**Interviewee:** More challenging. I guess it just becomes the, you can't be independent without a living wage job that facilitates independence. So, overcoming enough or mitigating enough of the sensory sensitivities to find that living wage job. And part of what I mean by that, so in this Project Search thing, I still debate whether it was the right decision that we made or not. In some ways it wasn't because he was in a cohort of extremely disabled individuals, and he's not, like I mean if you met him, like if he woke up I’d have him come look at the camera, you’d be like, *“I think this lady is lying, he's not actually autistic.”* I mean, you just wouldn't know it when you talk to him. And so, what that Project Search did though, is it…you become like your peers or you become excessively on top, like you look at your peer group and you say, ‘I am not that, so I'm going to therefore be 10 times better.’ That's actually what happened with Parker, which was great. But that organization, most of the jobs that they were connecting people with were McDonald's, the movie theater, Domino's Pizza and places like that. And I kept saying to the organization, I said, *“you are funded by the Department of Vocational Rehab, we live in the state capital. Why aren't some of your employer options these state agencies?”* Like why are…he got this list, he was like, *“did he want to have the internship at McDonald's? Domino's? The movie theater or…?* And I was like, *“no, I thought we would have opportunities where he could be an intern at DNR, an intern at the Department of Ecology, an intern at…”*, you know, and they just haven't done any of that. They're like, *“our kids aren’t gonna be able to do that.”* I was like, *“oh, this kid can, if you facilitate it,”* right? And so there's this sort of, I guess what I would say, you know, what I worry about independence is there's this natural lowest common denominator that happens in society. I mean, you could even go so far as to say that's what's happening in all of our racial issues that are going on right? Like, oh, oh, you're black? Therefore, you must be poor, you must be stupid, and you must need only a job doing blah, right? Oh, you're autistic? Oh well, that must mean that you're going to flap your hands and you're going to spin around in circles, and so we’ll get you a job at McDonald's. People like to label and then box and then lowest common denominator the individual. And that's a problem in society that affects everyone of us, whether we realize it or not.

I was actually having a conversation with my boss last night and he was asking, *“well, do you want to do a project that works with…”* this other gentleman? I said, *“no, he's a masochist, and I'm sorry, I shouldn’t have probably said that,”* but no. He is so demeaning to women and he does not understand that women can be leaders and he thinks all women should be at home raising babies with their hair in a bun. No, I don't want to work on a project with him, but if you tell me I have to, sure, OK, I like my job. So, no matter what sort of labeling you are, there's an oppression, there's a collapsing of that label.

**Interviewer:** Absolutely, makes total sense, I understand. And so, at this intersection of sensory in this transition, what do you think would help your son?

**Interviewee:** More tolerance by employers. So, I'm thinking about a conversation where Parker came home and he said that the Cardinal was just really noisy and it was really hard for him there, and my husband's response was, *“it's a job, deal with it.”* And my response was, *“get your headphones, you've got the extra special ear pluggy things, ask your boss if you can have your headphones on when you're doing this work that doesn't involve anything…”* blah blah blah. And so, he did that and it actually worked.But he was scared to ask for those accommodations.And so more tolerance by employers, and maybe it's not tolerance, but more awareness.So, I’ll use a stupid example; every forklift when you back it up makes the most *horrific* beeping noise, because one time, somebody got run over by a forklift.Can we change the beeping noise?Can we make it a vibration instead of a hissing alert? Can we…I could go on to lot of different examples but you get the idea, right? Can we take things we've done in our world and understand what that thing sounds like to someone with sensory sensitivities?

**Interviewer:** That makes complete sense.

**Interviewee:** And I think the answer to that is no **[chuckles]**, but I mean, I would love to see that.

**Interviewer: [00:29:18]** Yeah, no, for sure. Besides these more employer led changes, do you think any specific services or interventions would be helpful at this intersection?

**Interviewee:** Oh sure, like I wished this Project Search thing that we had become part of had…like I would love to take that model and expand it tremendously. So, for whatever the root causes are, the ability to graduate high school, launch yourself into some form of independence, become an adult that is self-functioning, and a solid member of society is very, very difficult these days, more difficult than any of us – I was gonna say ‘any of us,’ but actually you're still pretty young **[laughs].** If you're over 40, I mean, it was just sort of like that's just what you did. You graduated high school, you had your high school job, you got your other job, you went to college, you just did that. And if you didn't, you were one of those people and you just worked at the movie theater, whatever. And so, we've grown a lot as a society, but I would take this project search model and I would say…and I would have it as almost like Boy Scouts or Boys’ Club, Girls’ Club stuff for adults. One of the ways I described it was, when you're in school, you have Boys’ Club, you have Boy Scouts, you have Girl Scouts, you have DECA Club, you have club, club, club, club, group, group, group, group, teacher, teacher, teacher, counselors. You have this whole environment that surrounds kids aimed at helping them become successful. Does it work for everyone? No. Are there all kinds of problems with it? Yes, blah blah blah. Then you walk across that stage and you look out the door and you go, holy crap! There's nothing! There’s just nothing, like it all just comes to a screeching halt. There's no group – or it can become very difficult. There's no groups to become part of, there's no social circle that you can just tap right into. I wonder if part of it is because you're just supposed to go to a 4-year university. And so, you just extend the concept of groups and clubs and social circles and built-in friend groups and blah blah blah by going to University. Well, if you're not on the track to 4-year university, then what?

We're not a particularly religious family, but I would take Parker to church and I would have him in church youth groups and be part of the church young adult groups, just so that there was some transition of an identity, a group that would welcome him. There's an organization you might be familiar with when you were living here, called the Mountaineers. And so he's part of that. And that gives him a group to be part of, but the dues, like to be part of that group, you're taking a year-long class and mountaineering that costs $500. OK, well, we can afford that, but for every kid that can afford that, for every 22-year-old can afford that, there's another hundred that cannot. So, I would love to see just more conscious effort towards support systems.

**Interviewer: [00:32:53]** Makes complete sense. This is gonna be a bit of a gimme question, you kind of just answered it, but do you feel like there are gaps in the available services and interventions?

**Interviewee:** I do **[laughs].** Yes, actually, I do. Yeah.

**Interviewer:** Anything more than you just described?

**Interviewee:** No, I think it…I think there are funding gaps, which is a different kind of gap. Funding gaps in the way government funded support programs work. So, for example, he was a client of the Department of Vocational Rehab and he had a DVR counselor assigned to him. And we met with her once and then one more time and at the second time she goes, *“you know guys, like you just probably don't need a lot of help. So, I'm going to have to take you off my rolls because I've got 100 kids I'm helping, and the other 99, they just need a lot more help. So, I just can't help you anymore.”* I was like, *“but he still needs help. Like he doesn't need help 'cause he's got me? But what if I died tomorrow and he’s no better off than those other kids tomorrow if I wasn't here?”* And so, there was this natural substitution that because I'm incredibly involved in his life that I could then play the role of what this DVR counselor could do because her funding is set up to help the 100 most in need, and he doesn't qualify as most in need. That doesn't mean he doesn't need.

**Interviewer:** Got you, thank you. And so now thinking broadly again, how have your son's sensory sensitivities impacted your goals, hopes, and expectations for him as he does navigate adulthood?

**Interviewee: [00:35:01]** You know, in that area I'm going to switch back more to the positive because we've seen *so* much improvement and change that, you know, I'm comparing myself to another family that I worked with and it was really hard, it was a different perspective – ‘cause I did some adult, parent to parent coaching kinds of programs and things. And so, this other family that I worked with, the dad of that group was like, *“she just needs to handle the socks I get her.”* I was like, “*but the socks you give her hurt her. Imagine if you were trying to wear socks that had needles in the seam of the sock, that's what it feels like to her. And if you buy different socks, you won't have this battle every morning trying to get dressed.”* *“She just needs to wear the socks I give her, she just needs to get over it.”* I was like. *“OK, that's one approach. I don't think you're actually ever going to be successful with that one.”* But I'm not a Neuropsychologist, I don't have any credibility, I'm just another parent who's saying you might try a different way. And so I use that as an example to say that I'm more hopeful than I am not for Parker, I am less hopeful than I could be for other kids who don't have the level of familial support that Parker has.And so, what we did, what I explicitly did with him, is we *named* every sensitivity.It was named, it was owned, it was transparent, it was described, it was acknowledged, it existed so that…and when he went off to Idaho, we kind of made a list of like all the things he's sensitive to, and I said, *“you pick 3 that you're going to work on this year, pick 3, don't worry about the other 20. The scratchy socks, I’ll mail you – if you put holes in your socks over the course of the summer, I'll mail you your special socks, don't worry about that. Pick 3 that you've named, owned and accepted as being real, and let's work on mitigation strategies to get rid of those 3.* Let's pick another 3.” And so that process of acknowledging that they're real, I think it's helped him a lot.

**Interviewer:** Got you. And because he has been able to tackle these, do you feel like he is able to navigate adulthood?

**Interviewee:** Yeah, yeah, I do.

**Interviewer:** Got you, thank you. So, last chunk of questions, we’re almost done. So, as a caregiver, as a mom, as a parent of someone with autism and some sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee:** Terror, terror. You probably want my instinctual answer and then then I need to think about how to make it be a little more effective.

**Interviewer: [00:38:08]** No, whatever answer you want to give is perfectly fine **[chuckles]**.

**Interviewee:** Terrified.

**Interviewer:** That's great. Well, not great, but it's a perfect answer.

**Interviewee:** Yeah. Yeah, because – and I think it goes back to a lot of the things I was saying of the amount of social support, the amount of community support, the amount of understanding by more is so minimal that…and I think probably the most thing I worry about is the ability to be in relationship, and I don't mean…I don't necessarily mean intimate relationship leading to marriage blah blah blah, but just having a relational circle of people.

**Interviewer:** Yeah, totally. And has this perspective changed overtime?

**Interviewee:** I don't know that it has, actually. So, I think I described to you in our last call that when we first began accepting the…first began becoming aware, I think I should say, that Parker was different, we met with the one Doctor who said he wouldn't amount to much and *“you should just prepare for him to be in a group home,”* kind of thing. And I took that as like, “oh yeah, oh yeah? Well, watch me, you don't know me clearly. And that became kind of this galvanizing – I’m a bit competitive. But I was like, *“oh yeah? I'm gonna show you,”* kind of thing. And so, because of that, I never bought into the idea that Parker wouldn't be successful. I never…except for maybe in private quiet moments of fear kind of thing, but I never believed that we couldn't overcome it all. And I think about like when I – I have two sisters, one that's older, one younger. And when we finally got the diagnosis, I called my older sister first, and she said, *“oh my gosh. What are you going to do? This is terrible. This is…oh, it's like damn. Oh, I wish I could help you, but I just don't even know what to say.”* And I held the phone, I was like, it's not like I just told you he's dying, I didn't just tell you he has stage 4 leukemia and there's no cures. I mean, I was sort of like really taken off-guard. Like for her, I had just told her that my son had a death sentence. My younger sister was like, *“rock on! This is cool. What book should I go buy?”* And she became really like…I would say that my younger sister is almost like a best friend to Parker, and so she really just…and that was two different societal reactions to this label. Obviously, we lined up with the idea that if we read enough books, if we do enough therapies, if we believe in him enough if we do do do do do do do do do, we can overcome these things.

**Interviewer: [00:41:13]** Got you, thank you. And what do you see happening in your son's future?

**Interviewee:** I see him being able to successfully get a job that is what I call an acceptable job. No…actually that sounds bad. I mean, I see him being able to do more than mediocre work. I see him successfully being able to integrate with groups at a…I’ll call it a stand back level. So, what I mean by that is…hang on just a second, a kid just hollered from upstairs.

**Interviewer:** Oh no worries. Do you want me to pause?

**Interviewee:** No, he's good, I can text him.

**Interviewer: [chuckles]** Fair.

**Interviewee:** OK. So, I see him being able to like – when he was part of this Mountaineers Group and was in a couple of the classes, he integrated well, he sat at the group tables well, he made a connection to one of the other students well, he went out and did the – it was a map and compass class, he went out and did the field activity well. But if you asked him, *“what were the names of the students at the table you were with?” “****[mumbling]*** *I don’t know.”* *“What was the name of the girl that gave you a ride out to the field activity?” “****[mumbling]*** *I don’t know.”* *“What was the name of the instructor who was teaching on Saturday?” “He was the guy who had a white beard.”* *“OK.”* So that's the scripting, this kind of he sort of participates, but one step removed.And some of that is the sensory challenges of touch. He doesn’t wanna shake somebody's hand. ‘Why would you shake my hand? Don't touch me, don't get in my bubble.’ Some of that can be the social skills deficits, making small talk is an almost impossible thing to do.So, I see him being able to have a good job, I see him being able to be connected in society enough.Hm, I hope that his younger brother will watch out for him when we're gone, not entirely sure that's going to happen, so gotta figure that one out.But I think he will need some…I'm going to use the term in quotes – guardian. And I don't mean a legal guardian, I don't mean an assigned guardian, but he will I think for a long time, he will need a guardian that can steer him, direct him, help him to be that that person that he can turn to.

**Interviewer: [00:44:28]** Absolutely. And you see him moving out full time eventually?

**Interviewee:** 50-50

**Interviewer:** Fair enough. Do you see him finishing college after he does take this break?

**Interviewee:** 50-50.

**Interviewer: [chuckles]** Super fair. And do you see him having a family of sorts, whatever that may mean?

**Interviewee:** 50-50.

**Interviewer:** Alright, super fair. Last question: how have your son's sensory sensitivities impacted this perspective you just articulated?

**Interviewee:** I think that they affect that perspective probably less than just the overall social society system. So, if I were to take those two statements, I would say his sensory sensitivities are going to cause trouble 25%, will cause 25% of the trouble he experiences, and the social society will cause the other 75%.

**Interviewer:** That makes complete sense, thank you. So, it's all I have on my end. Would you like to add anything else?

**Interviewee:** No, this has just been wonderful, you know. Because we have ended all of the programs and therapies and groups and everything that's available when you're in school, it's been a really opportunistic moment to reflect and to have an opportunity to step back into what he was and then what he's becoming and what we think he might be. So, I'm very grateful that that this happened.

**Interviewer:** Oh, great, thank you. We’re **[crosstalk]** sorry.

**Interviewee:** I was about to say we’ve expressed interest in studies and being part of research studies, and someday I would love to get qualified for a study that maps his brain, I would give *anything* to just see…I was taking care of my mom who had a stroke and she got all kinds of CAT scans during this time and I found it fascinating, like could you just, *“my son's with me, could you just stick him in the machine real quick?”* **[Rachel chuckles]**. Like it's great that that's my mom's brain and you're showing me where the stroke happened, and you’re showing me the exploded blood vessels and you're showing me all this stuff and I can see it, like could you stick him through there real fast? 'Cause I would *kill* to see his brain, but we've never qualified for one of those kinds of studies. I actually asked his doctor once, *“can we just do like…I have health insurance, I have means, can we just do an optional CAT scan of his brain?”* You can't even find a provider that will do it.So we never were able to do that. But between your study and then talking with Brooke around all these social skills and relationship and intimacy and all that stuff, these are really the things that matter most to his transitioning to adulthood.Like at this point, beyond abject curiosity, knowing what his brain looks like really is irrelevant.

But being part of these studies has been great, so I'm glad you guys are doing this, I'm glad that we are…like when I think back to what…even just until…he was born in the year 2000 and the whole genre of Asperger’s is a thing, turns out Asperger’s is not a thing, turned out we're going to call it ‘the spectrum’, turns out we're going to add levels to the spectrum. I mean, the amount of knowledge that's been gained in just 20 years is *phenomenal*.And when Parker and I were talking about whether he wanted to do Brooke’s study, I was like, *“look, it may or may not help you specifically, but your contribution to it could help the next 20 years of programs and knowledge and services and other things that are available for the next generation of kids.”*

**Interviewer:** I agree.

**Interviewee:** It's great.

**Interviewer:** No, but truly, thank you. Like you are helping us and this has been truly invaluable, I've learned so much from you and I just appreciate you making time for us.

**Interviewee:** Excellent. And how did your last great interview go?

**Interviewer:** It went wonderful, so it's been really good so far. I've had 5…4, I’ve had 4 and they're going good.

**Interviewee:** OK. And do you like…is it any one of the schools you're fine with or do you have a preference?

**Interviewer:** I definitely have my favorites, but I would be happy going anywhere. I'm excited to do my doctorate, so whoever gives me an offer, hopefully I get more than one, but if I get one, I get one, that's all I really know.

**Interviewee:** You already know what you want to do your doctorate on?

**Interviewer:** I am interested in autism, so I am interested in like…

**Interviewee:** Really? **[laughs]**

**Interviewer:** Go figure, right? It’s my job.

**Interviewee:** Like if you're interested in marine biology, exactly why are you doing this study? **[both laugh]**

**Interviewer:** Right. I'm interested in looking at a – it’s called like a biopsychosocial, ecological approach. So, thinking about how biological components like neural…like EGG, things like that, how those biomarkers map on to behavioral outcomes. So, like social functioning daily, daily living skills, and then what about the person's environment intersecting with those interactions, that’s what I'm really curious about.

**Interviewee:** Fascinating. Yeah, alright.

**Interviewer:** So, let's see.

**Interviewee:** But yeah, if you have more studies later in that, what you just described, I think is the trifecta way that we try to approach this, right. 'Cause it was, ‘alright, you've got something in your brain, something…like this is real, this isn't just fake. You’ve got something real and we can create an environment that maximizes learning that, maximizes mitigating that or not, right? And like I described, the family I worked with, they're creating an environment that’s like, ‘man up and be normal.’ Like I don't know, I'm not sure that's gonna work for you.’ So, you need to figure out how to get more families to not take that approach.

**Interviewer:** I’ll do my best. Do you know anyone else who might want to participate? We're still looking for a few more folks. It’s OK if you don't, I ask everyone.

**Interviewee:** No, what I would say is there here in Olympia there is a really good group in the parent-to-parent transition group, it's called South Sound Parent-to-Parent.

**Interviewer:** What's it called, sorry?

**Interviewee:** South Sound Parent-to-Parent. And of course, then Seattle Children's and U-Dub both have pretty robust networks of people. I’d try reach out to those ones, those are the ones I know.

**Interviewer:** No, it's wonderful. Thank you.

**Interviewee:** Yeah, South Sound Parent-to-Parent, one of their key focuses is in adult transitions.

**Interviewer:** Perfect, that's very helpful. Thank you. Any final questions or comments for me, anything I can clarify?

**Interviewee:** Do we get any kind of final report out or?

**Interviewer:** I don't typically consolidate everything into a report, but I can send you the forms that you completed if you would like?

**Interviewee:** No, that's OK.

**Interviewer:** Are you sure?

**Interviewee:** I was only asking that 'cause…I'm good with that…no, Brooke was saying that when we're done, she'll send the…what did she call it? **[To Parker]** Parker what did Brooke call it yesterday?

**Parker:** What?

**Interviewee:** Come here.

**[Grunts]** I knew you were gonna stay at eventually.

**Interviewee:** Here's that kid we've been talking about for a couple of hours

**Interviewer:** Hi. Good morning, how are you?

**Parker:** Hi, I'm good.

**Interviewee:** Anyway, Brooke described that in her study, he would receive some compilation of information at the end or something, so I didn't know if that was part of **[00:52:25 inaudible]**.

**Interviewer:** I mean, I'm happy to send you the forms, like it will take me 2 seconds to email them, it's no problem. I just don't usually make them into a sample.

**Interviewee:** I want your insights after everybody.

**Interviewer:** Oh, those reports! Oh yes yes yes, we will send you that. I thought you meant the form you filled out directly.

**Interviewee:** Oh, no no no no, I want that the insights you've gleaned from the 100 interviews you've done.

**Interviewer:** Yes, you will definitely get those. Yes, don't worry. And we ask you in one of the forms, we say ‘do you want to know our results?’ And you said yes. So, you're on the list. You will get them.

**Interviewee:** I don't remember if I said that or not, OK **[laughs].**

**Interviewer:** Everyone has said yes so far, so.

**Interviewee:** Yeah no, I think if you're gonna participate in these studies, one of the things that becomes important is understanding, so what did you learn in this that can help me? Because you're on a path for the next 20 years to create different environments for the next set of kids, right? But give me your report, 'cause I still gotta deal with this one, I’m trying to get him to launch.

**Interviewer:** Well, I think he's launched well, from my perspective.

**Interviewee:** Yep, alright. Thank you so much.

**Interviewer:** No, thank you. It's been lovely to meet you and learn from you. Nice to meet you too Parker.

**Parker:** You as well.

**Interviewer:** Have a wonderful day, and enjoy meeting Brooke.

**Interviewee:** Alright, bye.