**[Start of transcript]**

**Interviewer:** Right. We are recording. Well, thanks for coming back. I appreciate you making time out of your busy day.

**Interviewee:** Sure.

**Interviewer:** So we left off: we were talking about where your son is in his transition to adulthood.

**Interviewee:** OK.

**Interviewer:** And the specific question was what would help him move into adulthood and you just were talking about how your daughter’s going off to college.

**Interviewee:** OK, so I think the presence of male role models would definitely help him, just folks setting an example for him of what it looks like to be a good man. And then, with my daughter going to school, for the first time in my son’s life, I’ll be the only female in the house and it will be him and my husband, and I almost expect him to step it up a little bit. **[1:00]** So I think that that would help. And I also think the presence of outside organizations, like the vocational rehab services they have here in Alabama … We’re originally from Pennsylvania and it looks to me like the services are very similar to the ones in Pennsylvania, which is good because they have a pretty strong program. You typically think everything in Alabama is backward—OK, there you are—But I think that that would be the most important thing would be the presence of strong male role models in his life.

**Interviewer:** Awesome, thank you. And now, putting these two things together—his sensory sensitivities and his transition to adulthood—how do they intersect for your son?

**Interviewee:** I almost feel like the sensory sensitivities keep him a little boy and prevent him from growing, because I think that he has fears that … just, he knows if something’s … he’s … before looking forward to an event, he is ascertaining all of the possible limitations that he’s going to have with an event. Rather than jumping in excitedly, it’s, “*OK. Well, what if … what if it’s too bright? What if the … you know, what if it’s too cold? What if somebody wears perfume? I can’t*.” So he has a lot of anxiety toward entering into new things because of his sensory sensitivities. Although, like I said earlier, you know, my hope would be that some of those maybe could be extinguished from gradual exposure and maturity, hopefully. But, you know, even as an adult on … who is not on the spectrum, like, I have sensitivities. There’s stores that I do not like to go into because they’re always cold or restaurants that I know the bathrooms smell, so I won’t go there because of how the bathrooms smell. And at this point, I’m not on the spectrum, but … I just adjust my life accordingly and, hopefully, Will will learn to do that as well. And I can help him and his dad.

**Interviewer:** Absolutely. Thank you. And then, would you consider his sensitivities to be an obstacle, a vehicle, a bit of both or neither towards his independence?

**Interviewee:** I would say a little bit of both, because it limits and … so I would **[4:00]** say, like, there’s no way in the world he could ever work in food service or own a … maybe he could own a restaurant, maybe, but he’s not going to clean dishes, OK, as a 16-year-old. But then there’s a lot of other 16-year-olds that wouldn’t choose to clean dishes either, you know, and they might prefer to work at Target or something like that. So I think that the world we live in is more open to making adjustments for people and, given the right supervisors and the right team, that he would be with I think that … honestly, I think they probably could help him because he would be more sensitive to things than other folks might be. So maybe if we capitalize on those sensitivities that could be part of finding, like, the best fit for employment in a future career.

**Interviewer:** Absolutely. And then, relatedly, what do you anticipate as being challenging, as he does gain more independence in relation to his sensitivities?

**Interviewee:** Challenging … So I think maybe if we could find an environment that he could work in and be successful at, but they have a dress code. So being able to meet all of the sensitivities in one perfect environment, I think, might be difficult and perhaps he would have to make some compromises or we would have to work toward some compromises there.

**Interviewer:** Yeah, thank you. What do you think could help your son in this intersection of these two things?

**Interviewee:** I would say a job coach. I used to be a job coach years ago and couldn’t go into the work ... I’m not sure what the laws here in Alabama are, but we were able to make modifications in the environment and we’re talking—oh gosh—30 years ago. So I would think that a job coach would help be a bridge builder for him into environments and roles and responsibilities. I also think, with Will, his anxiety is very well controlled by his med management and his mood is also controlled by that. And since the medicine has been a good … on a good … let me figure out how to say it. Since he’s been on a good regimen, med regimen that is working for him, he is more open to trying new things and tolerating more. And **[7:00]** so if we can continue with his current doctor, who I know we can at least see till he’s 21, I would imagine that that would help him. And I even think, like, social empowerment would help him. If he could find a way to forge more friendships, he would be more empowered and have more self-confidence and then, with the self-confidence, he would be more courageous to try different things or step out of his comfort box.

**Interviewer:** Do you think there are gaps in the services or interventions for children like your son or young adults?

**Interviewee:** I know that you have to fight tooth and nail in Alabama to get the bare minimum. So, as far as gaps, I would say, in first and second grade, I asked for him to be tested for disabilities and I was told, “*No, you’re just used to having smart daughters*.” And then, after he was repeatedly bullied, we pulled him out, put him in private school and, within a month, the teacher said, “*Something’s going on*.” Which Rick and I always knew, something neurological was there, whether it was the sensory … there’s a diagnosis, it’s like a sensory disorder. We just didn’t know and we had never in our lives ever heard of Asperger’s and I had also … I had worked in the field for 25 years prior to having him. And I just … the only thing I knew about folks with Asperger’s was that they would eat ravenously from the fridge and that’s not my son. And I mean, that wasn’t … that was a reputation that followed maybe some of the folks that I had. So, once we got him a diagnosis, then we got an IEP and people still don’t do their job. So I think that with … the question was do I think there are hindrances or gaps, was that …?

**Interviewer:** Gaps, gaps. But you’re answering it still. You’re on the right track.

**Interviewee:** OK, good. I wanted to make sure. OK, so the other thing is, teachers and special education instructors or aides do not get paid a fair working wage. They don’t in Pennsylvania, they don’t here in Alabama, that’s a major issue. I think when you start paying people what they’re worth, you get their expertise. Otherwise, they’re just bombarded with work and it’s impossible. Unless you’re the squeaky wheel kid, you don’t get the attention that’s needed and, honestly, I am … one of my students that I tutor has an IEP and I’ve been fighting with his school all week because they won’t even follow his IEP. And but all you have to say is “*advocate and lawyer*” and then they **[10:00]** start. So, for my son, he did not get what he needed until we hired … until I contacted an attorney and hired a lawyer. Now, we have people from the district, like, as high up as you can go, bringing work to our home for him to do, because they’re going above and beyond because they don’t want sued. So the hindrance would start with … I would say, it probably starts with early intervention because those folks don’t get paid enough, either. So that they’re not valued in society and their salaries reflect that. And, having worked in the field for 25 years—no, you’re not valued and you make less than you would if you work at Target or Audi’s, which is very, very sad. It’s not that there’s not good people out there. The people that are out there are overworked or don’t get paid enough to do … they will just do something else, so they can pay their bills and not be on welfare.

**Interviewer:** Yeah, we all have to survive, you know.

**Interviewee:** Right. Right.

**Interviewer:** Thank you. And then, thinking broadly, again: how have your son’s sensitivities … how have they impacted your goals, hopes and expectations for him, as he does navigate adulthood?

**Interviewee:** So I think we’ve had to reframe what we thought his adulthood would look like. You know, my husband and I both have bachelor’s degrees, my husband has a couple master’s degrees and, of course, like, our expectations of our kids were: you will go to college, you will be a professional person. So with Will, we’re not sure if he’s going to go to college or a technical school. We’re fortunate in that our school has a vocational component that he is interested in. Although he says he’s interested in college, but I’ve told him, “*I’m not going with you. I’m not* …” you know, lots of universities have special education programs where he could get what he needs. But I’m not sure that that’s what he wants. You know, his goal is to be an … he says he wants to be an electrical engineer and that fluctuates between electrical engineer and electrical technician. And I think he wants to work with his hands. I’m not … I really don’t know what electrical engineers do. I have a sociology, women’s studies and psychology degree. So that’s very, very far from my expertise. But, so we’ve had to reframe and we learned early on that all three children need parenting differently. And so I **[13:00]** guess at the beginning, I wish I would have known that all … your children all need parenting differently, because that would have solved a lot of headaches over the years. But now, we just sort of go with it every day, how it evolves. You know, he said … he told me when he turned 14 that he thought he was bisexual. And I was like … well, first he said, “*Mom, I think I’m bi*.” And I knew what he was talking about and I said, “*Bi what?*” Well he said, “*Bisexual*,” and I said, “*OK, that’s not something that identifies you. And what you really need to focus on is your behavior because your behavior is off the wall right now. And we’ll talk about your sexuality when you can get your responsibility under control*.” And so, OK, so, as a parent, like, my initial reaction was, “*OK, he is what he is*,” but there’s a level … for me, at that point, there was a level of sadness because I want him to be able to experience all the things that I, as a heterosexual person, can experience. But that has completely evolved that I don’t … I mean, like, I’m excited, if he is a gay man, he still wants to be a dad and that will happen. And so the initial, “*Cathy, this was not in your plan*,” me getting used to … I think I learned probably over the last four years that it’s not my plan. And I am a religious person and I do believe that it’s God’s plan. It’s also just Will’s plan. It’s not my plan at all. So, wherever he goes, we will be there to support him and he is fully capable of living independently and he will and has that desire. It might not be when he’s 19. You know, I have a 19-year-old college student who lives in an apartment. Will may or may not be able to do that. But, you know, at this point … I was thinking about this today … he doesn’t like to do dishes because it’s so gross. Well, honestly, he doesn’t really ever have to do dishes. If he moves into his own apartment, he can eat off paper plates and throw them away and he can make his own accommodations. And, I mean, we eat off paper plates all the time. So I don’t … because I run out of dishes, so we don’t have to do dishes. So we can help him make the accommodations he needs to make to have a full and successful life. We have, though … we are … we’re very frugal. We have … we’re not rich and wealthy people. When we pass away, though, we do have a trust, because our assets are protected. He is in that trust. But he is also protected as a person with a **[16:00]** psychiatric disability, which is where the autism falls under. So we are aware that he might need financial support, more so than our daughters. And he has a … in the event that my husband or I will pass away, there is a financial trustee who would step in and take care of those things for him and our other children until they’re of a certain age. But it’s important to us to try to accumulate some wealth and savings prior to, you know, just to help Will, if he needs, Will and the other kids if they need help … Will might be the one who doesn’t need anything because he doesn’t spend a fortune on shoes, so … but we want to be prepared to be able to help him however we need to. Sorry, my other daughter was trying to call me back.

**Interviewer:** No worries. We’re almost done.

**Interviewee:** OK, very good.

**Interviewer:** This reframing that you just described—was that because of his sensitivities or because of kind of who he is as a whole individual?

**Interviewee:** I think that his sensitivities make part … make … are a part of who he is. So I would say it is because of his sensitivities. There are certain things that he just cannot tolerate and so we just adjusted to that. So, specifically, the noise and the textures and the lighting and, yeah, I would say, noise … as a family that’s … that has been a big one that we’ve just adjusted to it. But we’ve, honestly, made those adjustments for all of us. My husband doesn’t like people to be in his way, so we bought a house that has wide entryways for major … wide thresholds for each room, so nobody’s underfoot for him. So we just try to … it’s almost … it’s probably a little bit codependent when you think about it that way, but it’s what works for our family.

**Interviewer:** Absolutely, thank you. Last chunk of questions are the shortest ones, so we’re almost done.

**Interviewee:** Do you mind? I need to just text my daughter because …

**Interviewer:** Yeah, go for it.

**Interviewee:** But I’m still listening to you. I’m just going to text her and tell her I’m on a call.

**Interviewer:** Oh sure. OK, do you want me to wait to … I can wait for my question.

**Interviewee:** OK. If you just give me one second, I’m going to voice … or I’ll text or …

**Interviewer:** You can have two seconds.

**Interviewee:** OK. So I got my husband to take my son to get his hair done, so I didn’t have **[19:00]** to go back out and my daughter is already there. So somebody’s … well, my daughter’s bringing Will home, so I just want to make sure that he’s not freaking out because he’s having to get his hair cut so … which could happen. But anyway, I’m back.

**Interviewer:** Oh, no worries. No worries.

**Interviewee:** Oh, she said “*Never mind*.” So it must not be bad.

**Interviewer:** Oh, good. Excellent. Glad to hear that. So, finally, as a caregiver, as mom, as a parent to someone with autism, but also some sensory sensitivities, what does transitioning to adulthood mean to you?

**Interviewee:** I would say that it means having career goals and working toward those goals … creating a network or having a—not necessarily intentionally creating a network, but having a natural network be created around … **[inaudible at 20:00]**

**Interviewer:** I think you froze.

**Interviewee: [inaudible at 20:06]**

**Interviewer:** Sorry, you froze for a moment.

**Interviewee:** Oh, OK. But him having a network of natural supports, I think is very important. And he has a network of professional supports at this point and familial supports, but not natural supports in his world. So, having that network, having goals and working toward the goals, having a goal of living independently, which he already has, but taking steps toward that, which would be, you know, getting better with his physical hygiene and personal hygiene and … which he does well, we just … I don’t want to have to call my 28-year-old and say, “*It’s … got to take a shower tonight*,” you know. “*You shower every night, make sure you brush your teeth*.” That … I would like him to be able to do those things on his own. Understanding finances and how to budget. And I would say being able to interpersonally relate with others. And as he is working towards that now and getting better at it, but he needs to be able to have relationships that are beyond Mom and Dad’s involvement. And even, you know, my 19-year-old still will call me in, you know, with problems about her relationships or friendships and she’s still very needy in that way. So maybe there are just people like that. But I would hope that he attains that skill **[22:00]** before he’s probably 35, like I was when I first got it, so I want better for him than I have for me.

**Interviewer:** Absolutely. I think most parents do. Has your perspective changed over time?

**Interviewee:** Has what, I’m sorry?

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

**Interviewee:** Oh, yeah. When he first received his diagnosis, I thought that he would be living with us forever. And I just thought, “*Oh my God, what am I going to do?*”—just because it was hard to have three children so close together and never have time. But now, like, I definitely feel hope for his future. There have been times when I’ve felt very hopeless and so has he. But I believe that, right now, both he and I both and his dad have hope for his future of independence and gainful employment and positive, meaningful relationships.

**Interviewer:** That’s wonderful. What do you see happening in your son’s future?

**Interviewee:** I see him having a job coach and have the job coach helping us determine and helping him determine a part-time job that he would really enjoy. I see him going to our … his high school’s vocational program and learning on-the-job skills. I mean, they set it up like a workplace where he would clock into school each day, clock out, dress the part, where, if he’s going to be an electrical person, he would dress like an electrical person dresses and all of his subjects would be geared toward electricity, I guess, or, you know, it would be, like, history of electricity or something like that. So I see that happening. And then I see a ... some type of post-secondary education, whether it be Auburn University … they actually have a wonderful special ed program that we might be able to tap into, or a technical school. Really, I think that’ll be driven by him. It will … he … we will insist on some type of post-secondary education and that is a non-negotiable within the household. So he will be at least somewhat prepared for a career.

**Interviewer:** You mentioned … do you think he’ll be able to move out one day and be independent?

**Interviewee:** Oh absolutely. Yes. I think that at some point, he’ll be able to live on his own. I do not see, like, a group home situation at all. I see an independent living situation. It might be … like, years ago when I worked in the field, there were independent living situations where your case manager checked in on **[25:00]** you once a month. I do not know if that’s available here in Alabama. That could be something that possibly would benefit him when he’s in his 20s. And we, you know, we haven’t even started looking down that road yet. He’s certainly welcome to stay with us as long as he wants but, you know, any child that stays with their parents too long stops growing and we want him to constantly grow.

**Interviewer:** Absolutely.Do you see him having a family of sorts?

**Interviewee:** Absolutely. Even if he … you know, I don’t … while he says he’s gay, everybody who’s gay that I talked to say that you don’t get to pick when you’re gay and when you’re not gay, you know? And he’ll say that he’s gay, but he’s not interested in a sexual relationship. So I don’t … I just don’t know, I think he’s questioning. And so, if he has a … he’s fully prepared to have a relationship with a man and have a child with a man, adopted child. He also talks about when he has his own son, so I know he wants to be a dad. So I do believe that that will happen for him in some type of relationship and, of course, we would support whatever path he chooses or whatever path has been chosen for him that way.

**Interviewer:** Wonderful. Thank you. And then, last formal question: this perspective in terms of, like, what it means to transition into adulthood, how did your son’s sensory sensitivities impact that perspective?

**Interviewee:** I think that we just had, again … with having to reframe what our expectations are and, in a way, as parents, when you have children, you have the expectation that they’re going to be smart, they’re going to go to college, they’re going to do this, this and this, they’re not going to do drugs, they’re not going to smoke, they’re not going to, you know … I don’t know that it’s necessarily fair to the child to have those expectations prior to having the child and learning who they are and what they’re capable of. So I think throughout all of our children’s lives, but most definitely with Will … Will would probably be the catalyst for us being able to reframe: what does it look like to be an adult? We know a lot of adults who are not great adults and not even prepared for adulthood and still, you know, people who are our age in their 40s and 50s, that are still dependent on their parents, and we don’t want that for him. We want him to be as independent as possible. So I think that certainly, **[28:00]** we want him to be safe, but whatever occupation he chooses, whatever his sexual path ends up being in the long run, whatever that is, that’s fine with us and we will support him. Did I answer that question?

**Interviewer:** Yeah, I think so. I asked, like, how did his sensory sensitivities impact your perspective and you said it was the catalyst for reframing, is that …?

**Interviewee:** Yes, it was the catalyst. So all of his sensory things … when it was, “*Well, we’re the family that goes to Alabama football games, where there’s fifty thousand people and noise*,” and then, all of a sudden, we don’t go to Alabama football games anymore, you know, and my husband was a great athlete his whole life growing up, and now he has a son that’s the farthest thing from an athlete that you can imagine. And so I think, like, initially, those are blows maybe. Of course, I don’t really care about football, so that wasn’t a big deal to me, but the whole sports thing, I think, was a big deal for my husband. So I think that we’ve just … over the years, as we’ve learned who our son is, we’ve reframed. We can do things within the realm of possibility for him. And when it’s a safe time to try to stretch him a little bit, we do that, or he might want to stretch himself a little bit, when it’s safe time to do that. But for the most part, we’ve just sort of built our family around who our children are and Will is a conglomeration of all of his super sensory everything. That is part of what makes Will Will.

**Interviewer:** Absolutely. Thank you. That was a wonderful note to end on. That was all of … those are all my formal questions. Would you like to add anything else?

**Interviewee:** No, just I have appreciated our talking because it’s helped me think about a lot of things with regard to my son and things that I’m very happy about and excited about, and even seen my own growth over the years. When we got the diagnosis of autism, I cried and my husband said, “*Why are you crying? We knew something was up. Now we just have a name for what it was*.” And we’ve sort of gone through life with that, well, it was just a name for what’s going on and it helps us learn better. But I remember the hopelessness and desperation, like, when we received his initial diagnosis, and now I’m like, “*No, there’s no way this kid’s not marrying somebody and not*,” you know … he’s … he will have a job and he will move out and he will do all of these things. And I just … I have no doubt in my mind and so I feel like I’ve grown just from talking to you. So thank you very much for your time with me.

**Interviewer:** I’m so thankful. That means so much. Thank you. I have really enjoyed our conversation. I’ve learned a lot as well. **[31:00]** It’s been wonderful. And we can’t do this work without parents like you. So truly, thank you. I’m glad you were able to get something out of it, too.

**Interviewee:** Thank you. Now, I get to have a … when you … so the abstract that you submitted, is it for this study, is it …?

**Interviewer:** It is.

**Interviewee:** Oh, OK. So if it all goes through, then we’ll … I’ll be able to see the results of it.

**Interviewer:** Yeah.

**Interviewee:** Yay!

**Interviewer:** Yeah, so I analyzed the first 30 … I analyzed a portion of the first 30 interviews I did. You were my 50th interview.

**Interviewee:** Oh, OK. I hope I was the best.

**Interviewer:** It’s been out there. No, truly, this has been a wonderful conversation. It’s been really wonderful. So yes, assuming it gets accepted—hopefully, it will—I will send everyone … so they want to learn about the study, like the results. So you will get a copy of the poster, the abstract, all that jazz and …

**Interviewee:** That’s great.

**Interviewer:** eventually, down the line, when we get, like, more formal papers, you will also be sent the papers as well.

**Interviewee:** OK. That’s great. Well, feel free to contact me anytime. If you have more studies that will happen in your educational career, please call me because I’m happy to share. That’s the only way we learn and grow as a community is by sharing, so.

**Interviewer:** That’s wonderful. Thank you, I will. Do you know anyone else who might want to participate in this study?

**Interviewee:** Actually … I have a friend who has a son who is … he’s two years older than Will and she might want to do it. Yeah, he’s autistic. He’s more pronounced in his autism than Will is, so she would certainly have different perspectives than I would. Do you want me to call her? Would you like me to give her … give you her number or would you …?

**Interviewer:** Whatever is easiest. If she … if you think she’d prefer to be contacted by you, that’d be great. I can send you our flyer. If you don’t think she’d mind being contacted by me, I can do that. Whatever is just most comfortable for her, that’s what I care about.

**Interviewee:** Well, how about if you send me your flyer, I’ll send it to her and tell her that I think that she would have a lot of great things to add. Is it OK if I give you her number—do it that way?

**Interviewer:** That sounds like … perfect. And if she says “*Nope*,” that is OK. We want … we don’t want to … her … we don’t want her to feel pressure.

**Interviewee:** OK. And I’ll think. I have another friend too who might be able … I know a handful of folks I will share with who I know. I probably know about three or four different people.

**Interviewer:** Wonderful. I have to do another 25 interviews, so the more the merrier.

**Interviewee:** OK, well, I can even let his Asperger’s specialist know and she might … I’ll give her a copy of the flyer and she might share it with some of her … the other clients she has.

**Interviewer:** That’d be wonderful. We’d love to have everyone come. Thank you.

**Interviewee:** OK, great.

**Interviewer:** That’s wonderful. Can I do anything to help you? You’ve been so helpful for us.

**Interviewee:** No, I’m just excited to share and looking forward to seeing your publication some day.

**Interviewer:** Thank you. I hope so, too. But I hope you have a wonderful evening and I’m glad you got to run into your friend and got a haircut today. Hope you have a nice weekend.

**Interviewee:** Thank you. You too. Have a great weekend.

**Interviewer:** Bye.

**Interviewee:** Bye.

**[End of interview]**