

OCALI | Podcast – Episode 23 Rewind: We Get Stuff Done

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SIMON BUEHRER: Welcome to "Rewind," the Inspiring Change podcast series, featuring conversations and connections from OCALICON, the premier autism and disabilities conference. Each year, OCALICON brings together a cross-section of internationally-recognized leaders, educators, service providers, self advocates, and many others, for a multifaceted approach to improving the lives of people with disabilities across the lifespan. Rewind is the audio showcase of some of OCALICON's best moments, the speakers, sessions, and stories that make it all happen. I'm Simon Buehrer.

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SUSAN ROTHSCHILD: Most of the doctors just didn't think girls were on the spectrum. And they give us other kinds of diagnoses.

SIENA CASTELLON: That is something that I'll always be grateful for, that I was able to get diagnosed so quickly, because that was definitely helpful, and me having the answer that I was autistic, and that changed the way I viewed myself. And I definitely gave myself a lot more grace for the anxiety and the challenges that I had.

KELLI YEAGLEY: When I was working, supporting people with very, very high support needs, I found support in that experience as well, because I found an education, and understanding that there were people who were out living their lives, using accommodations, and kind of this hacker mentality of, like, you know what? We get stuff done.

SIMON BUEHRER: While autistic people can share many similarities, autism often presents differently in girls and women. This can lead to an inaccurate, late, or even a missed diagnosis. And especially knowing how important early intervention can be for those on the spectrum, girls often miss out on important services and supports that are available to boys who are diagnosed. Those services and supports can be really critical in addressing a range of communication challenges, social difficulties, emotional regulation issues, and even mental health issues, such as anxiety or depression.

And while a diagnosis in itself is not the end all and be all, it can also help autistic girls, and women, and their families, and friends better support and understand why they are who they

are. It's important that we continue the conversations about women on the spectrum, so we can continue to improve and sustain supports, services, connections, and opportunities for autistic girls and women.

My colleague, Amy Bixler Coffin, directs The Autism Center at OCALI. She and Dr. Ruth Aspy, a licensed psychologist, specializing in transdisciplinary assessment and intervention for people with ASD, facilitated a discussion at OCALICON with two autistic women and the mother of a young adult on the spectrum. It was a candid and very personal conversation about their individual journeys, their challenges and successes, hopes and aspirations.

AMY BIXLER COFFIN: My name is Amy Bixler Coffin. And I'm the Autism Center director at OCALI.

RUTH ASPY: I'm the other person who's co-facilitating. My name is Ruth Aspy. I'm a psychologist with The Ziggurat Group. And my focus is often on girls and women on the spectrum.

AMY BIXLER COFFIN: And I'd like to have each of our panelists introduce themselves. So we'll start with Kelli.

KELLI YEAGLEY: Hi, my name is Kelli Yeagley. I am a woman on the autism spectrum. I am also a stay-at-home mom and an autism and disability consultant.

AMY BIXLER COFFIN: Susan?

SUSAN ROTHSCHILD: Hi, my name is Susan Rothschild. I have a daughter on the spectrum. Her name is Chloe Rothschild and she's 29 years old. I, myself, am not on the spectrum. And I am a stay-at-home mom, and I help support Chloe as a young adult.

AMY BIXLER COFFIN: Great, and Siena?

SIENA CASTELLON: Hi, I'm Siena Castellon. I'm a neurodiversity advocate, and author of *The Spectrum Girl's Survival Guide: How to Grow Up Awesome and Autistic*.

AMY BIXLER COFFIN: Great, thank you, ladies, so much, for participating in this panel. Susan, when did you suspect your daughter may have autism?

SUSAN ROTHSCHILD: About age four or five. She was not socializing well, but she also had a vision disability. So at first, some of the things that were autism, I thought were the vision.

AMY BIXLER COFFIN: And how did you navigate those systems to get her diagnosed?

SUSAN ROTHSCHILD: Oh, for us, it was very difficult. Most of the doctors just didn't think girls were on the spectrum. And they'd give us other kinds of diagnoses. We saw a specialist in Cleveland, Ohio. And he told us that she had little bits of it, but not enough to be diagnosed. And he thought she had ADHD.

It's definitely autism. And it just-- I think it took time for the world kind of to catch up with us. I feel like sometimes we kind of paved the way a little bit, started before everybody else. We just kept going to doctors. I believe, around age eight or nine, our pediatrician just said, you know what? I'm diagnosing her.

RUTH ASPY: Well let me follow up on that. So at age four or five, you knew something was going on with Chloe? You didn't necessarily suspect autism?

SUSAN ROTHSCHILD: No, I would say about age two to three, we knew something was going on. 2 and 1/2, 3, she was diagnosed with a visual impairment that made her legally blind. You know, as a mom, I-- maybe we want to deny it a little bit, or-- I just thought, well, she's watching the other kids, because she could see some. You can usually see some when you're legally blind. And, you know, and it's confusing for her. She's not seeing like everybody else. But by the time she was getting ready to leave for preschool, it was apparent to me that it was probably autism.

RUTH ASPY: So you suspected it for at least four or five years before it was diagnosed?

SUSAN ROTHSCHILD: Yes.

RUTH ASPY: OK. All right. Siena, can you tell us about how old you were when you were diagnosed, and what your characteristics were like when you were young?

SIENA CASTELLON: Yeah, I was diagnosed when I was 12. So that's pretty early for autistic girls, but I still consider it late, because lots of boys get diagnosed when they're three and four. And I had to go through primary school and the beginning of secondary school not knowing why I was different. And it was very challenging, because the way I presented was, I had social skills. I could communicate with people. I had a very difficult experience in school where teachers would make fun of me for the way I acted.

And so I ended up learning how to make eye contact, learning how to conform to the standards that they pushed me into. And so by the time I was 12, I didn't have many of the symptoms that I'd shown when I was younger. I would make eye contact. My body language was different, because I've spent so much time learning how to mask. But then I had some pretty significant mental health problems. I developed a lot of anxiety. My sensory processing disorder flared up to the point where I couldn't leave the house, because everything was so overwhelming.

And so at that point, my mother started taking me to different doctors and to different professionals. And she took me to a pain management consultant-- my sensory processing disorder-- and he said, this is a sensory processing disorder. This isn't so much like a pain management thing you've got. You've got SPD. And then we started talking about the anxiety I was having, and how I was having a really difficult time, socially, and how I had been bullied previously. And he said, you know, you could have autism, because a lot of the people I see with sensory processing disorders are also autistic.

At first, we kind of dismissed that, because of the stereotypes that were there around autism. In the media, we just kind of see-- and when I say "we," my mother and I would kinda see like Rain Man and Sheldon from Big Bang. And we didn't think, well, that's not the way I'm presenting. But then I went home. And I did a lot of research on it. And I realized, yeah, I'm probably autistic. I ended up getting a diagnosis.

We went to a specialist for autism in girls, because we had read online how many people-- how many women had been misdiagnosed and dismissed by professionals. And so we decided to go to that specialist to reduce the chance of that happening. And I was diagnosed. And then from that point, I had answers to why my school experience had been so different from my peers.

KELLI YEAGLEY: Yeah, my story was a combination of both of them. I was born in 1985. And so the information about autism and women was sparse to not available at all. [LAUGHS] A lot of what my challenges, and even some of my strengths, ended up being attributed to was, actually, because I was born two months premature. And so it was common for my doctors and my parents to assume that a lot of my challenges were due to prematurity, including my intense sensory-processing disorder, and a lot of my textural issues, specifically with food, and clothes, and all that kind of stuff.

And even-- I'm glad Siena brought it up, because a lot of times, in conversations, it doesn't come up-- some of the physical issues-- gastrointestinal issues, intense joint pain, and chronic illness, things like that, that often don't come up in many autism conversations at all, just chronic pain issues that I think sometimes just get ignored.

When children talk about them, they kind of call them growing pains. But I was chronically fatigued and in chronic pain a lot when I was a kid. And it was just dismissed most of the time. It was attributed a lot to me being born premature. And so when I was in school, what ended up happening was I had kind of what is called, now, a spiky profile.

And so I was in, kind of, gifted and talented classes. A lot of what would have been supported in other classes was dismissed, because I was kind of a smart kid. Like, my handwriting was really, really difficult and challenging. Some things that, like, I would need accommodations for was just outright ignored or dismissed by my educators. I would go home a lot, especially during gym class, or recess, things that were just really intense for me, just a no go--

[LAUGHS]

--gym class, lunch periods, group activities, things like that. I did a lot of parallel play. Or I just would, almost intentionally get in trouble. So I would spend time inside with my teachers, reading. That was a lot of my school time. So there was no seeking a diagnosis for me until I reached adulthood. I didn't get a professional diagnosis until going through the mental health system, because I had gotten to the point of reaching several periods of burnout, which I did not have a vocabulary for until, like Susan had mentioned, society kind of caught up, and established that vocabulary within the disability community

I didn't know what was going on with me. I assumed that I was broken.

[LAUGHS]

I assumed that something was wrong with me, not that having a mental health issue is wrong or broken, but that is the mental health mindset that I was in at that point. I didn't know what was going on. And so I assumed it was a me issue, and that I ultimately was failing at something. And so I went to the mental health system and ended up getting several wrong diagnoses before finding the right one.

AMY BIXLER COFFIN: Wow, so it appears there were many challenges, through all of your stories, in getting that diagnosis. Let's go and talk a little bit more about the positive, then. What was the greatest help when you were going through the diagnostic process? Or who was the greatest help?

SIENA CASTELLON: Yeah, I mean, I would say, for me, the greatest help was definitely my mother, pushing for me to get that diagnosis. I mean, I was 12 at the time. And so I wasn't the one who paid for it and found the specialist. And she took me there. The other element that was helpful is-- I'm from the UK. And so when I was diagnosed, I was in a system where they had the NHS.

And so there are people in the UK who go through the NHS system, and it's covered for free, if you want to get a diagnosis. But in order to do that, there is incredibly long waiting list. And it can be two or three years, now sometimes it's more, because of COVID. And so I was able to get my diagnosis pretty immediately, because my mother funded it. But had we not been able to do that, it could have been years until I got that diagnosis. And I don't think it would have been possible for me to go to a specialist in women and girls. It would have just been whoever was assigned to me.

And so that is something that I'll always be grateful for, that I was able to get diagnosed so quickly, because that was definitely helpful. And me having the answer that I was autistic-- and that changed the way I viewed myself. And I definitely gave myself a lot more grace for the anxiety and the challenges that I had. And I was able to find coping strategies for them, knowing that I was autistic.

RUTH ASPY: You said you gave yourself more grace. Before you had been given the diagnosis, what was your understanding of your own self?

SIENA CASTELLON: Well, I knew I was different, but I had no idea why. So it was the kind of thing where I would go to school, and everybody could socialize so naturally. And whatever path the conversation took, people could just adapt to it in the moment, whereas for me, most of my conversations were scripted. If something came up that I hadn't thought of a response to, I would have difficulty answering and interacting, let alone do it in a fun, playful, like, kind of banter way that a lot of kids would interact with, like in school. And I had no idea why I was-- why that was a challenge for me.

And I would stay up all night watching TV shows and videos on YouTube, trying to memorize body language, writing scripts, trying to come up with answers to questions that people had asked me, socially, in school. I definitely gave myself a lot of grief for having to do that. And I thought, why is this a problem for me? Because it's not a problem for anybody else. But then once I had my diagnosis, I had that answer. And so it was more of a, OK, this is something we have to do, rather than a, why do I have to do this, what's wrong with me that I have to do this.

RUTH ASPY: How did you know that other girls weren't going home and memorizing videos and body language, and writing scripts for themselves?

SIENA CASTELLON: I always just assumed it. I went to schools where the majority of my classmates were neurotypical-- mainstream schools. And when I would interact with a lot of my classmates, it was clear that the conversation wasn't scripted, because of the way it would go. Like, naturally, conversations move and flow. And yeah, sure, you might have an answer to when someone asks you, oh, how are you? But when you start talking about a niche television show, or reacting to a story that somebody else is telling you, that can't be scripted.

And so, when I saw that people weren't struggling with those, I knew I was different in that way, because if somebody came up to me and asked me how I was, I was fine with that. But if somebody told me a story about something that had happened in their day, often there would be a little bit of awkward silence, because I'd be like, I don't know how to react. And so I would come up with something blanket, like, oh, that's good. But other people had a lot more to comment on.

AMY BIXLER COFFIN: Susan, what-- as a mom, going through this journey of diagnosis for Chloe, who-- you said your pediatrician, finally. Was there anybody else who supported you along the way, or helped move obstacles or challenges?

SUSAN ROTHSCHILD: Chloe's dad did, you know, some, but he worked a lot, and wasn't around it as much as I was. And he also has the same visual impairment as Chloe, so he doesn't drive or anything. So taking her to doctors and everything was all on me. I would say that my parents, especially my father, was very supportive. They would just keep telling me I'm doing a good job, just keep going. They also were able-- since we were still more just starting out-- they were able to support extra therapies for Chloe, so she would get OT privately, and OT at school.

And then all the extra doctors we went to, if they weren't covered, or-- my parents would cover. And I think that we were just very lucky. I don't know that we, or Chloe, would have been where we are today, had we not had that. I had her in everything We tried, you know, tee-ball. We tried ice skating and roller skating-- it became weekend family activities-- and horseback riding, gymnastics, dance. We pretty much did it all.

We would start with doing it with neurodiversity individuals. And if we needed extra help, then we would, you know, try to find a softball league that was for special needs. I mean, she couldn't see a softball coming at her, so that would have been a very difficult sport for her. But she still plays, actually. She didn't play for many years. And she started back this year.

And they just helped change whatever. She bats at a ball being pitched to her. And she can't even see it. But someone stands behind her, and tells her, swing. And she hits the ball. So, I mean, I think that's a good lesson for all of us, that with just some adjustments, we can do many things.

Also just to go back a minute. Chloe was also a premature-- seven weeks. And she also was very verbal. So people kept telling us, along the struggle to get the diagnosis, that there's no way she-- they thought of boys who were nonverbal. So they say, there's no way she has autism. Listen to her speak.

It was hard. It was hard with other parents. It was-- she also got a test read to her, because she couldn't see it or follow the multiple choice questions. So they would say-- you know, she would keep getting A's. And they would say, that's because someone's helping her. You just had to ignore those things, do what I need to do for my child, and with the support of my family, we just kept going.

AMY BIXLER COFFIN: And Kelli, do you have any-- anything to add to that?

KELLI YEAGLEY: To touch on, a little bit, of who was the most supportive, I worked, for many years, supporting children and adults with very high support needs. And I think that it's also important, when we're talking about autism and any disability is to also bring them into the conversation as well. We're sitting here having this conversation.

And I think sometimes, especially when I'm communicating and talking about my story, sometimes we get the question of saying, oh, well you're nothing like my child. And, you know, how could you ever understand my experience? Or I cannot expect my child to ever go to college or go to graduate school, because we're here. There's no way to know, at five years old or nine years old, who your child may become, what they may do. And it's good to have their future open-- [LAUGHS] and to know them, and get to know them as individuals as they grow and as their interests flourish.

I don't know what would have been said to my parents at-- in 1985. There were many doctors who told my parents that they should just give up and leave the hospital. So had they done that-- [LAUGHS] --when I was on a respirator and a heart monitor, I don't-- I wouldn't have been here. And so I think it's just, be careful what we say to people. When I was working, supporting people with very, very high support needs, I found support in that experience, as well, because I found an education and understanding that there were people who were out, living their lives, using accommodations, and this hacker mentality of like, you know what? We get stuff done.

That one support has been such an inspiration to me, from my years of working with other disabled people, and finding community in person offline, and then, as the internet grew-- because I'm older than the internet-- as the internet grew, and then community followed, and disabled people found connection and community on the internet. And we started sharing our stories, and good, bad, and the ugly, and found community there, and supports and resources, and became hackers online.

And sharing all of that, I found an amazing wealth of knowledge and resources online, and continue every day. And that the generations that have followed continue to innovate all of those resources and supports, I mean, I don't want to glamorize the internet, because it can be a really ugly place sometimes, but if you are able to find those resources and those little pockets of community in autism, and neurodiversity, and disability, grab on to those, because they are invaluable resources-- truly.

RUTH ASPY: What are the online resources or the online communities that each of you find to be helpful?

KELLI YEAGLEY: So one of the greatest resources that I have found is the Autism Women and Nonbinary Network, which I think is a good place to start. It supports women, but it also supports people of all gender identities as well. It offers resources that are for free. One of the more, I think, lesser-known pages on their website is a doctor database. I don't know if it's international. You'll have to check that. It might be only US-based right now. But it's doctors who are autism and neurodiversity-informed, which is a really invaluable tool.

[LAUGHS]

So and then another resource that I have found really helpful, honestly, is just searching hashtags on Twitter. It's an open thing. So you can find anything on those hashtags. But sometimes you can find some really good threads to read that can be helpful as well. Oh and the Disability Visibility Project by Alice Wong.

SUSAN ROTHSCHILD: I often enjoy following bloggers, usually parents of kids with autism, some closer to my daughter's age, and some much younger I just I get a lot of perspective, a lot of-- sometimes I'm able to help them. They'll ask me questions, since Chloe's older. Kind of part of going through this is reaching out and being able to make it easier for others. I also have a lot of friends who have kids on the spectrum. And we have a group. We call it the Whole30 group, because we started doing the Whole30 diet together. [LAUGHTER] And all but one person in that group has a child with autism. It's just nice to have friends that understand, that are going through the same thing.

AMY BIXLER COFFIN: Siena, how about you?

SIENA CASTELLON: Yes, I want to second what Kelli said about Twitter. Twitter can be incredibly helpful. When I was at school, I had difficulty actually finding websites and resources that were designed for autistic individuals in the school system. A lot of the advice was more for parents and for teachers, and so I ended up creating my own resource, which was QL Mentoring, which is a website designed for children with learning differences and autism. And it gives them advice and tips for how to succeed in school.

AMY BIXLER COFFIN: Great. That's great. We've talked a little bit about your journeys of diagnosis, and some of the obstacles and challenges, and some of the positive influences through the journey. Ruth, you've been in the field of autism and assessment for many years.

From a professional standpoint, what do you feel might be some of the reasons why girls are going undiagnosed or misdiagnosed?

RUTH ASPY: When I have been listening to the others here, who've been first hand through this experience. I hear a lot of the reasons. And each of them talked about being premature, visual impairment, some factor that people may have focused on, and missed the autism that was there all along. Often there will be something that seems to be really salient, something that stands out to people. It could be-- for some girls it could be a behavior difficulty, that they do destructive things, or-- and so people focus on their behavior.

And they say things like, she's spoiled, or she needs to be disciplined, or something like that. Or it could be they focus on anxiety, or they focus on ADHD. But for some reason, the idea of, hey, this could be autism, doesn't come to people as quickly as it does if it's a boy. So I think we get sidetracked by things, just because our idea of what autism looks like comes from what we've seen of autism in males. And it's kind of a vicious cycle.

KELLI YEAGLEY: I definitely think that is true. And I think it goes doubly, triply, a hundred times so for people of color, especially folks-- Indigenous folks, Asian folks, people who live in underserved and historically underrepresented areas. As I've done my professional work, it's just having devastating impact on communities, people going undiagnosed of all genders. So I'm really glad that we're having this discussion. I hope, as the years progress, we can use this as a starting point, you know, this is the floor and not the ceiling. [LAUGHS] We can continue these conversations as we go forward.

RUTH ASPY: Sure. We've got a long way to go.

KELLI YEAGLEY: Right?

AMY BIXLER COFFIN: Yes. What suggestions do you have for families for-- who are suspecting that their daughter, or self, may be on the spectrum, and they're not sure where to turn? What suggestions do you have for them?

SUSAN ROTHSCHILD: I have had friends come to me. I would say get advice from your friends, if you know anybody. Look for specialists in your area. Ask at the schools. Get an evaluation. I asked some of my friends that would maybe know in that area. I think if everyone else-- everyone keeps helping everyone, and reaches out, we can help direct people where to go. Just keep reaching out and go with your gut. That's kind of my big thing. You know, a lot of people would tell me it can't be. And I thought it was. And I wasn't going to give up. I mean, it's your child. How do you give up? I want her to be the best she can be.

KELLI YEAGLEY: I also wanted to say, just in my experience with talking with folks over the years, if you're able, if you're comfortable having that conversation, sometimes it's good to know that a diagnosis is not necessarily the most important thing. It is sometimes the best for a person, especially if you're trying to get supports and services in your area. But there is a lot of things that you can do without an official diagnosis. There are a lot of supports that you can do

without having kind... I just want to make folks aware that you don't receive kind of like an official gold star diploma of autism at the end of the diagnosis trail. At least I didn't, you know, like a Hogwarts letter or something.

[LAUGHTER]

There is a lot that a diagnosis can give you, especially if you're under 18 or 22, depending on where you live. But if you're an adult, and you're seeking diagnosis, and that's a confirmation for you, and that is what you want to do, it can be very pricey, particularly if you're going through the private process. I did just want to say, diagnosis is great, but it doesn't have to be your only option. If you are a child, or if you're a parent or a guardian, and you want to seek diagnosis because it's going to give you access to services, then that's a separate conversation. So it's good to establish where you are on that timeline, and what you're seeking.

AMY BIXLER COFFIN: Go ahead, Siena.

SIENA CASTELLON: No, I mean, I would say that I would recommend, like, reflecting on whether a diagnosis makes sense. Normally, I recommend for people under 18 to try to get that diagnosis, because it makes you eligible for services. But depending on your situation, that may not even be necessary.

And so I'm diagnosed, but my sister isn't. And she's in-- she's at a school where it's enough to be self-diagnosed. And they give her all the supports and all the adjustments that they would give her with a formal diagnosis. But then again, that is a unique situation. And there are some schools that are very strict about needing a diagnosis to give you support. And so I would definitely just explore your options, and see what makes sense for you.

RUTH ASPY: That's very interesting to hear you all talk about that. In my experience, of all the years of seeing people go through the process of diagnosis, I've only seen one person who, even if it turned out in the process, that the diagnosis of autism was the result. I've only seen one person that really had a strong negative response to that. And of all the others-- and you know, I'm old enough now, I've see like 7,000-- but of all the others, there has been some sort of positive response.

There tends to be an increased understanding. Like, I've seen some people go, oh! Like a light bulb goes on. And they kind of are able to put in perspective experiences they've had that didn't make sense to them before. Also, very often, if it's an adult who's going through the process, they figure it out a long time before the professionals ever did. You know, so you're right, self diagnosis is a legitimate thing.

KELLI YEAGLEY: Thank you for saying that. [LAUGHS]

RUTH ASPY: Sure.

KELLI YEAGLEY: It's a point of contention. [LAUGHS]

RUTH ASPY: I know. I just-- I just said a really risky thing. And I know that. Yeah. [LAUGHS]

AMY BIXLER COFFIN: Let's go different avenue now. I want to go back to when Siena was talking. At the beginning of our session, she shared a little bit about sensory processing differences and that. And I just wanted to go a little bit further into that with your sensory differences, or, in Susan's case, Chloe's sensory differences, and how they have impacted you, and what strategies you use on a regular basis to support you in this very sensory-based world.

SIENA CASTELLON: No, it can definitely be a challenge for me. I'm hypersensitive. And so sound is louder. Lights are brighter. And that's something that I definitely struggled with, growing up in a city, because I grew up in London. And we would have to use public transport. I would have to be out, about in crowds. And it gave me a lot of anxiety. From a very young age my mother knew that about me. And so we came up with strategies.

So I would wear a headset. I had-- I would get very stressed out by the sound of slamming doors. And so we knew, in our household, not to do that. And so all of those kind of accommodations were made for me at home. But then, at school, teachers would call me a drama queen, dramatic, for having, essentially, panic attacks, over the sensory environment at school. It's challenging, because there are certain things you can do to reduce the anxiety you have. But at a certain point, you just have to leave the environment.

And so I do use headsets. I use sunglasses. But I do know that there are some places, like certain concerts, or certain activities that I just do not go to, do not attend. If I end up in a crowded room, or a room that's very bright, I just leave, rather than trying to make that sensory friendly for me, because at times, the best thing you can do is to just find an environment that works for you.

RUTH ASPY: Siena, what does a panic attack in that situation look like for you?

SIENA CASTELLON: I had panic attacks that were rather subtle. So some teachers wouldn't even notice them. My heart rate would get very, very, very high. I was actually diagnosed with sensory tachycardia. I'm mispronouncing that, but a high heart rate. And I was prescribed beta blockers to reduce that.

At times I wouldn't be able to breathe, where I felt like I couldn't breathe, but I could. And so I would hyperventilate. And that would cause kind of numbness in my body, because I just had too much oxygen in my blood, because I was hyperventilating. And so I wouldn't be able to feel my hands. And so there were times when I would have panic attacks in school. And I wouldn't be able to do my work.

The other element that I would have is I would get black spots in my vision, because of the hyperventilating. And so that was very stressful, because already, you're kind of in an environment that you don't feel safe in. And now you can't see, and you don't feel comfortable in this environment, and so-- but those were the extremes. That wasn't something that would happen regularly.

KELLI YEAGLEY: I can echo all of that. I feel like I'm just-- I hear Siena's story, and then I'm like, oh, yeah, I know all of those feelings. [LAUGHS] In addition to all of those, yeah, I also started experiencing migraines from a very young age, because I was premature. Like, my parents were also very used to buying very specific clothing from a very young age. They literally dressed me in doll clothes for many months, because I was so small. And there was one, like, boutique retailer in Pennsylvania that they had to drive to, because they made children's clothes very small.

That was kind of my most sensory-- and then something that I don't think we've talked about yet is hyposensitivity. And so I, from a young age, also had to do body checks frequently, because I would not feel when I would have a cut or a bruise, because I don't necessarily feel a lot of the time, because of some numbness due to the anxiety. I don't know. I'm not quite clear on how that works. [LAUGHS] But sometimes, due to hyposensitivity, I just won't feel if I hit into something or bump into something.

And then I'll have a cut or a bruise that I'm not aware of, and might need to treat, as I think some autism parents or autistic people might know, we're quite clumsy sometimes. And we have difficulty with balance. Many of us do. I shouldn't generalize. That's something that I dealt with quite a lot from a sensory perspective. I also had difficulty with just-- because of the migraines, I wear sunglasses a lot, or keep the lighting very dim a lot. So I had a nickname of being a vampire, basically, my whole life. [LAUGHS].

RUTH ASPY: Susan, for you, for Chloe, did her vision differences make her sensory functioning and her sensory needs different in some way?

SUSAN ROTHSCHILD: That's a difficult question to answer. Chloe definitely has-- is a sensory seeker. I would assume, when thinking back, that the vision definitely changed things, made it more difficult, probably. She also has interception I don't know if everyone's aware of that, just your internal state of the body, both conscious and unconscious, the ability to access, and understand, and respond to the patterns and internal signals of your body. She used to say, like, if she had a sore throat, she would sometimes tell me her neck hurt. Or waking up hungry, she didn't really know what that feeling was. You know, makes sense to us, but it's common not to know.

RUTH ASPY: Everyone has talked about really significant sensory differences. It's unanimous here. And all of you still are talking about strategies that are critical to functioning in your daily life, or in Chloe's daily life, that are related to your sensory functioning. Looking forward, do you see any signs of hope for girls and women on the spectrum? Anything that you think is improving?

SUSAN ROTHSCHILD: I think kids are learning now to be more supportive. And that could be for boys or girls on the spectrum. And that probably comes from their parents or other teachers teaching them. I see hope with doctors making diagnoses. I am very hopeful that the road will get easier. But that being said, also, Chloe having autism was not the worst thing. She's happy.

She does very well. She has made me a better person. So we try to see the positivity in it. I don't think that I would be the person I am today without Chloe.

AMY BIXLER COFFIN: Kelli and Sienna, we want to get your last minute thoughts before we wrap up here.

SIENA CASTELLON: Yeah, I've definitely seen a change. When I was first diagnosed with autism at 12, I would go online and try to find resources for autistic girls and autistic women. And I really wasn't finding much. There wasn't a conversation about autism and how it presents in women, and really difficult to find resources. And now when I go online, it's still not great, but there's definitely more.

There's definitely a bit more of a movement, a bit more understanding of autism in women. And that's definitely where we need to go. But we need to move away from the male stereotype of autism that prevents so many women from getting diagnosed.

KELLI YEAGLEY: Yeah I would agree. And I think, as I said earlier, I think this is just a starting point. I think this is the beginning. And the more we move away from just talking about it as different silos that are impacting just boys, just girls, just whatever, and we start talking about it as something that is neurodiversity, and disability, and how all of these things intersect, and impact community, and all of that kind of stuff, I think these conversations are larger than these individual silos. But also it's important to have these individual conversations as well. I think we can think about multiple things at once, and make progress in multiple areas at once. [LAUGHS] We are complex things, these humans.

[JAZZ MUSIC PLAYING]

SIMON BUEHRER: That was my colleague, Kelli Yeagley, a consultant, educator, and advocate, specializing in autism, disability, and accessibility. Before that, we heard from Sienna Castellon, author of *The Spectrum Girls Survival Guide: How To Grow Up Awesome And Autistic*. We also heard from Susan Rothschild, the mother of a young autistic woman, Chloe Rothschild. Chloe was actually featured in another podcast episode that we did back in 2019, called, "It's Different For Girls: A Conversation With Four Women on the Spectrum." If you haven't heard it, check it out. You can find it at ocali.org/podcasts, or wherever you get your podcasts.

Special Thanks to my colleague, Amy Bixler Coffin from the Autism Center at OCALI, and psychologist Dr. Ruth Aspy for facilitating this discussion. You're listening to "Rewind," the Inspiring Change podcast series featuring conversations and connections from OCALICON, the premier autism and disabilities conference. You can learn more about OCALICON at our website, ocalicon.org. Thanks for listening to Inspiring Change, because the need for change is everywhere, and inspiration can come from anywhere. I'm Simon Buehrer. See you soon.

[MUSIC PLAYING]