

[RADIO SCANNING THROUGH STATIONS]

[MUSIC PLAYING]

SIMON BUEHRER: Welcome to *Inspiring Change* from OCALI, our monthly forum of stories and connections from our ongoing work of inspiring change and promoting access for people with disabilities. I'm Simon Buehrer.

[MUSIC PLAYING]

KIM CLAIRY: The traumatic experiences that I had within that setting because of being misunderstood, it drives my passion, because I don't want other people to feel like that and to experience that.

**CHLOE
ROTHSCHILD:** And it was 'cause it was unintentionally taught. And even some of the kids that I work with, when there's a meltdown, she'll look at you during right when she comes out of it and say-- or he'll say-- I sorry. And my heart melts, because I just look back. And I'm like, you don't need to be sorry. It's OK. This is what I'm here for.

**SONDRA
WILLIAMS:** The problem I have is with women, even though I'm a woman myself, they go through every emotion in the book in five minutes. And I don't know how to respond to that.

[LAUGHTER]

And so I avoid them, being honest. I just avoid them and stay very in the professional tone and then hurry up and get back away from them.

[LAUGHTER]

**LINDSEY
NEBEKER:** I've had some really dark experiences in my life from trying to manage all this and figure out-- I sometimes question how I'm even still alive today. Shortly after all of the, I guess, the public exposure and because I didn't manage the negativity well, I ended up-- I nearly, nearly-- I'm trying to maybe verbalize. I tried to take my own life. And I nearly lost my life to suicide.

KIM CLAIRY: I have to shut down and shut out everything, everyone, everywhere, so I can later be here with you and with me.

[MUSIC PLAYING]

SIMON BUEHRER: There's a popular phrase from Dr. Stephen Shore that you've probably heard. If you've met one person with autism, you've met one person with autism. Autism is unique. It's personal, individual. It can so radically different from one person to the next that it might not even seem like the same thing, which is why it's categorized as a spectrum disorder that can manifest in a variety of symptoms, characteristics, or behaviors-- sometimes similar, sometimes not. Many people even object to the notion that autism is a quote, unquote "disorder" much less a quote, unquote "disability."

Take Greta Thunberg for example, who has described herself as a climate and environmental activist with Asperger's. She recently tweeted, "I have Asperger's. And that means I'm sometimes a bit different from the norm. And given the right circumstances, being different is a superpower-- #aspiepower."

One thing we know for sure is that autism does not discriminate. People are diagnosed across all racial, ethnic, and socioeconomic lines all around the world. Now, the degree to which people are diagnosed is a whole different story. For instance, when you look at the most recent data from the Centers for Disease Control and Prevention, autism is four times more prevalent in boys than in girls. So if you've met one girl with autism, even if that girl is Greta Thunberg, you may have only met one girl with autism. Right? Well, maybe.

There's growing reason to believe that the imbalance in the CDC numbers is not entirely accurate. Many of the traditional tools used to diagnose autism are based on what ASD looks like in males rather than females-- and white males at that, if we're being honest. This can mean that girls are misidentified or identified later in life or even not identified at all. So it's very likely that there are a lot more undiagnosed or misdiagnosed autistic girls and women than are accounted for in the CDC numbers.

[MUSIC PLAYING]

So regardless of those numbers, what's it like to be a woman on the spectrum? We recently convened a panel of four autistic women of different ages, from different parts of the country, for a frank and open discussion about their diagnosis, their work, their personal and professional relationships, and their communities. The panel was moderated by Dr. Ruth Aspy and Dr. Barry Grossman, both of whom are licensed psychologists specializing in assessment

and intervention for people with ASD. We'll introduce the panel in the order that you'll first hear them in the podcast.

[MUFFLED CONVERSATION]

CHLOE Yeah. I have my weighted blanket even extra weighted.

ROTHSCHILD:

KIM CLAIRY: What do you have weighted?

SIMON BUEHRER: Sondra Williams is a national speaker on autism and trauma related topics and is employed at the Learning Spectrum in Columbus, Ohio, where she works with kids on social and self advocacy skills. Sondra is also a parent to four adults with autism. Chloe Rothschild is a teacher's aide at a school for children with autism in Northwest Ohio. She is also a writer and frequently speaks at conferences about autism from her perspective. Full disclosure, both Sondra and Chloe serve on the OCALI advisory board.

The third participant you'll hear from is Lindsey Nebeker. She's a musician, photographer, and disability rights advocate currently working in the Washington DC area as a development specialist at the Autism Society. Lindsey was also featured in the 2015 documentary *Autism in Love*, which she talks about during the discussion.

Kim Clairy rounds out our panel. She's an occupational therapist from Belleair, Florida, with unique expertise in understanding the intersection of autism, eating, and sensory processing disorders. She's also a poet. You'll get to hear some of her original work.

Later in the discussion, you'll also hear from William Miller, Kim's husband. Kim and William speak frequently together, often including personal insights into their relationship and marriage. A few other things to briefly note-- Kim used a balance board during the discussion.

As she puts it, I talk best when moving around. So because she is standing and using a different microphone, her audio may sound a little bit different from the other panelists. You might also notice some audible clicks on occasion from a tactile device that Kim used to help regulate herself during the discussion. The discussion was recorded in front of a live audience in a packed meeting room at OCALICON in Columbus, Ohio. We begin with Dr. Ruth Aspy.

[APPLAUSE]

RUTH ASPY: All right. Well, I'm Ruth Aspy. And I am honored to be able to be a part of this panel today. And some of you are new faces. So I'm glad to get to meet you and learn more about you. And this is Barry.

BARRY GROSSMAN: Yes. This is one of the highlights of my career, to have the opportunity to be here at this panel and to learn more. I really, really want to learn more. And it's just a thrill for me to have this opportunity to be here.

RUTH ASPY: No better group to learn from.

BARRY No.

GROSSMAN:

RUTH ASPY: So why don't we have you all introduce yourselves? And if you will tell us who you are and then tell us how old you were when you were first diagnosed, and then we'll go from there.

SONDRA So you just want us to share just the age? No story with it, just how old?

WILLIAMS:

RUTH ASPY: Right. For now, just tell us who you are and how old you were.

SONDRA OK. My name is Sondra Williams. And I was a late diagnosis in my age is of 30.

WILLIAMS:

CHLOE My name is Chloe Rothschild. And the preschool first told us something wasn't right at four.

ROTHSCHILD: We first heard the word autism around eight to nine.

LINDSEY My name is Lindsey Nebeker. And I received my diagnosis of autism at around age 2 and 1/2
NEBEKER: years old.

KIM CLAIRY: My name is Kim Clairry, and I received my diagnosis at 24.

RUTH ASPY: All right. So that's quite a range, isn't it? We have from 2 and 1/2 to 30. And I know that those are going to come with very different stories of your histories. So if we could then have you talk about, briefly, your experience with getting identified, and were there some challenges associated with that?

SONDRA Start with me?

WILLIAMS:

RUTH ASPY: Sure.

SONDRA WILLIAMS: For me, I was misdiagnosed for many, many years with multiple other things, intellectual disability, mental health stuff. But when I got the diagnosis in age 30, everything made sense for the first time. And I've shared many of times in presentations that it felt like when a woman is in labor and been in labor for 30-something years and finally delivers the baby. And then it is a relief. It was a relief for me to finally make sense of what was really going on with me.

CHLOE ROTHSCCHILD: So the pre-school told my parents, around three or four, that I just wasn't playing with the other kids. They thought something was up. At three years old, I was diagnosed with a visual impairment. And then I was diagnosed with developmental apraxia, which isn't even a real diagnosis, because it's just apraxia or dyspraxia. But a clinician around us gave that diagnosis a lot.

So then our pediatrician said it's autism. It's autism somewhere. Then we went to a really well-known specialist, and it just wasn't. They were saying some characteristics. But then we went back to our pediatrician. He said, no, this isn't right. It's autism.

RUTH ASPY: All right.

LINDSEY NEBEKER: So I was born in Tokyo. And I lived there throughout my entire childhood, early, early childhood, with my family. So I guess around when I was a toddler and so forth, my parents noticed just some developmental signs that just didn't seem to catch up.

Like, I wasn't speaking at all, and I wasn't responding to when they were trying to call my name and so forth. And so they were trying to figure it out. And I think the research, they found this information on autism and decided they wanted to try and see--

RUTH ASPY: Your parents found that information. Is that right?

LINDSEY NEBEKER: Yes. Correct. My parents found the information. And so what we would do in the summertime, we would go to home leave to the United States. I'm a US citizen. My parents are US. And we went to UCLA, where I received my formal diagnosis of autism from Dr. BJ Freeman.

RUTH ASPY: She knows what she's doing.

BARRY Oh, yeah.

GROSSMAN:

RUTH ASPY: All right. So yours was pretty straightforward in a sense, Lindsey. It sounds like it was really the first formal diagnosis that you got.

LINDSEY NEBEKER: Correct. Yeah. And then I returned two more times during my childhood to get reassessed.

KIM CLAIRY: Can you repeat the question?

RUTH ASPY: Yes. The question is to tell us about your experience of getting diagnosis. And were there other diagnoses that came before the autism was recognized?

KIM CLAIRY: Yeah. So I was first diagnosed with ADHD at around six or seven. And then I got some conduct disorder and ODD added onto that. And then it wasn't until I was in college that my OT professors took me aside and said, we think that you have autism. And I looked into it. And I was like, yeah, this seems like it's right. But I didn't get a formal diagnosis until 24, when I went to the TEACCH Center in North Carolina.

RUTH ASPY: OK. What led you there?

KIM CLAIRY: Well, in college, I didn't see the point of getting diagnosed, because I was already having accommodations for the ADHD. But when I graduated and got into the workforce, I was having a lot of difficulties with certain things. And then also, when my eating disorder developed and I was in and out of treatments, I wanted to get a diagnosis so I could get accommodations, although they didn't really understand it even with the diagnosis.

RUTH ASPY: Right. It didn't work as well as you had hoped.

KIM CLAIRY: No.

RUTH ASPY: All right. Would you all please share, have you had situations where people have found out about autism, your autism, and questioned that you have it and how they go about questioning it and how you respond to that.

SONDRA WILLIAMS: Through my earlier years, there was no questions. But as I progressed and gained skills and learned how to regulate myself more, there's been more questions about whether or not I was correctly diagnosed or if it is autism.

So that was really difficult for me, because they would say things. Well, you look good for an

autistic person. Or are you sure that they really diagnosed you right? Because you don't look autistic. And I'm like, well, I'm not sure if there is a true look to autism, but--

[LAUGHTER]

And so I try to be polite, but yet almost with the same candor, if you will, with how they're asking it. Some people will say, I would have never guessed. If I'm in work, when I'm in my work mode and camouflaging a little bit, then I go into that mode and stay functional there. But as soon as I get in my car, everything goes off-- pushing on those ceilings and flapping and smacking the wheels and things just to get home because I held it in all day.

RUTH ASPY: And that's part of why they question it, because they don't see the same things that you express in other situations.

SONDRA WILLIAMS: Yeah. But if I'm walking in the hallway and I'm stressed and I don't see anybody in the hallway, I realize that I'm flapping and doing things. And then I'm thinking, oh, stop myself and try to stuff it a little bit, because then I keep remembering there's cameras all over. And I'm thinking, mm. So I try to present myself so that I'm more credible for my job.

RUTH ASPY: Right. Well, when you say that when people question it, that you try to respond in a similar way to the way they've questioned it, what does that mean?

SONDRA WILLIAMS: Well, I feel like if they're trying to be nice and they think that if they say, well, you don't look autistic, that that should be, like, a token of economy that well, look, you look so great. But in the same way, it's almost, in a metaphorical way, like a slap in the face.

Because you've worked so hard to be where you are and to have it discredited all the way-- I mean, I've in the past even been attacked online years back through-- back then, it was listservs. And some lady said, I'm sick and tired of all these adults suddenly becoming autistic, and they're not. And she was more credible about it, because she had two sons with autism, that I couldn't be that way. And I'm just mentally ill and should be locked away.

And those kinds of things were hurtful. And it would spiral me into deep routes of depression and suicidal thoughts, because I thought that was a crash in my ability to be who I was with my autonomy. And so that was hard.

RUTH ASPY: Sure. Sure. Chloe?

CHLOE

I feel like Sondra read my mind, because a lot of-- like, I can't tell you how many times I've

ROTHSCHILD:

been somewhere and someone said, I would've never guessed, or you must be so high functioning. They must think it's a compliment. But it's like a slap in the face, especially when we're advocating for services.

I've even videoed and sent it to people. I once had someone tell me, well, I'm used to working with intense individuals, placing them in restrictive environments. In which I looked at my computer screen, and I was like, am I reading this right?

It was, like, 2015 at the time. And I'm like, we don't do this anymore. What are you talking about? And then I went into this whole thing about how she may not see it, dah, dah, dah, dah, dah. And the response was, I've been doing this 12 years. And I'm like, I don't really care.

[LAUGHTER]

RUTH ASPY:

Thanks for sharing. All right.

SONDRA

That's funny, Chloe, because really and truly, sometimes the professionals know nothing. But

WILLIAMS:

they act like they do. And so I just go with the flow. And then I do like you do. Give it back.

LINDSEY

So I'm trying to verbalize. So yes. As far as the questioning and so forth, I think my family had

NEBEKER:

told my schools initially. And then, when I was in middle school throughout high school, I think they were trying to give me as a "normal" life as possible. So they would've held that information from the school.

So it wasn't really until after college time when I started becoming publicly open about being autistic. And that's when a lot of the questions would come in. So I think it initially started to be just annoying in a sense. And it gradually turned into feeling very upset and angry. Because that way I had felt, the energy I have to put into living and existing each day and even being in this room, people don't realize how much energy that takes for me. And then it then shifts into, well, frustration and anger and then shame.

I remember after *Autism in Love* had come out. And we were dealing with the public exposure, my husband and I. I didn't even have to post anything. They just see small clips of me on film.

On social media and the internet, there were hundreds and hundreds of nasty comments on she's so fake. She should be exiled from the community. She's taking advantage of the system. Just awful things. And it led me to feeling very ashamed that I had even opened up

about it. And so there's times when I still question opening up about my story and myself, because it makes me so upset when people call me fake.

RUTH ASPY: Sure. Sure. Do they sometimes do that not online, but directly to you?

LINDSEY Mm-hmm.

NEBEKER:

RUTH ASPY: And when that happens directly to you, Lindsey, how do you address that?

LINDSEY Well, directly to me, it's usually what Chloe and Sondra were saying, that they think they're
NEBEKER: complimenting, like saying you're so "high functioning," or it must have gone away or something.

[LAUGHTER]

Really, yeah, like they were saying, it's like a slap in the face. I mean, I feel like I'm repeating what everyone else is saying. So yeah, absolutely.

RUTH ASPY: OK. So you've all had similar experiences.

SONDRA And I might add to that, sometimes-- I don't know about the other two. But my experience has
WILLIAMS: been-- and it's just being honest in the room-- that sometimes it comes from parents of autistic kids. And that's painful.

Because when your kids make gains and they become an adult and more functional, how are you going to feel when that's done to your own child? So that's some of the pain that we deal with. We're trying to advocate as hard as we can. And we get the slap from the autism community.

RUTH ASPY: That's very hard.

BARRY I was wondering if I could interject a real quick question.

GROSSMAN:

RUTH ASPY: Please.

BARRY Because I'm hearing one common theme so far, is that, online or in person, people have
GROSSMAN: rejected this. And it's made you all have some pretty dark feelings-- suicidal, shame, frustration, and anger. But you're here. And you're writing. And you're talking. And you're

presenting. And I'm grateful for that, personally.

But I guess I want to know, what is it? How do you shift from having those reactions to then saying, well, I'm going to go and present. And I'm going to go and talk. Or I'm going to write that next book. Or I'm going to--

RUTH ASPY: Let's let Kimberly tell her story first. And then let's talk about how people cope. Is that all right?

BARRY Yeah.

GROSSMAN:

KIM CLAIRY: Can you repeat your question for me?

RUTH ASPY: Yes. The question is, have people ever questioned the autism? And how do you handle it? What do they say? And how do you handle it? OK.

KIM CLAIRY: So have people questioned the autism? In the medical community, it hasn't been so much questioning it as it has been not understanding it and really denying it or trying to find other reasons for symptoms or behaviors. So they don't say, no, we don't think you have autism. But we think you have all these other disorders instead-- or not instead, but just all these other disorders.

I think, in the non-medical community, I get a lot of, like, you must be a high functioning and that thing. And I usually respond, well, if you put me in a room that's really loud with a lot of people and make me stay there, then I won't be high functioning. And if you take away my headphones and if the lights are really bright, then I wouldn't be high functioning.

RUTH ASPY: So they're having a hard time seeing some of the challenges that you're dealing with.

KIM CLAIRY: Yes. Because it's really easy to hide them.

RUTH ASPY: Mm-hmm, for awhile.

KIM CLAIRY: Yeah. I regulate before and after I do things. But the people who see me, they don't see that. My husband sees it. But they don't.

RUTH ASPY: Did we introduce William?

KIM CLAIRY: No.

[LAUGHTER]

RUTH ASPY: Why don't we introduced this guy at the table?

[LAUGHTER]

WILLIAM MILLER: Hi, I'm William Miller. A lot of people don't know this, but I'm a novelist. And everywhere I go, people come up to me and they go, you're Kim Clairy's husband.

[LAUGHTER]

One day, somebody will recognize me as a novelist. But no, to get to your question, yeah. We see this all the time.

Kim and I were out with a friend of mine who was a former CIA agent. He is trained to really study people. And he's sitting across the table from Kim, saying, you're so intelligent. You're good looking. You're intelligent. You're well-spoken. Do people ever question this diagnosis of autism? So even he had a very hard time understanding that. And I think Kim's family had a really hard time understanding that.

KIM CLAIRY: My sister did. Yes. My mom knew that there was something more than the ADHD. My dad was in denial about all of it. My mom, when my autism diagnosis came, she was like, yes. This makes a lot of sense. My sister, on the other hand, was like, you're faking it. You just do stuff for attention, that kind of thing.

WILLIAM MILLER: And it made it incredibly hard for Kim.

RUTH ASPY: Sure. Sure. Even your own family is thinking that you're trying to pass something off on them or trick them into thinking something.

KIM CLAIRY: Yeah, my sister.

RUTH ASPY: OK. Your sister. So Barry's question then, to follow up, was-- help me, Barry.

BARRY I don't remember.

GROSSMAN:

[LAUGHTER]

RUTH ASPY: Oh, thanks.

BARRY No. Well, I'm grateful. But it sounds like you've all had some pretty challenging experiences.

GROSSMAN: And in spite of those experiences, you're sitting here today in front of us. And we are grateful. And I guess that's what I wanted to know, is how did you go from-- what pushes you to continue on? And what pushes you to--

RUTH ASPY: To contribute.

BARRY To contribute and to continue and whatever it is that some people responding to negatively.

GROSSMAN:

SONDRA WILLIAMS: So for me, I know that if I put the energy in, it drains me. It really does. But I also know that if I want to see change, if I want to see children who are born with autism today have a better successful future, then it's worth it to me to do what I do, even though there's days that is not going to be so great. But here at OCALI, I feel so intertwined with the support and the true care for who I am as a person and acknowledged with that and supported with that. So that allows me to feel comfortable in most settings.

CHLOE ROTHSCHILD: I would say that it's people that I've been mentored by, like everybody at this table, who have just encouraged me. And really even when I've been like people tell me this, people tell me that, and on Facebook Messenger, they've been like, look, this is how it is. And my parents and I have advocated like crazy for the right services. And it's people like Kelly Mahler and I, who work fabulously together, where I feel understood.

And then my job three days a week, I work with individuals with autism and at a school. And it's my passion. And I can only do that job because of how supported I am and how understood I am. When I presented it to the staff before I told them that, I was like, I want you to realize what I hold in here all day and then what happens as soon as I get out of here.

RUTH ASPY: It takes a lot.

LINDSEY NEBEKER: Honestly, it's really difficult for me to answer that question. Every time I speak up, whether it's giving a presentation or just sitting here at this table with all of you right now, there is still that little part of me that questions myself.

There's that part of me that feels really insecure and not sure why I'm still here today, why I'm still speaking up and so forth. But when I think back, and I know this relates into the camouflaging, which I knew we were going to get into, but I've had some really dark

experiences in my life from trying to manage all this and figure out. I sometimes question how I'm even still alive today.

Shortly after all of the, I guess, the public exposure and because I didn't manage the negativity well, I ended up-- I nearly, nearly, I am trying to verbalize. I tried to take my own life. And I nearly lost my life to suicide. And it was during that time and that time when I was going through the recovery process and the healing process and getting support, that time was really a moment where I would see the true colors of people around me.

RUTH ASPY: Are you speaking literally, in color, or you're describing their character?

LINDSEY NEBEKER: Oh, I'm sorry. Yes, I'm describing their character. Yeah, I'm describing their character. And so it's during those difficult times and even other dark times in my life-- I had an eating disorder too-- the people that have remained, they are incredibly strong people, incredibly strong people. And that includes my husband, Dave. But I think it's them that have-- makes me be able to sit here today. And it's close people, friends like Chloe and Sondra and people that are just really, just--

SONDRA WILLIAMS: And if I might interject that a lot of times you may feel that way, but many of us look up to you and respect you and value you as a friend and a person, too, as a mentor. So we mentor each other a lot. So I just want you to know how valuable you are to us in the community, as well.

LINDSEY NEBEKER: Thank you, Sondra.

BARRY GROSSMAN: And it's clear that you're surrounded by strong people, but you're clearly a strong person.

LINDSEY NEBEKER: Well, thank you for saying that.

RUTH ASPY: Kim, we were asking about your response to what it is that gives you the strength to be here and to participate in these kinds of tasks.

KIM CLAIRY: I think that my experiences within the mental health system-- so with my eating disorder, I was in and out of psychiatric facilities for over 10 years. And I was just so misunderstood, and I tried to make people understand by educating them about autism. I would highlight information and give it to the providers, which some of them appreciated it, some of them didn't.

[LAUGHTER]

But I think just spending so long trying to make people understand and then the traumatic experiences that I had within that setting because of being misunderstood, it drives my passion, because I don't want other people to feel like that and to experience that.

RUTH ASPY: Absolutely. And I do think that you all being willing to be here and talk about your experiences and some of the painful part of your experiences is helpful to the community and to those around you. It's helpful to the professionals who maybe have been insensitive in the past to be able to have this information and to go forward with better understanding.

KIM CLAIRY: Can I say something with that?

RUTH ASPY: Sure.

KIM CLAIRY: I educate a lot of providers, and it happens to be that some of the providers that end up at my trainings were some of the ones at the treatment centers that I had been to. And I get feedback from them, saying, thank you for making me understand, and I wish I would have known this then. And they also call it-- I get emails from them, as well, saying, I just had a patient who identified as having autism, and I was able to get them the right accommodations, and they were succeeding. And so, yes, it's important that we all share our struggles to everybody, because it helps.

RUTH ASPY: It's making an impact.

KIM CLAIRY: Yeah.

RUTH ASPY: Absolutely.

BARRY GROSSMAN: It's very generous. And we have heard a little bit about this, but I wanted to open the door here to discussing this. We often hear that females develop strategies to fit in. Some people refer to camouflaging and masking and have so many other names, as well.

And we wanted to know if this is something that you-- I guess it's a two-part question. Is it something you find true for you, that you've engaged or you engaged in masking or camouflaging these strategies? And if so, are there any drawbacks or costs for using these strategies?

SONDRA

WILLIAMS:

For me, when I'm at work, it's a little more difficult, because I'm more focused on the children with autism that I'm serving. So what's funny is that they correct me with my grammar. And I'm OK with it, but the teachers, if they ever hear it, sometimes they'll say, oh, that's kind of rude. And I'm like, no, it's not. He's being honest. And so I advocate for them and what they're saying and doing.

But I do remember my counselor last year or so when I first started working about three years ago, I guess. She said, how many of the co-workers do you know by name? And I had to think, and I thought, just the boss. And I work with all these teachers. I couldn't tell you their names, but I could tell you where their rooms were at, their faces.

But if you said, oh, it's the room with so-and-so in it, one of the kids, then I knew exactly what room to go in. And then she said, well-- I said, well, the plus side is, I know every kid there. But I don't know the adults, and I'm not-- the problem I have is with women, even though I'm a woman myself, they go through every emotion in the book in five minutes, and I don't know how to respond to that.

[LAUGHTER]

And so I avoid being honest. I just avoid them and stay very in the professional tone and then hurry up and get back away from them. And so--

BARRY

GROSSMAN:

And in the workplace setting then, do you find yourself engaging in camouflaging or masking strategies, pretending to fit in or to appear more--

SONDRA

WILLIAMS:

Yeah. When I'm in the classrooms around the teachers, I do. But when I'm in my room, I tell the teachers, stay out. I don't want nobody in the room when I'm working with my kids. Because I tell them they can flap, they can walk, they can do whatever. And the teachers are like, no, we're working on them sitting down.

I said, well, I'm working on then being them. And so when I go into the room, I let them do their things. And only one school site was having a problem, and they wanted to micromanage my group. And I said, you need to stop micromanaging. Go somewhere else and do something else. Take a break.

[LAUGHTER]

But I hated it, because the kids felt like they had to sit like this and not even function. You know

what I mean? It just depends on which teacher. But I camouflaged a lot. And yet, there was other times that I would be very strong in who I was as a person, and I would advocate.

We had a sensory room where kids can go, and they sometimes shut themselves in there or whatever. Well, one of my kids was really upset, and he chose to go in there. And some of the staff, when I first started working, they said, oh, you don't want to go in there. I said, I'm not afraid, and I walked right on in.

And of course, the kid had a pillow and kept saying, I'm gonna slice you up. And I said, I'm not afraid. I'll wait. And when he calmed down, then we started talking.

And he says, why do you talk third person? And I said, well, why do you have faulty scripts? I said, if you're going to call me out on my autism, I'm going to call you out on yours.

[LAUGHTER]

And so he just looked at me, and he said, "I'm going back to class." I said, great job. That's what I wanted you to do in the first place. So, I mean, I camouflage on where I need to, but in other areas, I don't. I use a lot of strategies, a lot of tools, fidgets, keeping my hands busy, list if I'm in the grocery store. And lord forbid, the grocery stores are constantly rearranging everything, and then I'm totally lost for months trying to find a certain product I used to get. But we just learn, I guess. I don't know how we do it. We just learn to mask it and fit in.

**CHLOE
ROTHSCHILD:**

Yeah. I think we're masking it because it can only be held in for so long. When I was in school, teachers would say, well, you don't do it in so-and-so's classroom, so why are you doing in my classroom? Or I would get home or in my mom's car and immediately start screaming. And all I could tell her was, call Mr. and Mrs. so-and-so, 43216.

And they'd be gone for the day, and then I would say, I'm not going to school unless you reach them, because I could only hold it in for so long. And now I work at super small place, so opposite to Sondra. I think I know all the staff names, but maybe not all of the kids' names, because I'm so into my one-to-one little world with the two I work with.

But I'll even give suggestions, like, no, we need to allow them to do this. And they're very receptive to things like that. But I've only been using my AAC device for eight years, because I was so verbal and articulate that it was never even a thought that maybe it was easier for me to write until we really explored it. And it was just hard to think, like, do some people really know how much I really know before all this happened?

SONDRA WILLIAMS: Good point, Chloe. A lot of people make assumptions about our intellect, just simply by the way we respond or act to the world around us. And it's not true, but it hurts all the same.

RUTH ASPY: And are you saying the device is part of how you can express yourself more clearly sometimes?

CHLOE ROTHSCCHILD: Yeah, and even when I was in high school, these kids would try and pick on me and stuff. And part of me wanted to-- afterwards, thinking about it, I wanted to say, really? Do you want to be doing this? Because I think my grade is higher than yours.

[LAUGHTER]

So I would be careful.

RUTH ASPY: Good point. Good point.

LINDSEY NEBEKER: I love your comeback, Chloe.

CHLOE ROTHSCCHILD: I never told him that.

BARRY GROSSMAN: You were masking at that point.

LINDSEY NEBEKER: So I have been pretty much masking as long as I have been aware that I was different. And I camouflage.

RUTH ASPY: So when do you think that that started, what age, your awareness that you were different?

LINDSEY NEBEKER: So it's interesting, because I was diagnosed at two and a half or so. But I think I started being aware I was different maybe around six years old or something. But then my parents told me about my diagnosis when I was about 10.

But I feel like I'm still camouflaging today. And it's real energy draining. It's an energy suck. And one thing that I think really needs to be shared here and is what's important to mention is that it's just like when we camouflage our own sorrows and anger and our trauma. We bury it, right, whether it's because we don't want other people to know about that part of us or whether

we're just trying to bury that from our lives.

But the problem is, whenever we take something, and we bury something in without confronting it and without coming to peace with it and then opening up about it, it's always going to come out somehow, in some way. And so, because a lot of my life, because I didn't really know and wasn't pointed out to where I knew how to bring that out in a positive way, it would come out more in a negative way, in the sense of harming myself. So whether it was dealing with my anorexia and the eating disorders I've been dealing with throughout my 20s, whether it had been when I was cutting myself in high school, and when I had nearly lost my life to suicide in 2016-- that was all because it was all built up, that camouflaging, right? And there's a point when it just-- it bursts, right? It just bursts.

So I think what I try to do now is-- I think acknowledging that you're camouflaging is helpful and talking about that. And then also what I try to do is tap into my creative side from my outlets. I have a music degree and minor photography. And so I write music, and I love to play on my 1909 Steinway that I have at our home. And I take a lot of photos, as well. So that's the way I try to channel that energy out in a positive way.

RUTH ASPY: Relieve some of the stress from having to act all day, is that right?

LINDSEY Right, yeah.

NEBEKER:

KIM CLAIRY: I started masking very young. As a child, I would watch what other people were doing, and I would just mimic them. So if they were smiling, I would smile. If they cried, I would cry, or if they laughed at something, I laughed. I didn't know why I was laughing, but I just knew it was funny, because they thought it was funny. And it wasn't until William took the time to help me understand the social cues and just understand-- help me out.

WILLIAM MILLER: Yeah, social cues. You nailed it with that.

KIM CLAIRY: OK. Through TV that I understood why people might be looking a certain way or reacting a certain way. And just like Lindsey said with her masking, it led to maladaptive behaviors. That's what happened with me, as well.

So when I was little, I would do things like flap my hands and spin and click my tongue and do a lot of those things to help regulate myself. But then I was told that I look retarded or that was babyish. And so then I started hiding it by doing things like pinching and scratching myself and

pulling out my hair and throwing up and things like that, because those were regulating my system, as well.

But they are more easily masked. And then I had to learn how to undo those. And ironically, when I learned to undo those, the things I returned were the things I did as a child.

CHLOE

I thought of something else too. I think by masking, it made me-- because I think I was taught to feel guilty for it, so I thought I had to say sorry. And to this day, when I get overwhelmed or melt down, I'll say, I'm sorry, I'm sorry, I'm sorry, over and over again. It was because it was unintentionally taught.

ROTHSCHILD:

And even some of the kids that I work with, when there's a meltdown, she'll look at you right when she comes out of it and say, or he'll say, I'm sorry. And my heart melts, because I just look back, and I'm like, you don't need to be sorry. It's OK. This is what I'm here for.

And when people question, and when I have to mask, I think that's when we see more behaviors like self-hitting and stuff. And people will say, well, this didn't happen until this, this, and this. And I'm like, well, let's think why, because this has been stressful, and you've been questioning.

SONDRA

I think it's important that there is a theme that I see, too, is knowing that you're different and not being told, first of all, or not having the correct answers. What it led to was the masking, even though we didn't understand it was masking. And what it did was cause a lot of us females to grow up with poor self-image, self-esteem, not knowing how to value ourselves or value our worth with anything. So we constantly are self-degrading, think we're *less than*, not *worthy of*. And all of those things impact, and it comes out as, well, then it's mental health, and it's not autism.

WILLIAMS:

But through my teen years and adult years, before the correct diagnosis at, well, 13, I started going and being locked away in mental institutional settings for long periods of time. And so what I had to imitate was those with severe mental health issues. And it's not that it was a direct part of me. It was an indirect, but I took on the masking of what was in that environment at the time. And it was making it harder for a correct diagnosis to happen, because it was so enmeshed with trauma, self-esteem, those valued issues on top of having the undiagnosed autism.

WILLIAM MILLER: As neurotypicals, we often fail to realize how much work goes into masking. Because I see

Kim, and she'll go, and she'll give a four-hour lecture to a crowd of 100 people. And then people come to me afterwards and go, she's so smart, she's so intelligent, so on and so forth. And they really have a hard time believing that Kim would have trouble with daily tasks like opening mail or things like that. They can't understand that she might be able to give a four-hour speech on neurological issues and then go home and not be able to fix a meal or open mail. And that's something that neurotypicals just miss if you don't have somebody with autism in your life.

BARRY

GROSSMAN:

This a question-- I'm not even sure I can formulate it properly, but I'll do my best. What advice would you give? Because it sounds like masking and camouflaging, it's a double-edged sword. We say that there may be some benefits, but that it comes at a cost, and in many cases, a great cost.

And I'm imagining that teachers and counselors and parents and other people are thinking, what advice should I give to this person on the spectrum? Because you could imagine that they might want advice, well, in this setting, here are some things to do so you don't stand out so much or so you'll be more successful in the setting, but at the same time not realizing that those very things that they could be asking you to do are replacing adaptive coping measures and things you're doing with maladaptive-- what would later turn maladaptive?

I hope that question makes sense. So what advice would you give to people who are trying to-- maybe they're working with someone on the spectrum. It's their son or daughter, and how should they advise their child student client, whatever it may be?

KIM CLAIRY:

Can I jump in?

BARRY

Please.

GROSSMAN:

KIM CLAIRY:

I would tell them to let them be themselves. Because if they-- for me, yes, I can mask. And I can sit down in a chair, but I won't really be present, and I won't be able to talk as fluently, and I really wouldn't be as successful doing that. And so you have to let them be who they are.

So when I first got my noise-canceling headphones, I was embarrassed to wear them out in public, and William helped me feel more comfortable with that. So we were at a bookstore, and it was nighttime, and it's too bright in there. So here I come. I needed to have my sunglasses and my headphones on. And I said, William, I'm embarrassed, because it's nighttime, and I'm

wearing sunglasses.

And he's like, well, I will go in and wear sunglasses and headphones with you. And so he did. He put on sunglasses and headphones, and we went into Barnes and Noble. And that meant a lot to me. I didn't feel as alone or as different, because he was willing to be different with me in that moment. And so now I'm able to accept, this is what I need to do for me. And that's OK.

WILLIAM MILLER: We live in a society that talks a real good game about tolerance and acceptance, but it's all a sham. We say, oh, yeah, be you, be you. But when you is rocking or fidgeting or making funny noises, then it's, eh, don't be you. Be us, be normal.

For me, yes, I married Kim. I didn't marry the mask. I don't want the mask. Do whatever you gotta do. When we go to my parents' house or something like that, and Kim says, can I stand up? Can I bring my fidgets? Do whatever you gotta do. My parents aren't going to care. When we're out in public, I told her the same thing. If people don't like it, that's their problem.

RUTH ASPY: Absolutely.

BARRY Anyone else want to--

GROSSMAN:

SONDRA Go ahead, Chloe.

WILLIAMS:

CHLOE Are you sure?

ROTHSCHILD:

SONDRA Yeah. Go ahead, and I'll go after you.

WILLIAMS:

CHLOE I have the same thing with the headphones. And my social worker at the time said to me, who are they, and why are you worried about what they think? And that really went deep with me. And I was like, well, you make a really good point.

ROTHSCHILD:

And we also thought about, would you rather have headphones or a complete meltdown? And I'm like, well, headphones and-- they make pink headphones. And my mom doesn't know it yet, but now they make headphones with cats and llamas on them.

[LAUGHTER]

So it's pretty cool. But I guess the coping strategies are way better than the other strategies. So you could walk through our house and probably find a fidget almost anywhere in our house, probably, from me leaving them. And I travel with so much stuff, and sometimes people will be like, you travel with so much stuff. Do you to really have to travel that much stuff? And I'll be like, yeah, we do. Do you want to sleep on this trip? Then we're bringing the weighted blanket.

[LAUGHTER]

SONDRA

And for me, I'm fortunate enough to have a job where I can work with students with autism.

WILLIAMS:

And when I work with the girls, I'm always buffing them up, always talking to them, supporting them. And they know I wear a lot of hats, because lights like that bother me.

So I wear hats, and I said why I wear them. And now one little girl-- she's older, but she's very tiny and petite. And she's starting to wear her hats. And they're starting to feel comfortable with who they are as girls.

And one particular girl at our school, she's masked so well that the doctors are trying to take away her diagnosis. And I'm so angry for that, because then she's going to lose services and supports. And that's something I'm seeing more often of, and/or some of the young girls that come into our school that have similar disabilities like ADHD or whatever.

And they come in and say, oh no, I'm not diagnosed autistic. I'm ADHD. And I said, I think I need to think about that a little more. Because they're definitely presenting autism, but they're being missed. And so they're not getting the appropriate services. So that upsets me, so I'm buffing them a little bit more so they don't have to mask so hard. And when I feel like my autism is a part of me and someone questions that, it's like they're questioning a part of who I am, like any other characteristic, I guess.

BARRY

Actually that's a really good segue here to the next question, which is, what do you think are

GROSSMAN:

the main differences in how autism manifests in females compared to males?

SONDRA

For me, one of the things I noticed is that women tend to be more intuitive, almost to a fault.

WILLIAMS:

We can maybe not read the face, but it's like this energy or something about them that we can overly interpret real quick. And so I think we do that, not trying to, just naturally.

And I think the masking is more in females than the males, that we have more-- we're taught as women that in our society, we should be social. And we're usually around mothers more as we're traveling, so we're being intermeshed with all that socialization. So we learn to mask it and do it. But it interferes with correct diagnosis and supports.

KIM CLAIRY: I see a lot of-- I see more sensory difficulties in females with autism. I also-- well, in general, in child development, girls develop language quicker than boys do. And so this goes back to one of the earlier questions with the diagnosis. I think that can make it hard sometimes to notice the female with autism, because their language development is a little bit more advanced-- not chronologically, but in child development. And also with females, I think that-- well, William, can you help me out?

WILLIAM MILLER: Are you going towards special interests?

KIM CLAIRY: No, a different one.

WILLIAM MILLER: I'm not sure. I do agree about sensory. We have found--

KIM CLAIRY: Oh, yeah. So I think that females with autism also have more comorbid diagnoses. I see a lot of ADHD diagnoses with it, which also I think can make it hard for them to get diagnosed, because the ADHD symptoms are more magnified at the younger age, more magnified than the autism symptoms. And it can also mask-- I'm kind of going off topic.

RUTH ASPY: No, you're good. You're good. We're talking about the differences between males on the spectrum and females, and you're saying that you think that maybe females have more comorbid conditions?

KIM CLAIRY: Yes.

RUTH ASPY: Or maybe those conditions are recognized more in females than they are males.

KIM CLAIRY: They're recognized instead of the autism.

WILLIAM MILLER: Yeah.

SONDRA WILLIAMS: Especially, though, social anxiety disorders often tend to be another diagnosis with the ADHD.

BARRY: I think we covered that one, don't you?

GROSSMAN:

RUTH ASPY: OK. There is a term that is being used a lot that is autistic burnout. And is that a term that you use for your own experiences, and what do you mean by autistic burnout?

SONDRA WILLIAMS: It's the first time I've ever heard it. But for me, I live with it every day, so I can't let it burn out. I mean, it would be almost like extinguishing myself. That makes no sense to me, because I'm still going to wake up tomorrow and still be autistic. So I think for me the term I use more is the autism shutdown, when I'm overloaded and exhausted from all the energy of being used, and I really need a lot of downtime.

And that's one of the things I love about my job is I get to create my hours. And my contract says from one up to 30 hours so that it can accommodate my needs, as I need to do my employment. Not every employment is going to do that. But I think it's more of a shutdown than a burnout.

RUTH ASPY: So that flexibility helps you to keep from shutting down?

SONDRA WILLIAMS: Yes. But I still come home and shut down sometimes. And I put the weighted blanket on, and sometimes I'm so exhausted from the day that I'll just sit in a chair, and usually I turn the TV straight on. But sometimes I find myself at 8 o'clock, and I'm all of a sudden alert.

And I'm realizing that it's dark in my room, and I haven't done anything, cook supper, didn't even turn my TV on. I said, boy, I must've had a really rough day. And so that's how I gauge that. Oh. I was really in a shutdown.

CHLOE ROTHSCHILD: It's kind of an outside question, but sometimes I think the flexibility and stuff helps too. I work 18 hours a week, so three days at the school. But before I took that job on, I worked as a calendar editor for a paper and could work from anywhere. I could work in my pajamas, could work any hours I wanted.

And there's part of me that thinks, wow, that was maybe easier to regulate and stuff, but then there's the other part of me who's like, I would not take back any moment. Even when I travel and advocate and go to boards and speak places, I'll tell my mom, "Mom, I'm going to miss these kids." Because I love it. But sometimes I'll come home and my mom or my therapist take the brunt of it, because I'll just be so overwhelmed. But I do it because I love it. And I wish I could do it five days, but I just can't.

RUTH ASPY: Do you shut down, or do you do something that you would call burnout?

CHLOE
ROTHSCHILD: Mom, help me out here. I melt down in-- yeah, or become like what someone would see as bossy. And I can persevere like it is an Olympic sport, and win a gold medal in doing so.

[LAUGHTER]

It could become my hobby.

LINDSEY That's great, Chloe.

NEBEKER:

RUTH ASPY: Lindsey, what about you?

LINDSEY
NEBEKER: So again, I don't really use that term, autistic burnout. I go back-- when I think about that, I reflect back to what I was mentioning earlier about energy. So I think, like on weekends, typically, I'll end up pretty much staying at home, isolated, because I have to recuperate from all the energy I had soaked in from my job and other activities throughout the week.

So I think combining that camouflaging, that feeling need for camouflaging, with my empathic tendencies-- so when I leave a place or leave a situation, I'm not only taking back my emotions, I'm feeling like I'm carrying other people's emotions with me. Because I feel so compassionate towards people, and I love being present and listening to people when they need to feel heard and acknowledged. And that takes a lot of energy.

And things like this conference-- it's amazing to have these experiences, but I could tell you, once I get back home this evening, I get on that plane and get back home, I'm going to spend this entire weekend being in the house alone and probably just isolating myself, maybe just getting the covers and just trying to restore my energy so I can make it back to work on Monday OK. So yeah, I think that was everything I was going to mention.

CHLOE
ROTHSCHILD: Oh god, I'm jealous, because I have to go to Cleveland for a family bat mitzvah. But this is the time that I'm grateful that OCAL's the week before Thanksgiving, and I only work Mondays. And Wednesday and Thursday and Friday are off.

RUTH ASPY: So you're all talking about needing time to recuperate after spending the energy that it takes to do some of the things you need to do. What about you and the term burnout?

KIM CLAIRY: Like the others, I didn't really ever hear that term until I looked it up. I think of it more as a

shutdown, as well. And it's when there's just so much information that I've processed, either internal or external, that I shut down, and I can't do anything else. And I have to let myself do that, or I'll be in zombie mode, is what I like to say, for weeks at a time. Can I share a poem about shutdown?

RUTH ASPY: Please.

KIM CLAIRY: Exhausted from the inside out, my brain is a web of confusion. Scattered pictures and missing pieces, thoughts easily turn into blanks. I can no longer keep up. I can no longer keep up. Shutting down and shutting out everything, everyone, everywhere.

A choice it is not. An option it is not. Fighting it will result in falling down further and for longer. I do not need to fight. I need to accept, accept that it is OK to step out and away from this world, this world that is sometimes too much and too fast for me.

I will come back in, but only when I am ready. Readiness is not based on expectations, but on my ability to be fully present and able to process what is around me. I have to shut down and shut out everything, everyone, everywhere, so I can later be here with you and with me.

CHLOE I love that so much.

ROTHSCHILD:

KIM CLAIRY: Thanks.

[APPLAUSE]

RUTH ASPY: Thank you for sharing that. And you have other poetry that's so beautiful and so well-said. I hope that people will access that, so they can see some more of your thoughts. Oh, so I'm next. OK. What advice would you all have for professionals who want to be helpful to women on the spectrum?

SONDRA WILLIAMS: That's a hard question, because it really depends on how open the professional is going to be. Some are very closed off and what I call old school. And they've got their mindset. And so one of the things that I joke about is, who's the autistic one here? Because sometimes they can be so rigid in their mindsets that you're just wasting energy to try to change it.

But when you do find a professional that is open and willing to listen, it's great to have that dialogue and to talk about the experiences of females differently. So my experiences over the

years of-- I've had to fire different mental health people, because they get it wrong or they only focus on their strengths. And they don't want to acknowledge that sometimes the challenges need to be discussed, as well. Then sometimes the other ones only want to see the brokenness, or what they call brokenness, or the challenges and don't ever want to really see your strengths. So to find a good balance between those, especially those people who understand the expression of women with autism, is rare.

RUTH ASPY: It is. Is there something that early on you can see in a professional that you go, oh, this person's going to get it?

SONDRA WILLIAMS: When I run across those professionals, usually they're not book smart in the sense that that's all they talk about is book smart, what they learned. Sometimes I get a good sensing from the energy that they are knowledgeable because it's internal for them. And when it's internal for them, then they're more open to that change.

And like Lindsey, I also am a sponge, so I carry a lot of emotions. And some of the old school literature about autism is that we don't feel, that we don't have emotions. And some of the old school still believe that, that there's no way I could be autistic, because I have a lot of emotions and I'm very intuitive.

I'm not intuitive in the sense of reading somebody's face, but I can pick up the energy, whether it's negative or positive. And I can tell whether I'm liked by somebody right away or not. And so those things help me navigate a little bit around people.

CHLOE ROTHSCHILD: I think just having professionals be willing to step out of the box they're used to, because that's not going to work. One time my mom and I were at a psychiatrist's office, because my other one had retired in the same office. And I went to use my iPad, and he pretty much said, no iPads in my office. And I said, I don't think you understand. This is a communication device.

And he said, you're communicating just fine to me. My eyes went to my mom, and I started freaking out. And meanwhile, this guy is sending us out the door with a script for another medication after you didn't even get any words of what I said, and I am crying as we're leaving there. And we get the car, and I say, Mom, Mommy, this is not right. Why is someone saying I can't use my words in any form I can use my words? I'm not seeing him again.

We did not go back. I have some really-- it's almost like a spidey sense of being able to find professionals who can really be able to help me and are really understanding. I don't know

how I do it. But when I do it, it's amazing. My current psychiatrist, I'll walk into her office, I'll sit down on her floor, and then I'll look at her. And I'll go, you sit too? And unless, if today, she forgets I'm coming, and she wears a dress, she'll sit too.

RUTH ASPY: So that's a good match for you.

**CHLOE
ROTHSCHILD:** Yeah, people who are willing to step outside of that little box where you see me for eight to 10 minutes and then write a script and send me out the door, because I'm not someone you're going to be able to see in eight to 10 minutes and send me out the door. It's just not going to work. And I don't want you to medicate me to the point I'm a zombie.

**SONDRA
WILLIAMS:** Could I interject something? About the devices, when I went in crisis, and when I go in crisis, sometimes my language shuts down, the whole ability to speak and formulate thoughts. So when I need these devices, when I'm in a locked mental health, which is a whole other story-- but when I need that, they say, we can't allow you to have that. And you're there to get help and support and treatment, but they're basically putting duct tape on you so that you can't talk and communicate about what's going on.

And so I think there needs to be a shift in how mental health addresses. Even that time that I did go in crisis, they kept wanting to put me in these classes, and they forced me to do them for alcohol and drug issues, and I didn't have either one. And I'm just like, what the heck is wrong with this place?

And that's all I could think, because I wanted out of here. And so I kept trying to get out the doors, and they kept pushing me back. And so those were traumatic experiences, but it was all because they wouldn't let me have a device to communicate with.

**CHLOE
ROTHSCHILD:** Someone once told me at this place that was supposed to understand, at this camp, they once said, you know if you leave here early, and you don't stay at our camp, you're not going to be successful in the world, and you're not going to accomplish anything. And part of me wants to send them a copy of the book I'm co co-authoring with a little personal message.

[LAUGHTER]

**BARRY
GROSSMAN:** You should.

SONDRA You should. You should totally do that.

WILLIAMS:

RUTH ASPY: Go for it, Chloe.

SONDRA Autographed.

WILLIAMS:

LINDSEY
NEBEKER: So I'm going to answer this question in a different way, because, to be quite honest, I don't really know how to answer that question. So I think the reason why it's difficult for me to know what advice I would give to professionals or even loved ones when they provide services to females on the spectrum, I think it's because even in a world where I feel different, even within the world of autism and even within the world of autistic females, I can feel quite alone.

There were two prominent events in my life which had made me sort of conclude that I was not really in place. One event actually was-- there was a teenage girls' workshop that I had created. This was about, I would say, nine years ago or so. And I tried to incorporate different activities of things which I had personally thought would be helping confidence, self-esteem, et cetera, because these were things that I thought personally would help me when I was growing up.

But it turned out that-- I mean, we did it. But it turned out I received quite a bit of criticism, primarily with from other autistic people, because I think the idea was that they're like, we don't need to do this and conform to that. Why should people care about makeup, hair, stuff like that? And I think that was the first wake-up call for me in realizing that's so different and that maybe I was alone in there.

The other event which was my wake up call or, I don't know, was sort of the message, I actually gave a breakout presentation at OCALICON 10 years ago on females, women on the autism spectrum and various issues there. And later on after the conference, I remember receiving the evaluations back, because the presenters do receive the evaluations. And I was going through my evaluations, and there were a small number of evaluations that are turned in.

And I remember that there was this option in there that had mentioned, sort of check mark box marking, like, I would recommend this presenter returned to OCALI and be present again, or there was this option of, no, I would not recommend that the presenter comes back. Every single one of those evaluations had check marked not recommending I come back. And so

that was-- I got the message.

And ever since between then and now I've been asked several times, Lindsey, can you give a presentation on women and girls in the spectrum? We thought it would be valuable. And I've turned down every one of them, because I kinda spooked out by those experiences.

And so while there's other topics I do feel more confidence in presenting and so forth, that particular topic is so-- and so the main reason, I mean, the only reason, really, I agreed to come here today and so forth is because of the panel. And I think that's a lot easier at perspectives. And I'm also sitting with people who I respect and I know are supportive.

RUTH ASPY: Yeah. Those are some hard experiences to come back from.

LINDSEY Yeah.

NEBEKER:

SONDRA I didn't know that happened. And one of the things that's reassuring is that, evidently, there
WILLIAMS: must be a lot more girls on the spectrum, or this room wouldn't be packed. And so there's more need for the understanding of females on the spectrum. So I'm sad that happened to you, Lindsay.

LINDSEY Well, I think in recent years, I've started to connect with and bond with more women on the
NEBEKER: spectrum that I do feel are more understanding and that do share some common things and so forth. So it's reassuring. There are definitely some very incredible women on the spectrum.

SONDRA Yeah. And Kim's our new friend.

WILLIAMS:

LINDSEY And Kim's our new friend. She's incredible.

NEBEKER:

SONDRA Yeah, she is.

WILLIAMS:

BARRY What advice?

GROSSMAN:

KIM CLAIRY: What advice would I give? I would give the same-- well, I'll read you what I wrote. I'd give the same advice, the same as everyone else, because they may not know that the person has

autism or doesn't have autism. So they need to be open and curious and really listen, listen to them and not listen over them. I find that openness and curiosity and listening are the three top traits of a really good provider.

BARRY

GROSSMAN:

I have to say-- I know we're running out of time, but I have to say that-- I'll speak for myself, but I bet I'm speaking for a lot of people are listening-- it's that I feel like we're just scratching the surface here, that just hearing you all speak, there is so much I want to know. I wish the session were 10 hours longer. And I really appreciate and want to learn more and more and more. Thank you.

SONDRA

Thank you.

WILLIAMS:

[APPLAUSE]

[MUSIC PLAYING]

SIMON BUEHRER: You're listening to Inspiring Change from OCALI, our forum of stories and connections from our ongoing work of inspiring change and promoting access for people with disabilities. I'm Simon Buehrer. We've been listening to a panel discussion with four women on the autism spectrum, recorded live at OCALICON in Columbus, Ohio. The panelists included Sondra Williams, Chloe Rothschild, Lindsey Nebeker, Kim Clairy, and Kim's husband, William Miller. It was moderated by doctors Ruth Aspy and Barry Grossman.

One thing we wanted to clarify-- Lindsey mentions a session that she delivered at the OCALI conference back in 2009. The session was entitled, "Ladies Listen Up-- The Real Deal on Women with HFA" or High Functioning Autism. Lindsey recalls receiving an overwhelmingly negative response on her session evaluations, a presenter's nightmare. But when we went back and looked at the evaluations from 2009, they were overwhelmingly positive. For example, in answer to the question, I would recommend that this presenter returned to OCALICON again next year, 16 out of 18 responses selected strongly agree, which is the highest possible score.

We're not sure what happened. Perhaps we mistakenly sent Lindsay the wrong evaluation results. Or something else transpired that left Lindsay with the impression that the session was poorly received. Whatever the reason, we wanted to let her know and emailed her the 2009

evaluation results so she could see them for herself. Lindsey got back to us right away and said this.

In complete honesty, I am in a state of complete surprise to learn and review the full results of the evaluation for my 2009 presentation. I am still trying to process my emotions from learning about this, as I had become convinced for all these years that I was not good at discussing that topic and was too insecure to present on it. I'm not entirely sure what happened when I received those evaluations initially. But whatever misunderstanding had happened, I'm grateful to you for taking the time to look back at your records and for sharing the evaluations with me. It really means a lot to have this information and to know that it was all simply a miscommunication of some kind. Really, thank you

Thank you, Lindsey, for being part of this discussion and for giving so much of yourself to it. And thanks to Sondra, Chloe, and Kim for sharing with us your thoughts, feelings, and experiences. We know this took a lot out of all of you, and we really appreciate your openness, your honesty, and your energy. Thanks also to Kim's husband, William Miller, and our moderators, Dr. Ruth Aspy and Dr. Barry Grossman.

We look forward to featuring more first-person accounts from self-advocates, parents, professionals, and others in future episodes of Inspiring Change. Be sure to subscribe to Inspiring Change wherever you get your podcasts. And if you or someone needs an accessible version of this podcast, visit [OCALI podcast](#) and click on the link to Inspiring Change. Thanks again 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.