

DR. DARREN SUSH: Hello, and welcome to Holly's Huddle, a podcast series created to help people at every stage in the autism journey. My name is Dr. Darren Sush, Head of Autism and Psychology here at Cigna. I will be joined every session by actress, activist, and mother of a thriving autistic son, Holly Robinson Peete. We welcome today, Dr. Pamela Wiley, who is the founder of the L.A. Speech and Language Therapy Center, and Mary Kaufman, to discuss adult self-advocacy.

HOLLY ROBINSON PEETE: I'm so excited to have both of you here. Mary, I want to start with you. Would you mind sharing with us your autism journey?

MARY KAUFMAN: Sure. Probably my journey is a little different because I'm a older, I grew up in the '60s. I remember, probably four years old, decided to take me to go see some doctor to see if I was good to go for school. But I think it was more to less of, I didn't show affection, love, or being around kids. Anti-social and not really communicating with kids. I had an 11-month -- year old, older brother who became like my, best bud. But besides him, trying to socialize was difficult. I remember going through all these different kinds of tests, questions. Mom was brought up during the time where they didn't know what to call it, or -- or how to assess it, the one thing they said that I would have trouble socializing with other kids. Show love, hug, or something like that. I remember hearing these individual doctors in the corner. And I didn't understand it, because I'm like, is something wrong? I was temperamental, I was beyond grades. Actually, I was supposed to have been starting two grades beyond my brother, they felt that would actually would hinder the learning of my brother. At the same time, I think on the social side, I probably wouldn't be able to adjust. So it was best to keep me in the grade level that I was in. I noticed when I got to first grade, I settled down a little bit. I went to a Catholic School. If you did really well, they would think that you cheat. I like, math was pretty good, and they gave me this math book and I remember finishing it within a couple days, and I was really bored with it, so when the nuns said -- came back to me with the superior nun and said I was cheating, I'm like, all right, this is it. I'm not going to try this anymore. I lost enthusiasm as far as learning. I did drawing. Drawing the teachers that kept me captivated in class. I had an older sister that was 10 years older, but mainly concentrated on my brother.

Probably about in my art school years, when I was like, probably my second year, that's when my mom got sick. But I know when I was in art school and prior to, I felt like she was about to go. It felt like -- it was almost like a weaning process, I felt like her distancing. And then I remember she came to me, she said, in a year she would be gone. But she would always have these talks with me of how to deal with life, how to deal with people. So even though I probably wasn't, at least, looking like I was paying attention to her, I actually was. You know, it came in handy later on, because it was like, recorded in my head. But she would always have these talks at nighttime, while she was rolling her hair for the next day. So, it came in handy.

Before she passed away, I remember her saying -- giving me a bit of advice as far as careers, I was going down the medical path, because I was intrigued about science. But she felt that I wouldn't be able to deal with people because she said it's a system, and I would get frustrated, because of my temperament. And sometimes in the system dictated what you can and cannot do.

HOLLY ROBINSON PEETE: Your story and your journey is so fascinating. I love about hearing your journey, I'm thinking about my son, RJ, and so many of the hurdles pits valleys the experience that he's had to go through coming from the point of having autism and just not

always fitting in socially, emotionally, and everything you were talking about how your mother talks with you, and you were tight with one of your siblings. Dr. Wiley, who is on with us today, and I want to bring her into the conversation. Not only has she been a lighthouse and an angel on the path to our family -- she started working with our RJ at 5-years-old. She was the first person that made me feel like RJ was going to be okay. That he was going to be all right. And I want to bring you into the conversation, Dr. Wiley, because I want you to just share with us listening to Mary, it's so fascinating, I know you work with so many adults, and can really relate to her story. Share with us about the work that you do. I could go on and list your work because I know you so well, but I would love, especially as it enables adults with autism. I would love to hear your perspective.

DR. PAMELA WILEY: Thank you, and Mary, your -- your story was so compelling, and again, you're not by yourself. When you mentioned back in the day when they didn't even have the name for autism, I actually worked with kids and we didn't have the name for autism. This is when I was with the schools. And we called them "severe oral language handicapped/aphasia children. Now, aphasia means "without language," so we didn't really know a lot about it. But in time, once we came up with the -- a diagnosis, I realized, gee, these are the kids I actually started working with. And so, in my private practice, one of the things I wanted to do was to make sure that our kids, number one, understood autism, and that autism is just a label. And it does not define their potential. And that's something that we start with at the very beginning, when your kids are very young. We also work a lot on self-awareness and self-acceptance. And so you can't advocate for you, if you don't know you. And you also can't advocate for you, if you don't like you. So our kids feel good about themselves, they have autism, but they realize it's not the end of the world. And after 40 years of working with so many kids, I can -- I can look at a child, I can work with the family, and I can see success. And that's just how I see it. I see it as -- as a process where they children continue to evolve. And as they have evolved, and as problems or situations emerge, I have developed programs. So as a result, more than 20 years ago, I developed a summer camp program, which is intense speech and language based. Once I got the kids to kind of talking, I realized the social interaction piece was huge. Was real. So we started a social skills program. And then once my kids got even older and they were doing so well, I'm thinking, okay, now what's next for them? So as I did research, I found out our kids with autism has the lowest unemployment -- the highest unemployment. And the poorest outcomes of all the other disabilities. And that bothered me, because these are my kids that I saw infinite potential. And now I'm reading this, so what can I do? So I developed a vocational training program. And so the newest thing that we're doing now is really in addition to everything else, but focusing on how do we prepare these kids for the workplace, but also for me, it's not just getting a job, it's meaningful employment. And I believe each -- each of our young persons should be in a situation that's consistent with their interest and their skill set. And so what we do is try to find them now jobs in various settings. So we have one child -- one young man that said, "I want to work with birds." So we got him into an exotic bird store. Another one said, "I don't like people, but I love books." It took us forever, but we got him in the public library. So we have been able to find all of our kids meaningful employment, and we work with them and we also work with those that are going to be employing our kids. I want to make sure that they are ready for them. So it needs to be a win-win. I want my kids to do well, but also the business owners need to feel like you haven't just dropped something on me. There is support, and you've given me the best. And so that's where we are.

I forgot about our Spectrum Shield. And Holly was instrumental in me reaching that point, but I was on a panel discussion with Holly and other individuals, and we're talking about policing in African-Americans and African-American kids, basically, with autism. And one of the things I thought about was, as you prepare them for their independence, now what? When they get out there, they are driving, they are with the police, are they going to know how to act with them? So about four years ago, we started a unique program, Spectrum Shield, safety with law enforcement. And it's a very intense, weekend-long program and all the police that participate with us, 100 percent say, "I had some training, I thought I knew, but I didn't know. But now I know. And so we just continued to evolve, and continue to figure out ways to prepare our kids to be the best that they can be. And at some point, I know I've got to let them go and fly away from me, but I'm like that -- that mother that keeps everybody close, so even when my kids are gone, they will still call me and touch base and check in with me.

HOLLY ROBINSON PEETE: That's so hard when you're letting them go. That's one of the hardest parts. And Mary, and Dr. Sush, RJ was part of this Spectrum Shield program and it helped him so much that when he did end up driving, which they said he would never drive, and he did get pulled over, he knew what to do. And I have to say, it could have maybe saved his life. So I absolutely love what you've been able to do, Dr. Wiley. Dr. Sush, I'm going to let you get in and ask a question. Because you know, I can go forever.

DR. DARREN SUSH: Well, thank you. No, Dr. Wiley, thank you for sharing all the amazing programs that you're -- you're running, and -- and the resources that you've created. And just thinking about adults who are on the spectrum and working toward building that -- that independence and that autonomy and that self-advocacy. What would be some resources or some strategies that you might tell -- speak with them about in -- in developing, in order to be better advocates for themselves?

DR. PAMELA WILEY: I think just, again, being aware of themselves and what their weaknesses, their strengths are. Continuing to address them. And then what I'm looking at right now is preparing our kids for the new normal. So when you think about even virtual interviews, we're practicing that, because that's probably going to be the way it is. Or if it's staying at home working, executive functioning is important. So are you someone, if you get a job and they say, you get to work from home three days, are you able to organize your day? so just kind of thinking about where you are and how you want to come out on the other side. And I think for all of us, it's about trying to figure out how I want to come out on the other side, so I continue to have goals for myself during this down time. I'm looking at things, assessing everything, trying to figure out, what can I do. So I think that for our kids, the goal is just -- for our young adults. I keep calling them kids, but for our young adults, the goal is to be able to continue to self-assess, and continue to grow and set goals. That's how we can get through this.

HOLLY ROBINSON PEETE: You call them "kids" Dr. Wiley, because you've known them since they were kids.

DR. PAMELA WILEY: I know.

HOLLY ROBINSON PEETE: Hey, Mary, I want to ask you a question: How are you handling what's -- the pandemic and being at home and -- and is it easier for you, is it hard for you? What is -- what's -- what is your daily life like these days?

MARY KAUFMAN: Actually, I consider this a fun time, even though, yes, people consider it down time. Because I feel this is a opportunity to -- those who are creative, to actually create. If you have that mindset and you love to develop and design, usually that's where things come out of situations like war, famines, things like that. That's where technology thrives. So, this is a time, I think, that all of us should be really coming together and coming up with solutions. What you were talking about, Dr. Wiley, as far as the resources, it would be cool, because I look at the young individuals that I deal with, especially with those with the learning disabilities. We are not trying to live in a virtual world. And we should be moving towards realities, because in our heads, that's what we're in. So we can take these realities and bring it out to their actual realities. I think that would be the key. If we could learn through the younger ones, we're actually being more ahead of the game, and adopting at the same time.

HOLLY ROBINSON PEETE: Absolutely.

DR. PAMELA WILEY: Absolutely.

DR. DARREN SUSH: Yeah, Mary, I think, you know, one of the things you're saying to me, this is such an eye-opener, but it can be an eye-opener of opportunity, of how do we better support individuals, especially those with some -- some learning and connection challenges, and how do we, you know, move this more into the future? And Dr. Wiley, one of the things that you mentioned was, you know, practice. You know, if you're -- if you're a professional athlete, I would imagine -- you know, obviously, Holly, you would probably have more to say on this than I would, but if you're a professional athlete, you don't only play in the game, you have to practice before you get there. So, when then game comes, you're -- you're doing the best that you can. So, the same thing comes with -- with self-advocacy and connection, and interaction skills. It's practice before you're going to need those skills to happen, and it's great that your program really helps to promote that as much as possible. So thank you for all that you do. Mary, thank you for the advocacy that you've had, and for being such a great representative. And Holly, thank you so much for joining us again today. And of course, thank you to our listeners, and please be sure to check out our next podcast in the series, where we will discuss autism and racial disparities. Thank you, everybody, for joining.