

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, and I will be joined every session by actress, activist, and mother of a thriving autistic son, Holly Robinson Peete. And today, we're focusing on transition to adulthood, while on the spectrum, with Dr. Valerie Paradiz of Autism Speaks. Hello, thank you for joining us, Dr. Paradiz, I appreciate it. Valerie, would you mind sharing your son's autism journey?

DR. VALERIE PARADIZ: Absolutely. My son, Elijah, was -- was born in 1990, and by age two he began having seizures and was first diagnosed with a seizure disorder. And then with time, it became very clear that he was on the spectrum of autism and eventually was diagnosed with autism as well. Elijah is now 30 years old, and is thriving, and doing very well in his career as a standup comic. And actually, has his own podcast that he produces every week and it features other standup comics. So I'm very pleased for him these days. And that journey between 1990 and now was a very -- full of ups and downs, full of victories, and also upsets that we had to overcome. And I think probably the thing that has carried us both through all of that is the mission of ensuring that people with autism learn how to advocate for themselves, and that's not something that just kind of happens. It's something that you need to really focus on and teach and model for your child and your -- your older adult on the spectrum as well.

We -- we began our journey together with his autism, by becoming a part of very early activism among autistic individuals within the disability rights movement. So, you know, the ADA was passed in 1990, that legislation, and by 1994, autistic individuals were beginning to gather in small groups to support one another and figure out, how can we join the movement, right, along with the deaf community, and those with mobility differences. So Elijah and I were a part of that movement very early on, and it's been really a mainstay in our lives ever since. Something I'm very passionate about.

HOLLY ROBINSON PEETE: Valerie, sometimes when I think about my RJ's journey, and I'm always saying way back in 2000. You dealt with this 10 years before that. I consider you a pioneer. I encourage people and say, oh, there's so many more resources, and so many more things to help you as a parent, then I had in 2000 and 10 years before that, there was a lot less. So I think you were a pioneer parent, a pioneer mommy, in so many ways. I just have to say that. But what were some of the ways that you helped Elijah self-advocate and become ready for adulthood?

DR. VALERIE PARADIZ: Sure. There were a number of things. One, I always ensured that he knew other autistic people of all ages. Including leaders who could model for him what that looks like, and where you're headed, you know, as a young person. We have a very strong group of friends who are really leaders, who are from all over the country. And that was really, really key. It was something that wasn't being offered yet in schools, so it was something that I was also ensuring was happening for him in our personal lives, but then as he grew older and moved into those transition years, I co-founded a school program for children with autism in middle and high school, which back at that time, in the very early 2000's, was very few and far between. You didn't see programs like that. And we actually had a class called Self-Advocacy Class in the school. And people with autism would visit the class and mentor the students. It was very, very early days in that regard. And I loved the school, it was very hard work. The kids were

amazing. And that's something, you know, that we did together to support the community, but to also move forward together. I was also diagnosed with Asperger's syndrome at that time. I was in my early 40s by then and had had my own challenges, both as a school-aged student, as well as in college and through those transition years. And treated primarily for depression for most of my life, until that diagnosis. And once I had that diagnosis of autism, I was able to address things in a much different way. And that was -- that was life-changing for me, and I have Elijah to thank for that.

DR. DARREN SUSH: That's great. Thank you for sharing your own experience, as well as your son's. You know, I think we have this great opportunity here where we have two parents of adults who've been diagnosed with autism and so much of the conversation around autism, understandably so, is around early intervention and talking about young kids who are on the spectrum, and there's a lot of resources that are growing for that population, understandably so, but there does need to be so much more conversation about supporting individuals who are transitioning into adulthood, or currently adults. So, Valerie, do you happen to have any -- any resources that you might support families who are listening right now, who have a child who is going to be adult age, or even an adult right now that either the family can look toward to find support, or even the individual who is diagnosed themselves?

DR. VALERIE PARADIZ: Absolutely. As Vice President of Services and Supports at Autism Speaks, I've been very focused with my team and also just across the organization on expanding those resources for transition-aged youth, as well as adults on the spectrum across the lifespan. And some of these very new resources that we've developed in the past couple of years include what we call our transition road maps. They are located on our website at [AutismSpeaks.org](http://AutismSpeaks.org). And those road maps are step-by-step guides to guide families, autistic individuals, and -- and also professionals or people who are passionate about supporting those of us on the spectrum, to just learn about what are some very key milestones and steps you can take along the way, moving through those important years of transition. Whether it's focused on housing, post-secondary education and training opportunities, or employment.

We've also very recently launched a brand-new suite of programs at Autism Speaks called WIN, Workplace Inclusion Now. And those programs provide sort of an ecosystem approach for communities to come together; employers, people with autism, and also community leaders, to really help develop and move the needle on employment in autism. Right now, we know that the unemployment and underemployment rate among autistics globally is between 80 and 90 percent, and that is just too high. There is so much talent out there and so many employers wanting to hire, wanting to expand their whole sense of diversity and inclusion in the workplace. And, you know, create welcoming workplace cultures to autistic people. So we're very, very hard at work at building that pipeline between employers and job seekers. We're doing that through digital trainings, one of them is to teach self-advocacy skills in the workplace, which is very exciting to me, and then there is also trainings for co-workers of autistic individuals and those with related conditions. There's one for managers and supervisors of autistic employees, and there's also extended programs associated with that, to help with university, faculty, post-secondary ed training faculty, as well as service providers such as both rehab workers and job coaches. So it's a very extensive suite of programs and we're very excited about launching it this -- this year.

HOLLY ROBINSON PEETE: Something else I'm really excited about is the opportunity to work with Autism Speaks Best Buddies and Special Olympics with the Delivering Jobs campaign. That partnership is so near and dear to me with that beautiful PSA that was so well done. And essentially, the idea of young people with autism getting out in the workforce is something that, back in 1990 and 2000, we probably couldn't have imagined. That there were corporations or organizations that would even advocate for something like this. So this is progress and these are the things that I bring up when I get a call from a friend saying, "Will you talk to my cousin's daughter, who just had a diagnosis." You know, these are the signs of hope and the glimmers of hope that there is this in the future for these young people.

One question I do have, you know, as parents, you know, having kids who get older and move towards adulthood, that's -- that's tough just in and of itself, and managing that transition, but what tips or what supports would you advise other parents of kids who have been diagnosed with autism, who are moving towards that transition of adulthood, or are adults right now? How did you prepare yourselves for that transition?

DR. VALERIE PARADIZ: Well, I guess I would start with, you know, I think back to that time, right, because 30 now, but, you know, those were some bumpy years. And we know that they can be bumpy for any family, right? And I think for me, the biggest tip I would like to give is that, you know, it's important to ensure your loved one on the spectrum is safe and supported, and it's also important to ensure they have the dignity of being able to make mistakes, just like anyone else. And you know, autistics often are very concrete learners, so lived experience is sometimes the thing you've got to go through to learn something in real terms. You know, Elijah, for example, didn't really understand, why is a job even important? Why would you even work? What is the point of that? You know, and you have to go through some pretty tough stuff to learn those things, and to stand back as a parent and give the space for that learning to happen, but also be there to support along the way. That is a very -- a very fine dance and choreography, really. And it takes a lot of patience and love and perseverance, and also allowing those mistakes to happen when they need to.

HOLLY ROBINSON PEETE: Yeah, and all I would add to that, is also just I would advise other parents to early on start building a team around your son or daughter. Start building a community around them who understand who they are. They don't have to be family, because sometimes family doesn't even get it. So it could be just your best friend, a god parent, or someone at work that -- that has compassion for people on the spectrum. And I just think that that really helps because especially down the line, you never know who might be able to provide a work opportunity for them. So you hustle for all of our kids and we do whatever we need to do for our kids, but our kids that have autism and are on the spectrum that differently abled, and have different skills, it takes a little extra to get the community to understand who they are. And so, I would always encourage families, even early on, because, you can imagine, if you just get the diagnosis, right, a parent would be like, why are you talking to me about their job? I was just told they'll never have a job. I'm just trying to get them to say a word or eat something but in the grand scheme of things in life, the most important thing is community for them. And that can go a long way. So I would -- would definitely suggest going out and soliciting and constantly curating a community for your -- your child for his and her young years, early years, but also especially when they become adults and get out into the world.

The other is just shout-out to the moms and dads who are having trouble letting go and allowing them to have the dignity of making mistakes, which I thought was so eloquently stated by you, Val. The dignity of making a mistake only comes when parents allow those mistakes to happen. If you are a snowplow mom, like I've been accused of being, then you might not -- I'm just saying, it's okay, we have to get out of the way and allow your kids to make a mistake. I remember RJ got this great job at the Dodgers and then they decided to give him a shot at being a ball boy. And what that meant was, there's a whole timing mechanism when you hand those umpires that ball, there's a moment. And RJ didn't have that timing down, his timing was off -- that entire stadium, at Dodger stadium, had to look -- the pitcher stopped, the umpire stopped, and it was such a mortifying moment. And I remember a friend of mine was sitting closer to the dugout than I was at that game, and thank god I was there, and she texted me right away, "Don't worry, he's okay. He's all right. But the manager looked at him and said, "You screwed up, son." And he didn't use those words, he used dugout language, and -- and that was really pretty much the end of that experiment. But it was a learning experience for him, and had someone said to me, "We're going to try him -- let him do that," I would have said, "No, no, no, because he won't know -- he won't know when to go out there." And it turns out, he didn't, but he learned, and the rest of the game, he did just fine. But I say that story, just because, you know, as moms, we've got to let go. And that's really hard. We've been doing everything for our kids from day one, and protecting them from the world, and then so letting go can be difficult. Right, Valerie? I know you agree with me.

DR. VALERIE PARADIZ: Oh, absolutely. The letting go piece is really, really the tough one. And it's a process, right? It doesn't just happen overnight. Because I have been a snowplow mom myself, and I still am sometimes, you know, and I have a 30-year-old telling me, um, you know, back off. So yeah, yeah.

HOLLY ROBINSON PEETE: I love it.

DR. DARREN SUSH: Well, thank you so much, Holly, thank you, Valerie, for joining us 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 be discussing self-advocacy.