

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'll be joined every session by actress, activist, and mother of a thriving autistic son, Holly Robinson Peete.

Today, we're going to be discussing a very timely topic, autism and race disparities with Areva Martin, autism advocate and attorney.

HOLLY ROBINSON-PEETE: I'm so excited to have Areva here. Areva is not only an amazing advocate, she's everywoman, there's nothing she cannot do. But she's also a great friend. And you know, Dr. Sush, we've talked about how the network of parents and moms, that really helps you get through hard times when you're dealing with autism, and help you get over these little hurdles that hit you every now and then. And I have full disclosure, I have a text string with Areva and three or four other moms of children -- well, our kids are grown, it's hard to call them children anymore, but they always be our babies. And we support each other. It doesn't matter what it is. It could be about autism; it could be about other heavier stuff. So I'm really appreciative to -- to share a little bit of my support system with everyone today.

So Areva, would you give us a little bit of a backstory on your -- you and your son's autism journey?

AREVA MARTIN: Yes. First off, thanks so much, Dr. Sush, and Holly, for having me. And as you were saying, Holly, I was thinking back to when we first met and we did meet around our sons. I can remember, as you were starting to talk about RJ and your journey, I was just starting Special Needs Network, a non-profit that I started in Los Angeles, and we were starting this big event to honor women, but to raise money for the organization. And one of my paralegals -- I am a lawyer and I run a law firm and I remember a paralegal said, "Oh, my God, it would great for this inaugural event for you to have Holly Robinson-Peete, because her story is so amazing." I didn't know you personally at the time, and we were trying to find you. A good friend of mine knew your mom, so we had to go through all these different channels to get to you, but finally we did. And we connected, and you said, yes, which is so important. And we've had this relationship ever since. So I just want to just acknowledge you for saying "yes" to me, who you didn't know at the time, and here we are, some years later, I won't say, because I will date both of us, but I will just say, "some years later," here we are in this friendship, as you said, and we've been able to support each other. You've supported my non-profit, I've supported yours. So this network, I don't think we can overemphasize how important it is, particularly to mothers and families and parents of color; since we're talking discrimination and issues of race. My journey with autism started very lonely, a very lonely journey, because as I was getting my son's diagnosis, I had so many questions and so few answers. But I could not find families that looked like my family. Everyone that was being referred to me as a resource, and I had a lot of referrals coming my way, were not African-American families. And as significant as those families were to me and as appreciative as I am and was about the information they gave me, I still felt very alone in my journey. Like you, Holly, I have an amazingly supportive husband; my husband, Ernest. And I can remember when we got our diagnosis, walking outside of the office, I was in tears, he was in tears, but he said, you know, "The Martins are a package, so if you want to deal with us, that means that Marty comes with us." And that was a really important statement. And if you know anything about autism in a Black community, you know that Black fathers, many of them, have really difficult times accepting the diagnosis, so I'm really -- I've been blessed on my

journey to have a husband who embraced our son and embraced the journey, and really helped me, because I, like so many mothers, started a complete wreck. I was overwhelmed. Now I know I was probably depressed. I couldn't call it that at the time, but now I do a lot of work around mental health and I know I was depressed. And it took me a long time to move through that -- you know, that process of going from depression and anguish to now being an advocate and being able to help other families. We are not doing as great as I hoped we would be doing, Dr. Sush and Holly.

There's a new report out from the American Academy of Psychiatry, just September of 2020, that talks about the race and the discrimination that Black families continue to face, and here we are, you know, 20 years -- or not quite, because my son isn't quite that old, but let's say 15 years after my own son's diagnosis, when I started addressing the issues of race and racism and we're at the same point. And that's really saddening. And that's disheartening that we haven't made more progress when it comes to diagnosing African-American kids, getting them into services, and knocking down some of those systematic barriers that they continue to face even today. That was a long answer, but I was just so full, whenever I get to talk about this. You know, it's amazing to me because, you know, I talk about it like, 1200 times a day. But still, it brings up so many memories for us as families.

HOLLY ROBINSON-PEETE: I get it.

DR. DARREN SUSH: Well, I mean, it's such useful information and such important information for everyone to hear, not just families impacted by autism, not just families of color impacted by autism, but everybody to know of these challenges, of this information, because there is a significant disparity even today. I mean, to say "even today" sounds ridiculous, but there is a significant disparity today in how families are able to access services, gain diagnosis, or just gain information. So that representation and knowledge is so important to share. So thank you so much for -- you know, to both of you for the outpouring of -- of -- of information that you provide to -- to the public that's really, really needed. You know, thinking about both of your sons are young adults now, and men of color, can you give any advice or any insight about what their experience might be? Especially as young men of color who are on the spectrum.

HOLLY ROBINSON-PEETE: Well, I would just say that, our Jade doesn't quite connect with the fact that he is Black and a Black young man with autism that -- how that might make a situation worse for him. But he is inundated with -- he's very visual and he's inundated with these viral videos of people getting shot in the back, and he wants to know what happened before and did he do what he was supposed to do? I mean, RJs been trained, you know, he's driving, he's out there in the world, and you know -- I can't breathe when he leaves the house, but you know, that just is what it is. He wants to get out and be a part of the world. So he sees a lot of visuals that are very disturbing, and he has 999 questions about what happened and why did this happen? Is it because he was Black? Is it because he didn't do this? Like, he wants the concrete information as to how to stay out -- he wants answers. How to stay out of the situation. And so trying to explain to him the nuances of the intersectionality between autism and race and police and other situations, is very difficult. I find it very hard. I don't know if Areva has the same experience, but I find it very difficult to explain that to him. I listen to myself explaining and it sound hard I want to be, tender with him, and I also don't want him to have a false impression of what's really going on out there. So it's been a challenge. He has been pulled over by the police and he was fortunately was able to move past that. And the cop -- I called the police officer, to

just to tell him, "Thank you so much for doing his job and trying to make this traffic stop just a traffic stop. I do find that it's very difficult. I still struggle with how to explain it to him without scaring him to death. But also keeping him very vigilant.

AREVA MARTIN: Yeah, no, my experience is a little different, Dr. Sush, because my son -- I won't use the label that we usually hear used about, you know, "functioning level," but my son moves about the world differently. His language is more limited. He's not driving. He has more limited skills than RJ has, and some other kids. As you know, autism is a spectrum disorder and you meet one person with autism and you've met one person with autism. So they're all very different. So we have kind of an opposite experience of having to protect our son and keep him really close. This COVID environment, this COVID -- this pandemic has been really, really tough because his limited verbal skills, we are so incredibly afraid that if he got COVID and had to go to a hospital -- some of the families that are part of our Special News Network found their kids with COVID, in the hospital, and them not being able to communicate because they don't have the language skills. So this has been a really tough period and I can imagine anyone that has a child with autism that has limited language skills, because your biggest fear is you'll be separated, you can't go into the hospital yourself, you can't call him on the telephone, you can't do Facetime, because, you know, the language skills aren't there. So we are dealing with the reality of a big mass pandemic that's going on, and how do you protect an individual like our son? So that means we won't even let him go to the store with us, we won't -- very limited outside exposure. So fortunately, he was just able to get his first vaccine shot and he'll get the second one shortly thereafter, and the whole family has been vaccinated, so we've feeling that that will give us a little bit more comfort to let him go out. But a Black kid who's tall, 6'2", with limited language skills is -- is, you know, basically we have to keep him so close to family. We have a fear of him being out with anyone that's not a very close relative. It's -- it's a challenge to find social activities for him. To find, you know, ways for him to engage with other people. Now, fortunately, I have two daughters and they are close in age, particularly one of my daughters. So a lot of her friends have become his friends. So pre-COVID, you know, he did have some social outlet with Morgan and her group. But it -- it's a real challenge for, any young adult on the spectrum that has limited language. Because the fear of something happening and them not being able to communicate is real.

HOLLY ROBINSON-PEETE: And not only that, but then when you add the issues of race and color -- first of all, I can't believe Marty is 6'2", but okay. When you add to that, you know, we've known these kids, see these kids, they are so young and they just spring up. But then, they become men and they become Black men and then their -- you're scared of them, or you are in fear of your life, and then have communication issues. Yes, RJ does have language and he communicates, but he also has a lot of anxiety and other issues that cause him to really struggle in the moment he can -- like, anybody get scared if a gun was pointed to him, he might not say the right thing or do the right thing. And then we know that can end poorly. How do we get the word out about our kids in the community? What autism looks like in the community with young men and women who don't communicate extremely well? And what does that look like? Areva and I talk about this a lot, it has to start somewhere -- obviously we want to keep them close to us and make sure that, you know, you don't have these situations get worse, but we do need more training in police departments in awareness of what autism looks like, because you can't tell me, with the prevalence of autism, that there are not a lot of police officers who have kids on the spectrum. So we start there, I think, and just kind of get a little layer and build up a little layer of empathy and community, and understanding that, our kids all need support. And

then maybe you work backwards from there, and then we need so much reform and so much training and so much de-escalation tactics, because it's not just kids obviously on the autism spectrum, it's also, all kinds of mental health and special needs across the board that are really not able to advocate for themselves properly. So it's up to police and law enforcement in position of power to educate themselves and to make themselves a little bit more compassionate. I hear a lot of policemen saying, well, you know, we're not mental health experts and we don't understand this, that, and the other. Well, maybe you need to be. Or maybe there need to be more mental health experts within police departments to help train to de-escalate, or be prepared for a young person that doesn't communicate very well.

So, there are still, like you said, at the top of the conversation, Areva. We still have a long way to go. And my fear about COVID is that it's just delayed a lot of these issues and initiatives and conversations because we're so hyper focused on the pandemic. I'm really looking forward to moving forward, to having conversations about this again, that is not so much clouded by what's happening right now, that's sort of distracting us from other issues we've been working on.

AREVA MARTIN: But I think you raise a really good point, Holly, about the police, and I think there's this moment that's happening in the country. You know, there's this intense focus because of two pandemics. The pandemic of racism as well as the Coronavirus pandemic where the country is like a laser focused on how do we dismantle these systemic racist, you know, policies and systems that have held African-Americans in particular down in this country, and how do we start, you know, envisioning a world where there is more equality and equality? And a big part of that focus is on policing. And I think advocates like us have an opportunity to make sure that as those conversations are happening around mental health and changing and reforming police departments so that the focus is more on de-escalation, and the focus is on providing social services, and help individuals of mental health, rather than treating a mental health issue like a criminal issue that the autism community, and the special needs community is included in those conversations, because so many of the, you know, deaths that we see, African-American men in particular who have been shot, or killed by police, oftentimes there is some co-morbidity happening, if there is a mental health issue, many of them, a lot of the cases of people back in (indiscernible) and I've done this, a lot of those kids have what used to be called Asperger's or higher functioning autism, or some developmental delay, you know, and that's layered with what may be schizophrenia, paranoia, some other mental health condition. So I think there is this window right now in this country, where this conversation is happening around reforming our police departments with George Floyd, you know, Bill, that's making its way through Congress to reform police departments, where we have to be extra loud in our -- making sure our voices are heard, so that our community is not forgotten. Because oftentimes in these conversations, you know, we are not there. You know, the sole focus is on mental health, and that's an important part of it, so we've got to make sure that our voices are heard on this issue as well and that those police that are getting trained, or those social workers that are being brought on are also trained in how to communicate and effectively respond to cases involving, you know, kids that look like yours and mine. And you know, it's not enough that you do it, or I do it, or our mothers figure out a way to keep their individual kids, we need systems changes that will protect all kids, you know, across this country, whether their Black, whether their Latino, Asian, White, you know, the race shouldn't matter. But we need folks to understand what our kids look like and the fact that there's no one-size-fits-all approach to our kids.

HOLLY ROBINSON-PEETE: Dr. Sush, I wanted to just give Areva a shout-out because her Special Needs Network and neighborhoods kids and families that she serves are predominantly families of color. One of the hardest things that I know from my experience in working as an advocate, is so many families of kids with color tell me how they really struggle to get access to services. And so when you see an organization like SNN and you just, you know that that is your -- you know, that's your mission and getting these kids the services and therapies that they need, because I remember when we got our diagnosis in 2000 and I started to try to go to the regional centers and work through some of the red tape, and the IEPs and things. And I'm a woman of means and we obviously have all of this blessed privilege, but it was a struggle for me. And I know that so many of my friends and people I've met along this journey who have children of color, Black kids who -- these families are really struggling to get access to some of the therapies and all the "T"s we talk about to access and get their kids the best care that they can, trying to help them during this, autism journey. So I just want to say that, I wish we could clone Areva, 50 times, and just put you in every state, because we need that kind of access for our kids of color. They're not getting the services that they need. And oftentimes not getting those diagnoses until well after other kids in other communities. So these are things we want to do and I'm so glad Areva is here, because we really struggle with access. It's just really access.

AREVA MARTIN: And that's why I started with this study. Again, September of 2020, you know, it's two months, three months old, and it's documenting the research at Washington University and saying that African-American kids are still getting diagnosed three and a half years later than their non-African-American peers, and what was so shocking about this study is that these are families -- you mentioned, Holly, being of means, these are families with health insurance. So these are families who are no uninsured. So these are people with, you know, good insurance and who you think should go to a doctor, and their, you know, concerns should be heard and acted upon, but what the study found is that because of systemic racism, even African-American families who have insurance are still not being heard. They are -- you know, what they are telling their doctors about their child's behavior and their development is being overlooked, is being dismissed, and they are not being diagnosed. So -- and I think you and I can debunk any myth that's out there. You, being an actress, being of means, you know, I started my journey as a Harvard trained lawyer, my husband is a lawyer, so we have access but we struggled I won't say as much, because obviously socioeconomic matter, but you can have access, you can have means, you can have education, you can have status, and still suffer in this system. So there's something terribly wrong with a system where an actress and a lawyer are -- are saying that they are, you know, meeting with resistance and -- and obstacles. So that means that a single mother that's working two jobs, you know or who who's been unemployed, or who's had to quit her job to take care of her kids, imagine the barriers that -- that she or he face in this system. So we've got a lot of work to do in terms of, something's terribly wrong with a system that is creating so many barriers for people, despite where they are on the continuum as it relates to their income and their education level. And that's why this -- this report is so frustrating, because this is September 2020. You know, this is a problem we should have solved, you know, decades ago, but yet it's a persistent, and you know, systemic racism is just that. You know, it's pernicious and it's -- it's -- it's not impossible, but it's going to take a lot of work. I'm encouraged. I think we are in a moment in our history in this country, where we can start to break down some of those barriers, and that has to mean a faster pathway to assessment and services for kids, but particularly Black and brown kids with autism.

DR. DARREN SUSH: Right. And -- and -- and the thing is, is we know, based on the research, that the prevalence rate of individuals who should be diagnosed with autism is fairly similar -- it doesn't matter where you -- where you come from, what you look like, your socioeconomic status, or any of that. Yet, despite that knowledge, there is significant disparities at every stage of where you would interact with an individual diagnosed with autism, from diagnosis to services, to access to services, to funding for services, to providers who work in the communities across that -- that might reach the different individuals. So that conversation still needs to happen. It's not a conversation that should happen -- should end just because there's been progress. So I appreciate the both of you for making sure that that conversation is always on the tip of everybody's tongue, or -- and even more so. So -- so Holly, thank you very much. And Areva, again, thank you so much for joining us, I really appreciate it. And thank you to our listeners, and we're really enjoyed this series, and I hope that you have found it informative and helpful and for information on Cigna's autism resources, please make sure to visit Cigna.com.