

[THEME MUSIC]

THIS IS AUTISM POINTS OF VIEW, BY AUTISM SPEAKS

I'M FELIPE MAYA

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ACCORDING TO A 2015 REVIEW OF STUDIES IN THE JOURNAL QUALITATIVE HEALTH RESEARCH, FATHERS ARE UNDERREPRESENTED IN RESEARCH INTO PARENTS' EXPERIENCE OF HAVING A CHILD WITH AUTISM.

FICTIONAL DEPICTIONS OF DAD OF AUTISTIC CHILDREN LIKE THOSE IN CURRENTLY-RUNNING SHOWS, THE GOOD DOCTOR ON ABC AND NETFLIX'S ATYPICAL, TEND TO FEATURE FATHERS THAT ARE DISCONNECTED, DETACHED.

FOR THIS EPISODE, I SPOKE WITH TWO DADS WHO ARE TRYING TO CHANGE THIS MISCONCEPTION BY SUPPORTING OTHER DADS IN THE AUTISM COMMUNITY – MICHAEL HANNON AND ROBERT NASEEF.

THEY RECENTLY STARTED A MONTHLY SUPPORT GROUP FOR DADS AT DREXEL UNIVERSITY'S THE AUTISM INSTITUTE.

THEY WEREN'T SURE WHAT THE INTEREST WOULD BE BUT BEFORE THEIR FIRST MEETING, THEY ALREADY HAD 45 DADS SIGNED UP.

Michael

I'm Michael Hannon, I'm a professor of counseling at Montclair State University in Montclair New Jersey. I'm married to a wonderful woman LaShawn Hannon. We have two children Niall, our daughter is 17 and Avery, our son is 15. Avery was diagnosed at 24 months, at 21 months I'm sorry, with Pervasive Developmental Disorder Not Otherwise Specified and as a young man who was on the spectrum, his symptoms are not nearly as severe as they used to be but he is a young man living on the spectrum.

Robert

I'm Robert Naseef. I'm a clinical psychologist. I have a blended family with four children. So my oldest Tariq is gonna be 40 in November. He has autism. He's not speaking today but he had simple signs. So he has his system of communicating and as that became clearer you know it became easier to be around him and to do things together. So even though some fathers of kids like my son, we joke around because he'll hold my hand like a little boy so we joke around because now that our sons are grown what do people think of us when they see us you know. Do they think we're gay? Well so what if they do you know. But we joke around like that because that's part of the camaraderie that exists among fathers of young people like my son.

EVERY PARENT REACTS DIFFERENTLY TO LEARNING ANYTHING ABOUT THEIR CHILD THEY MAY NOT HAVE EXPECTED. SO I ASKED MICHAEL AND ROBERT TO TAKE ME BACK TO THE TIME THEY FIRST LEARNED ABOUT THEIR SONS' AUTISM DIAGNOSIS. MICHAEL WENT FIRST.

Michael

A lot went through my head when I learned. Concerns were raised at his typical developmental check ins with our pediatrician and our pediatrician is someone we trust. But Avery's expressive language wasn't developing as was recommended by experts and pediatricians and things like that. So our pediatrician recommended that we see a developmental pediatrician versus a general practitioner. And so that the early intervention screening to determine if Avery might be eligible for services and support in our local community those clinicians who, while they didn't diagnose, they certainly encouraged us to be ready to hear the word autism with respect to Avery's development. And it stoked fear. There was no one in my family of origin, my community that I knew of explicitly who was living with autism. And it was stressful and I was I was fearful at first. And over time it took an investment, it took an emotional investment certainly took a spiritual investment for us to wrap our minds and hearts around trying to be the best kind of help for Avery and for ourselves. I think what's one thing that stands out to me most with respect to Avery's development at that early age was I remember his older sister Niall, they're 19 months apart, being sad because Avery wouldn't play with her. And we didn't have answers as to why, we had some suspicions. Both my wife and I have worked in education for years. But at least at that point in time it gave us some indication about what was happening what wasn't happening and how we might begin to fill in the gaps to be the right kind of help again for Avery and for ourselves.

Robert

Well it was very confusing because he developed normally for about 18 months and then he stopped talking. So early intervention in the 80s started at age three as opposed to now you can get intervention from the day of birth on. So there was testing, you know for his ears and you know and I just thought well he'll catch up. He used to speak, he'll speak again. But nothing really changed much. And he was just pacing and flapping and you know stlmming as people call it now and. he had a good pediatrician but the pediatrician didn't really know what to do. But by approaching three no preschool would take him. And that was that was heartbreaking. And so then he started an early intervention. He was in a special preschool class. He was eventually diagnosed with autism at about four and a half which was the earliest you could get a diagnosis then most places wouldn't give one until after age five. So he got it just approaching age five and then he got specialized services after that but when I heard the word autism I thought my head was gonna explode. Sounded like life was ending as I knew it. Tariq's mom reacted more just to shut down and really have a hard time dealing with it. So I was making most of the phone calls and taking him places. I was like driving the process to get him help get him diagnosed and whatnot but she had a really hard time with it.

Michael

But my wife is a she's a systems person and she's a she's a she's a doer and she grieves for a much briefer time than I did and got right to work. Leaned on our support system. Thankfully we have a large family who many of whom live in close proximity to us. And so the the process of learning the services for which Avery was eligible and how we were going to attain them. That became her business, that became her task and whether I was coming kicking or

screaming or whether I was coming a bit more slowly and more times and that it was a bit more slowly. She was able to model a set of behaviors that gave me hope and faith and really just required that I and others who love Avery step up and have a set of greater expectations than what may have been communicated by way of a prognosis albeit that was 15 years ago or close to 15 years ago. Even that recently prognoses were not very encouraging at least from the guys that I've talked to, the dads that I've talked to who have kids of the same age around the same age. But despite the prognosis that we got he may or may not have expressive language he may or may not. And you can fill in the blank. We got into...she took the wheel and changed the gear into drive.

Robert

And then when he got diagnosed what I learned was to just celebrate what he could do and start thinking about what he could do. And then that changed me. It began the change of to stop trying to fix him. Stop trying to make him normal. Just be with him just mirror him just hang out with him, take walks, drive in the car, put him on the child seat of the bike which he loved. So the diagnosis around that time helped me to begin to accept and enjoy him as the unique little person he was until that point I am just totally trying to fix him.

AS THEIR SONS GREW UP AND THEIR UNDERSTANDING OF AUTISM BROADENED, MICHAEL AND ROBERT BECAME ADVOCATES FOR THEIR SONS.

Michael

Avery was much older. He's probably a sixth grader at the time. His symptoms weren't as severe. He was performing well academically. So all the academic data seemed to suggest that he didn't need the support that was identified in his individualized education plan. And Robert knows this story. There was some push and pull with respect to whether he needed the IEP and his district was suggesting that he didn't need it. And LaShawn and I were like No he needs it because his needs while they may not be significantly academic there are some social needs that he has that are met by way of his IEP. Well, unbeknownst to us after getting an assessment to determine if in fact Avery was still on the spectrum. His district. Secretly removed his IEP. Without our knowledge. And so my wife and I we typically don't go in spaces like, listen, don't poke the bear that's there. That's not our disposition. We don't. We don't do that. It's unbecoming and frankly I don't get down like that. You know if I could just be candid. But in that moment we had to assert our capital because otherwise we were just going to be assumed that we would just go with the flow. And I had to say to his case manager, listen I was a school counselor for years I know special education law and now I'm a faculty member and I know your professional organization has a code of ethics and I don't have any issue filing an ethical complaint against you. And it wasn't until that moment when they were like, oh we're sorry. But it was it wasn't contrite. I didn't I didn't experience it is as true and and and heartfelt. And in that moment we were like Don't poke the bear. But that's you know that's what parents have to do.

Robert

When my son was going on 9 and he was like the master of elopement. His neurologist called him, "Houdini." He got out of everywhere. He got out of the school bathroom through the window to the outside. He got out of the apartment where we were living through the fire escape turned up in the playground in the middle of the night, playing. I mean we were just like living in the fear of his death, really. And so I had to advocate for him to get a residential

placement and that was just...that was the most excruciating experience to have to prove how his disability was life threatening. And again I mean he came to the table. There was a meeting going on at his school, an IEP meeting to talk about this and during the meeting he escaped from the school. And you know I had to run and find him you know and many experiences like that of trying to find him where he was. And you know you can't lock the fire escape when you live in an apartment building. So all of the safeguards that were everywhere couldn't be there. ~~So he was out.~~ So you know I was able to advocate for him. And you know he was able to actually be less restricted in a residential school with a big campus and safeguards.

MICHAEL AND ROBERT RECENTLY STARTED A SUPPORT GROUP FOR DADS, TO SHARE EXPERIENCES AND LEARN HOW TO BEST SUPPORT THEIR CHILDREN ON THE SPECTRUM.

Michael

If we can get dads in the same room, they absolutely benefit from learning from each other. And to me that's the heart of the answer to your question why is it important. Because we can learn from each other and be the kind of support that is most helpful and most useful in our day to day experiences loving our children or adults with autism.

Robert

So we hope to have sort of a regular stream of dads coming going forward. And it's this is something I've been involved with over the years and in wanting to reach other fathers and help fathers express their inner thoughts and feelings about this experience that men tend to like hold on the inside, not that it's really that different from the experience of moms, but men tend to hold it all in. And we're trying to and it's not hard once you get them in the room together. As Mike was saying it pours out it just pours out it's great.

Michael

Yeah, I'm encouraged like Robert said. You know the first meeting it was clear that, it was clear to me, my interpretation was that these men needed time and a space to share their story. And that's clearly what we did. Robert and I came with a plan like hey this is this is what the agenda could look like. Total hard left. You know we did almost none of that because what was most important in the moment, was for them to be able to say this is who I am. This is how autism is affecting me personally and in relationally. And we sat and we listened to each other. And that took place for an hour and 45 minutes. We started that yeah remember like we each told our own story in a few minutes and then that's what everybody wanted to do.

MICHAEL AND ROBERT TOLD ME THAT ONE COMMON THEME BEGAN TO EMERGE FROM THE INITIAL SUPPORT GROUP MEETINGS. FRUSTRATION. FRUSTRATION OVER THE STRUGGLE TO GET SERVICES AND SUPPORTS THAT THEIR CHILDREN NEED. BUT ALSO CONCERN ABOUT THEIR CHILDREN'S DEVELOPMENT.

Michael

It's important to acknowledge that even when we challenged and did our best to support them talking about the victories that they're having and remembering that when we're caring and loving folks with autism the smallest victories to other folks can be the biggest victories that you've experienced and so folks talk to, Robert talked about his son taking a selfie with him and smiling. That's a big deal. Folks talked about you know the the comical logic whereby if

you say I'm gonna jump in the shower. This guy's son said don't jump in the shower because you're gonna get hurt right. But those are things that are rewarding because it's appropriate. It's developmentally appropriate. It's contextually appropriate and it demonstrates, it provides those dads some evidence that there is a connection. And so I think they're going great and I look forward to hopefully maintaining the momentum that we've tried to establish.

SINCE THE SUPPORT GROUP GIVES DADS A CHANCE TO LEARN FROM EACH OTHER, I WANT TO LEAVE YOU WITH MICHAEL AND ROBERT'S ADVICE FOR NEW DADS IN THE AUTISM COMMUNITY.

Robert

First thing I say is this is the same child you held in your arms and fell in love with and this is shocking news. But this is this is your same kid and you might be falling in love all over again. As you learn what your child really needs from you. The important thing is to show up and really be there.

Michael

You've got an opportunity to learn to love unconditionally and as a result you're going to grow and the child that you love, the children that you love, will only be better as a result of you learning to love unconditionally. I would tell those fathers to be ready to work because that comes as a result of parenthood no matter the ability status of your children and how neurodiverse or neurotypical they are. Parenting is work so be ready to work. But this has the potential. This experience in particular has the potential to grow you in ways you likely could have never imagined. And so I would I would attempt to genuinely express hope empathy and hope because I think that's valuable. The things we can learn, learning to love unconditionally make us better men, better fathers, better partners, better friends – these are profound life lessons. As hard as this is, it's an opportunity. I thought my son would be a better version of me. He's helped me be a better version of myself and he's a fine version of himself. Truth be told. You know, just not the version I was expecting.

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MAKES SURE TO SUBSCRIBE OR FOLLOW US WHEREVER YOU LISTEN TO PODCASTS TO GET NEW EPISODES AS SOON AS THEY'RE AVAILABLE. THIS EPISODE WAS WRITTEN AND PRODUCED BY ME AND EDITED BY DAX SCHAFFER WITH ORIGINAL THEME MUSIC BY DUSTIN GLEDHILL. I'M FELIPE MAYA, THANKS FOR LISTENING.