



Episode #226

**Autism in Black's Maria Davis-Pierre on ASD, Stigma,
Cultural Impact, and the Black Community**

September 15, 2020

Debbie: Hey, Maria, welcome to the podcast.

Maria: Hi, thank you for having me.

Debbie: I'm so happy to have this conversation for the show. And I would love to actually start by hearing a little bit about your personal story. And as part of that, I think this is probably very much wrapped into what you do but your personal why for the work that you do in the world.

Maria: Okay, so I am a licensed mental health counselor in Florida. And prior to having my daughter, my niche was not anything autism related. But then we had our oldest child and around six months, I started to notice things that would be characteristic of autism. But you know, I just pushed it to the side but then at 10 months, my daughter started to show a lot more characteristics so she started to actually regress in her speech, things that she knew that she was saying prior to, you know, this point of regression. So at that point I knew, okay, we need to start getting the ball rolling on getting a diagnosis because early intervention matters as we all know. So we went to our pediatrician, our pediatrician was like, Oh, she was a preemie, let's give her time, I had to tell the pediatrician. No, you know, we really want to make sure we get her diagnosis so we can make sure we're getting all the interventions that she may need. So we went to Early Step, because she was younger than three. And you know, when most parents go to Early Step, it's like five healthcare professionals and their testing on different developmental milestones. So you have the elemental pediatrician, the OT, PT, SLP, and they're all testing her and they're like, yes, you know, we do think she is autistic, but because she's not three, we don't want to give her an official diagnosis, but you can go to a pediatric neurology and they can give the diagnosis. So after finding the one pediatric neurologist went there, he made us do DNA testing that we would have already known by that time if she had the particular diagnosis he was looking for, but of course, they have to rule it out. We did that. He was like, Yeah, I do agree. But I also want to wait until she is three. So at that point, I was just extremely frustrated. And I told him, I'm just going to sit in your office every day from open to closed until you give me the diagnosis. He did not believe me and I sat in the office for a week. Come Friday, he handed me my paperwork. He was like, take your paperwork and go, so I did. And yeah, I thought it was gonna be easy street after that, you know, we have the diagnosis. Let's get the services rolling. But then what I noticed was that the health care professionals coming into our home never want to take our culture in consideration. And they didn't ask us as parents how we were doing when we were spending the most time with her. And when talking to other parents, I saw that this was a norm when talking to other black parents, so and then you're looking up stuff and you don't see anybody who looks like you. And it was a gap. So I said, You know what, I want to fill the gap. So I created Autism and Black.

Debbie: You created what you needed, which is how so many of us get into this work?

Maria: Yeah.

Debbie: But what a story. I'm wondering, you know, you're doing this work in some capacity before your daughter was born. What exactly were you doing? I'm just wondering how you, you know, this was on your radar. So you were obviously so clued in much earlier than many parents would be, right?

Maria: Yeah. So with being a licensed therapist, you know, I've worked with clients who were autistic. I was heavily involved in working with what they categorize as at-risk youth. Um, so I worked in a school system and was a part of a lot of IEP meetings. So I was familiar with the world of IEP meetings, categorization, and students who had a diagnosis. So with my own daughter when I started to see things like having adverse reactions to sensory things, the regression and speech I, I knew.

Debbie: Can I just ask about the DNA testing, because I've never heard that come up. What is that for specifically in the diagnostic process?

Maria: So he was looking thing for things like a Fragile X Syndrome, those kind of medical issues, chromosomal issues is what he was looking for, during the DNA testing, but of course, she was at that time one and a half, so we would have already known at that point, if she had the diagnosis he was looking for with the DNA testing.

Debbie: Right? And so how many years ago was that? How old's your daughter now?

Maria: She is eight now.

Debbie: Okay. And I would love for you to talk about Autism in Black, when you started it and what you've created. Just tell us more about your organization, and what you provide for families.

Maria: Okay, so Autism in Black officially started in January of 2018. Prior to that, it was an add on service to my other private practice, but it grew so large I had to separate it. And our mission with Autism in Black is to support black parents through advocacy. So we do parent coaching, couples coaching, co-parenting sessions, on how to help the parent either learn to advocate not only for the child but themselves. help with the relationships because we know that having a child with the diagnosis can impact you know, the relationships so much. So making sure they're on the same page. And then if it's in a co-parenting situation, as well getting them on the same page so they can do what's best for the child. And we also do advocacy within the school system. So, you know, supporting a parent at an IEP meeting, or reviewing an IEP to make sure that the goals are, you know, specifically for that child and customized to that child. And then on the other end, we do culturally responsive training for organizations, schools, health care professionals.

Debbie: So okay, I'd love to hear more about everything really, that you've touched upon. But I want to even start by if you could talk through what some of the challenges

are, the unique differences in raising a black autistic child versus a non-black autistic child. What is different within the black community?

Maria: So we have stigmas within our community and outside of our community that we have to deal with, when someone sees our child, the first thing that they're going to notice, of course, is that our child is black before anything else. And we know, of course, what currently is going on in the world that, you know, being black comes with a lot. So when they first see your child and that child is black and those preconceived biases come into play, there's things that like healthcare professionals don't even want to have conversations with black mothers, because of the stigma of being loud and aggressive and not intelligent, not knowing anything, looking for a check. So they don't even want to have conversations with black mothers about the child being potentially autistic. So of course that leads to a gap in getting the diagnosis. There's also issues within our community, because we don't get the right information when it comes to autism. We get so much misinformation, that when we say autism in the black community, it's like a big, bad, scary monster because we don't get the right information. And then also thinking of it as another label, because our child, our child is already black, male or female, and then having to add in a disability or a diagnosis, it's very difficult when we already have to navigate the world so differently just because we're black. So those are a lot of the challenges because we don't get the same kind of grace as other communities do when having encounters with police officers or healthcare professionals or anything like that. We're seen by our race first. So those are a lot of things that we have to first deal with. Then, you know, the disability, so the intersection of race and disability.

Debbie: Right. And I'm wondering for the families who come to your organization or seeking services from you. Where are their biggest roadblocks? I imagine, some of your work has got to be even just around helping them embrace or push for this diagnosis, you know, so there's that piece of it. And then also the support piece. So I'm just wondering, when they come to where do you find most of the need is for the families and parents that you serve?

Maria: So a lot of them come to me at the stage of they're in, in the school system, and they're trying to get certain services for their child. The categorization may be, you know, incorrect. You know, black children are widely misdiagnosed when it comes to school categorization. That's not even a diagnosis in the school. So we're constantly placed in one of the behavior categorization, the ABD categorization so you know, not even thinking that black children can be autistic. So it starts a lot to me in that aspect. But then there's also some who come at the early intervention phase where they're trying to embrace and accept that their child had a diagnosis. And now what that means to how they have to, to parent differently, especially when having generations living within the home that are trying to, you know, tell you how to parent your child. And it's quite different from what you actually have to do so struggling with how to be respectful of your elders, but at the same time knowing what you have to do right for your child. So there's a lot of peeling back layers within our community.

- Debbie: Yeah, I was going to ask about that, that intergenerational piece. And you know, I've had other guests on the show who've talked about that being a real barrier for them to even seek therapy for their kids and feeling this strong need to have to convince close family remembers that this is what's going on. Can you talk a little bit more about that? And how do you actually help parents work through that? What kind of advice do you give them in opening up that conversation?
- Maria: So it's very difficult in our communities because we are taught to respect our elders, our elders know best because, you know, they've been here, done that, you know, that's what we hear. So when your your child is diagnosed, and we don't have the right information, and they're, you know, saying things like, Oh, just give that baby time you didn't talk until you were six, you know, so that your child would be fine knowing that, you know, if I really wasn't talking until I was six she probably should have taken me in to have a evaluation done, you know. So, also in the black community, religion is a big anchor piece. So when we're looking at religion and knowing that one, we don't take our issues to anybody but God. We don't tell people our business. You know, so we don't we don't go to therapists to tell them you know, What's going on in our home, we don't tell healthcare professionals what's going on in our home, we take it to God and we pray about it. Um, so knowing that all of these factors come into play. It is one, working through church hurt, one, working through realistically what they can do within the family home. For me, I was able to tell my family, either you're going to accept and get on board or we won't see you and talk to you anymore. That is an extreme. But for me, I knew I could follow through. That is not what a lot of black families can do. Because you know, there's child care, living together, things like that. So it's what is realistic within your circumstances that you can do having a conversation. Sometimes I've had family sessions where we, you know, talk about it from the standpoint of what does it mean, if you, as grandma accept this diagnosis, what is holding you back from accepting the diagnosis? And a lot of it has to do with the label or What does it mean? Or, you know, I don't want people to treat my grandchild differently when they're already going to be treated differently, because they're black. So a lot of the time it's not even about the diagnosis itself, it's what comes with it.
- Debbie: Yeah, that makes total sense. This idea of the label is so interesting to me. I've been thinking so much about language lately. And the way that the words that we use when talking about atypical kids, they carry so much weight, and connotations. And that's some of the work that I'm personally trying to do is speak the words and the labels so they become more normalized. And I'm just wondering, what do you see in the black community in terms of embracing different labels or Or how do you see that vision of erasing the stigma and moving forward?
- Maria: I think it goes back again to the misinformation that our communities get. When we say the word autism, a lot of families think intellectual disability, you know, they don't know that it's not that. Can a child with autism have an intellectual disability? Yes, they can. But it's two different diagnoses. So, one, it's about giving the correct information on what autism actually is and how it presents itself in their particular child. As we know, it's a spectrum and everybody is different. So

giving that information is extremely important. And when it comes to, you know, the labels and things like that, I think a lot of people, when they look at the black community think that oh my gosh, they can't accept it. They can't accept it. And it's not that a lot of the time, a lot of times it is the, if I go ahead and give my child this diagnosis on paper, then how are they going to be treated now? You know, again, being black and now autistic, what is going to happen to my child? How are they going to navigate the world? How are they going to be when they have to go to employment? So it's a lot of, is my child going to be able to do a, b and c? You know, is my child going to be able to be independent? Is my child going to be able to go to college? So it's a lot of having to, to understand what the diagnosis means for their particular child more so man, oh my God, I can't even fathom my child having this diagnosis and I'm so ashamed, ashamed and embarrassed. It's not that it's more. Oh my gosh, now that I have this black child with diagnosis, how are they gonna navigate the world?

Debbie: Well, and I also love; you talked earlier about the fact that your goal is to help parents not only advocate for their children, but to better advocate for themselves. And I would love it if you could talk a little bit more about that. My community is aimed at parents and as much as our kids need so much support, I feel like the parents, it has to start with us. And so I'm wondering how do you support parents in better advocating for their needs?

Maria: So for us in the black community, one, it starts with knowing that the parent is also an expert. So we are taught in our community when it comes to doctor lawyers, teachers, you know, they've went to school, they know their craft. So if, in my instance, when my pediatrician said no, let's give it time, more than likely a lot of black parents have been like, okay, because they see that person as the expert and of course, they know You know, the medical side, but me pushing and going and sitting in an office for a week wouldn't be something that would be typical norm for the black community because we're taught to respect those in positions of power. So, with me, it's about telling parents that they are the expert in their child, they know their child, you know, they're with their child, you know, more than most people are, so they know what's going on and to trust that gut and giving them themselves permission to fire an expert to get a second opinion and not feel guilty for that. And then on the other side, knowing that if there is a bit of apprehension around, you know, accepting the diagnosis, knowing the impact that it can have on the child, so why I don't rush parents to say, Hey, you know, get on board and except I have to, at the same time, let them know that the more time it takes The more of an impact it has on their child. So, you know, just letting them know the reality of how important a parent is in regards to everything with their child, because they're the ones giving the permission, you know, and signing consent, so knowing that they play an important role, and as far as everything in their child when they're under 18, you know, it's important for them to understand that and know that. If they don't like something, then you know, speak up and say it, you know, with the professionals or don't feel that when you go to an IEP meeting, that, you know, there's 10 professionals over there, and it's just you and you feel like you don't know anything. No, you are the expert. So it's more empowering the parents.

Debbie: Yeah, it's so important that awareness that we are the experts, and it's so hard when this is just new landscape for most every parent who's confronted with This information and yeah, that IEP meeting can be intimidating for anybody to be looking at these speech language pathologists and teachers and guidance counselor's and yeah, so I love that reminder of helping parents own their expertise and their knowing they can trust their intuition about what they know about who their kid is. So you also talked about some of your work centering around helping people understand how to be culturally responsive when working with the black disability community. So can you talk a little bit about what it means to be culturally responsive? What are you trying to help organizations and systems bring?

Maria: So when therapists health care professionals are working with children, or clients in general, we're taught specific theories and interventions, and you know, this is how you do it. But we're not taught the cultural side of how those interventions work. So there may be some interventions that the black community is just not going to fall for. One of the theories I think about is a solution focus, and the miracle question. And you know, what, if you woke up tomorrow, and you know, a lot of people in the black community like, you know, I'm not, that's not going to happen. So you know, there's a reaction to that particular theory and intervention. So a lot of healthcare professionals come in and they're trying to just apply these interventions without first knowing the culture of that home. And knowing if this is something that will particularly work and then when it doesn't work, just saying that Oh, the family is resistant. Instead of looking at the piece of maybe it's something that I'm doing as a professional, and that I need to change to help the family. You know, taking our culture into consideration when you're coming into the home and understanding that they're such a long history of medical practices that have been done against us that make us a little leery. You know, when we hear the term social worker, we automatically think of somebody who is going to take our children. So you know, not not seeing it as the parent being resistant, but the parent kind of feeling you out and knowing what they can and can't tell you. You know, I'm a licensed clinician, and when therapists come into my home, I am myself leery of what I do tell them I'm like the only No, how are they going to use this information? Are they going to think that I'm hurting my child, I can try to take my child away from me. So knowing the full history of what it means when you as a professional, especially if you're white, coming into the black parent's home and what that means and how you should try to, to navigate that and have those those culturally responsive conversations because at the end of the day, we cannot not know that we're black. We can't go around the world and say, you know, we don't see color, you know, so when you come into the house, you're like, you know, I don't see color. This is, you know what I'm trying to help the family. Help the family by having a culturally responsive conversation and acknowledging that because they're black, there are systems in play that keep them from certain resources. So you have to bridge that gap.

Debbie: Are you finding that therapists and some of these systems are more interested in doing that work, in just questioning their approaches and being more culturally sensitive? Like are you seeing a shift happening?

Maria: Yes, I have definitely seen a shift in you know, the murder of George Floyd. So I've seen more companies reaching out to get their organization trained with this culturally responsive training. So I am happy about that and that they are wanting to do the work, but it saddens me that it took 2020 and this is being in a pandemic, where we're sitting still, to notice what's been happening for a long period of time in the black community. So, you know, it's sad but happy.

Debbie: Right. I was talking with my son about this, my son who's 15 now and just this time in our history is something people are going to be writing about in the future and talking about and it's so painful everything that's had to happen in order for things to meaningfully change. I mean, I'm hoping that things are meaningfully changing. It feels that way to me as well, but it is incredible what we've had to come to as a country, as a society to get to this point.

Maria: Yeah, totally agree. And it's, you know, something we as a community, it's not new to us, you know, we've been dealing with, you know, seeing in our brothers and sisters murdered right before I then, you know, I think that a lot of people don't take that into consideration, especially when dealing with our children and going into the school system and there is a police officer, an SRO officer, you know, and how that can be triggering for that child, you know. So I think there, there's a lot of work that needs to still be done, especially when thinking about our children returning to the schools.

Debbie: Absolutely. I wanted to ask you about the school system as well. You know, what changes would you like to see, like what needs to change, specifically to better support differently wired kids of color in the school system?

Maria: Definitely needs a culturally responsive training for the staff. You know, the teachers, any of the staff that's working in the school system, to understand the systems that are playing when it comes to being a black child with a distance ability, understanding that culturally we respond differently to a lot of things. So it might not be a particular behavior issue, but it's something that is accustomed to the situation that they live in. So, you know, we're looking at it from one lens of how they're reacting in the school and not looking at it from a systemic lens of, what are they doing at home and what's happening at home? And how is this impacting what's going on at school? Also, knowing that, you know, black children are coming back with at least one on the ACES (Adverse Childhood Experiences) score, you know, because racism is now a part of the ACES. So knowing that they're coming in with one particularly traumatizing thing, even though they probably have more so knowing that they're going to be coming back traumatized, how do we best support their mental health needs? What do we need to be doing to address this? You know, also decolonizing the curriculum, having a curriculum that shows in more light than just being slaves, you know, so anything else besides that, having history, Black History also knowing that when it comes to your SEL curriculum, that it is not culturally responsive, you know, and changing that within there, knowing that evaluations are biased to black children, knowing that and taking those biases off and confronting your own

biases before you're evaluating our children. So those are many things that can definitely be done.

Debbie: Thank you for that. So I would love to know what your big picture vision is. You launched a podcast this year. I saw your self care affirmation journal, which I love, I'm huge into affirmations and I thought that was wonderful. And you have a lot going on. And I feel like you've got big plans. So where do you want to go with Autism in Black.

Maria: So the Autism in Black book will be coming out at the end of the year. Definitely giving a perspective that is different because we're not, you know, well-represented within literature when it comes to the intersection of race and disability. So that will be coming out there is a conference that is coming up. And our main mission is to bridge that gap with not getting the information to our community. So I try to have as many avenues of parents getting the information as possible, you know, so we can be more well informed so that we can close the gap on our children having a one-and-a-half year gap behind my children when coming when it comes to diagnosis, because we do know how important early intervention is. Our children are getting diagnosed in elementary and middle school, and we all know at that age, we've lost a lot of time. So we're trying to make sure that we're closing that gap closing the school to prison pipeline. So that is the main mission of Autism in Black is having more and more of the information in an A to our communities. We're also, you know, COVID kind of messed up our plan for we're in the works of opening a wellness center where they'll be, you know, your developmental pediatrician, your OT, your SLP, your mental health therapist, all they're working as a unit as a team in regards to your child and their interventions and their, their medical diagnosis. So knowing that, if I'm over here, and I have my doctor over here, and then I have to go all the way over here and have the therapist they're more than likely not having conversations about what they're doing with my child. They're not talking to each other. Everybody is doing overlapping intervention, and it can be confusing for the child and the parents, so having everybody under one house makes it better. So we're trying to get our wellness center open.

Debbie: I love that that makes so much sense. What a cool thing it would be to have everyone on the same page about our kids.

Maria: Yeah. And that, you know, it's not just for black people, it's for you know, everyone, because when it comes to our kids, that is an important piece. We need to be working as a team, because there's so much miscommunication and people doing two different interventions and then wondering why the child is confused, because nobody's talking and you're telling them to do two different things.

Debbie: Right. So before we say goodbye, first of all, that's exciting about your book and congratulations, and please keep us posted when that comes out so we can support the launch of that. But could you let listeners know where they can find you on social media or check out your podcast and your website?

Maria: Yes, you can go to www.autisminblack.org And that has the podcasts on there, as well as all of my social media information and how to work with me and I'm on Instagram a lot, and it's autisminblack on there. And then on Facebook, it's autisminblk. And if you're wanting to join the newsletter to get information on the book, you can go to includetheexcluded.com.

Debbie: Awesome. Is that the title of the book?

Maria: Yes, Autism in Black: Include the Excluded.

Debbie: Awesome. All right. So listeners, I will have links to all of that in the show notes pages. So you can check out Maria's website and her awesome podcast and all the other goodies that we discussed today. And I just want to thank you so much. I'm so happy that I was reading an article in Forbes magazine and which also is so cool to be in Forbes magazine. Congratulations and, and so I'm really happy to have found the work that you're doing and thank you so much for sharing with us today.

Maria: 'Thank you for having me.

RESOURCES MENTIONED:

- [Autism in Black website](#)
- [Autism in Black Podcast](#)
- [Autism in Black on Instagram](#)
- [Autism in Black on Facebook](#)
- *Autism in Black: Include the Excluded* by Maria Davis-Pierre (coming in late 2020)
- *Self-Care Affirmation Journal* by Maria Davis-Pierre
- Freebies for Tilt Parenting listeners: autisminblack.org/tiltparenting or text "TILT" to 33777
- "For mothers of black children with disabilities, living with twice the fear" (article in Forbes Magazine)

