



Episode #161:

**Dr. Devon MacEachron on
"What's Next?" After Diagnosis**

June 11, 2019

Debbie: Hey Devon, welcome back to the podcast.

Devon: Thank you, Debbie. It's really an honor to be invited back.

Debbie: Yeah. Our conversation, I'm realizing, was a couple of years ago now where we talked about the diagnostic process. That was a very popular episode. Listeners, if you haven't checked it out yet, you should go back and listen to that after you listen to this conversation. And you've had kind of a busy couple of years since then. Before we get into the meat of our conversation today, can you just take a minute to introduce yourself and tell us what you do?

Devon: Sure. My name's Devon Maceachron and I'm a psychologist in private practice in New York City, in Manhattan. And I specialize in gifted learners and twice exceptional learners, but I'm happy to work with absolutely anybody. I take a very positive psychology approach to my work and emphasize the child's strengths and interests as well as areas for development. So it's, um, it's perhaps a little bit different approach that we take and it's very rewarding.

Debbie: Yeah. And just, I have to just say this as a disclaimer, Devon was the person that we took Asher to last summer here in New York City for a formal assessment process. And it was just such a positive experience. So I've just gotta throw that out there. I've been sharing this in different Facebook groups where people are looking for resources. So just full disclosure that we have that kind of relationship. So I know how good Devon is at what she does. Um, but I also just have to mention that you were in a video and now this video that came out, I don't know, maybe a year ago that really went viral. Can you, I'm sure that listeners know you from that. Can you just take a moment to speak to that and kind of the unexpected response it received?

Devon: It sure was unexpected. It was last July. My daughter, who is twice exceptional, is a journalist at NowThis and they were having a quiet month and she noticed it was mental health awareness month. So she asked me if I would prepare a, an opinion piece on any topic I was interested in having to do with mental health. So I decided to do it on neurodiversity, and I'll explain what I mean by that briefly, but it's very in alignment with your approach of seeing people as differently wired. Um, but, but so I did this talk and, and went down to her studio and got it done and it came out and it's now up to 29.8 million views. It's crazy. It just really took off and they didn't expect that at NowThis either particularly for an opinion piece on a topic that was sort of scientific.

Um, but I, I think what it suggests and from what I've heard from people, I've gotten an outpouring of responses from around the world, and what most people have said they found so exciting about this and the whole topic of neurodiversity, it's a, it's a positive way of looking at how people are different and finding ways for them to be themselves and be the best they can be rather than marginalizing them and looking at people as a medical diagnosis as somehow broken. And I think that that, um, way of thinking really resonated with, with a lot of people.

Um, and I think good things are coming. There has been a huge number in the past year, which may be totally unrelated, probably is, but of companies who are making a real effort, who are hiring neurodiversity consultants to help, you know, enlarge their, their acceptance of people who are neurodiverse in the workforce and so on. So it's, the momentum is building for that and, and it's, and you're no small part of that, Debbie.

Debbie: Thank you. But wow. I just have to say that's incredible. Uh, almost 30 million views and that, you know, I always think of this as a revolution, you know, and the work that I'm doing is a little piece of that, but just trying to change this paradigm and help people see neurodivergent people in a different light. And, um, it's so exciting to think that that many people have viewed this and are considering the things that you talk about and that message of inclusion and, and accepting people for who they are is really exciting.

Devon: Yeah, no, it is. It's, and I'm very proud of my daughter too. So fun mother daughter project.

Debbie: Oh, that's awesome. Okay. So our first episode we did together was about the diagnostic process. Today we wanted to talk about, okay, we get this diagnosis, we get this, you know, sometimes very thick packet of, of a report with all kinds of details and information about various tests and recommendations, et cetera, which can be really overwhelming. So we wanted to talk about what's next, what is a parent to do? So let's just start there. Say someone has come in to see you or worked with someone else and they've gotten this detailed report saying, okay, your child, you know, has been identified as x, y, and z. What is a parent to do first? Like where should they even begin wrapping their head around what they're learning and discovering?

Devon: Yeah, that's a really good question. I think parents often don't know what to do next. So this is good. I would start with questioning the report and questioning the evaluator about the information. In your own mind do you feel it fits? Does it describe your child appropriately or adequately? And ask them questions. You know, I know there's a lot of dense language in there that you have to use dictionaries to look up words, but the, it should all be able to be explained in plain English in a way that anybody can understand. And I think it's too often people are, are afraid to hold the evaluator to task, to, to really explain it to them adequately and question the actual things. I, so often I see a family who tells me that their child was found to have slow processing speed and processing speed is at the eighth percentile or something. And then when I look at the report, I see that the evaluator did one two minute test of processing speed. Within the WISC full-scale IQ, there's literally only one processing speed test. So unless they did more than one test, you really shouldn't be relying on one data point to make a lot of decisions. So I guess my first piece of advice is question. See if it sounds right and you're confident in, in what was recommended before you start taking the appropriate steps.

Debbie: I think that's such a good point and I think that it is probably something most parents don't do. Because we're not, I know that you, in raising your children decided to go back and get a PhD so you could, you know, really understand who

they are and, and work with this population. But most of us don't do that. Most of us don't have the background, the experience or information to even trust maybe our own instincts if something doesn't resonate. And we really are giving a lot of power to the people who make these decisions about who our kids are. So I think that is a really good piece of advice. And I guess, so if someone sees something that really doesn't land or resonate, I'm just curious, like, do you recommend getting a second opinion? Do you recommend having a deeper discussion and having a better understanding, what would they do if something really doesn't click?

Devon: Well, I think, and this has happened to me as a, as a parent before I went back for my PhD, so I'm, I've been in that, that position. Um, sometimes a second opinion is a good idea. I can, starting with going back to the evaluator and saying, hey, you know, this doesn't sound right to me. Could you explain it to me better so that I understand. How did you get there? You know, what, what's this based on? It's not uncommon at all to get second opinions either. And I do that a lot for families. Sometimes it's not even a second opinion, it's just reading the report that's there and saying, you know, here's what it really says. You know, if you don't understand what it says, here's what I think it says and here's what you should take from it. So that's not a bad idea to get a second opinion. Or sometimes a few additional tests might need to be administered. But if you feel, maybe in even going through that process of questioning the evaluator, you come to a feeling of trust or not. And if you feel that trust, I think you then can rely more on their expertise and professional judgment and not feel like you have to question everything, if you feel like the gee this person really does know what they're talking about and it sounds right.

Debbie: Okay. Also, I guess it's important to consider, and I think this goes more into what we discussed in the first episode, but in case people haven't listened to that yet, let's just briefly touch upon the goal in getting an assessment. Is it important to consider that? Because I think a lot of times it's really about getting services versus having a really good understanding of what's actually happening with the child. So is that an important distinction to make?

Devon: Well, I would hope that parents would want the big picture, which is understanding their child and getting services, both. But sometimes if you've gotten, you know, a quick evaluation at school, it might not really help you understand your whole child. It might be very surface oriented. But still question that and make sure that you think that the, the problems that have been identified as requiring services are the ones that require service.

Debbie: I remember when we did our, you know, an assessment when, when Asher was eight, it very much was about, she said, this is very subjective, but I, you know, I did, I made these decisions in part to make sure that he would get the kind of accommodations he needed.

Devon: Yes. And we do see that. I, I, I have families who come in to me and say, you know, my child got this diagnosis, you know, four years ago because we wanted extra time on the SAT, but he doesn't really have problems with that. Yeah. So you see that too, which of course after the recent news will be hopefully less

common. But yeah, no, I think you do what you have to do. So if you need to get, um, a diagnosis so that your child can get services, then you should try and make sure you get a diagnosis, but make sure that it matches the services you want your child to get.

Debbie: Right. Okay. So we've gotten the report, we've read it, and we've questioned it, now we're kind of, you know, I'm just imagining this blank canvas, right? So now we have this information. We may know more about our child's brain than we ever imagined wanting to know in our lifetime and we don't know what to do now. So can you kind of walk us through that process that a parent is likely to go through as they're digesting this information?

Devon: Yes. I like to sort of, before launching into what to do next, I'd like to just stop for a moment and talk about considering, for the parent to consider their emotional state, particularly if it's a first diagnosis for a child and you thought that everything might be totally fine and suddenly you're told that there's something going on that you, that you didn't expect and that's not, not positive necessarily. There are stages that one goes through in digesting and accepting this information. There's a really good book by a woman named Doctor Rita Eichenstein called *Not What I Expected*, which describes that process. And basically, I won't go into great detail, but the first step, and it's like the stages of grief, the first step is often denial. And I certainly felt that myself as a parent, it's, it's basically a defense mechanism of rejecting and retreating from the diagnosis.

No, that's not possible, my child couldn't have that. You know, or often one parent will say, well, you know, I was just like him as a kid and I turned out fine, you know, there's nothing really all that wrong. And the denial stage can take a little while to work through, if parents go there. Not all parents land on all stages. The next stage is often anger. Um, sometimes directing your pain towards school for not catching things earlier or sometimes towards yourself thinking that you did something wrong as a parent. I've been there too. I mean personally, um, I blamed the school and was very angry at the school and felt I had to go into these IEP meetings with the equivalent of a bunch of valium in my system so that I could not be as angry as I felt. Cause it's hard, it's really hard. And you want to be a, you know, a mama bear and protect your child and that, that can be a stage that we get stuck in.

I've seen parents who are stuck in a position of suing their school district year after year after year for six, seven, eight years without a lot of progress. And I would advise them to try to move past the anger stage into the next stage. And the next stage is where you get into doing the actual planning and that's, it's called the bargaining stage, but it's where you're seeking solutions. And so I think once you can kind of get past the cloudiness of the denial and the anger, going for solutions is, is where you're really starting to be helpful and thoughtful about deciding what next.

Debbie: Yeah, that's so fascinating. And, and I will just say that you've introduced me to Doctor Eichenstein and we're scheduling her to come on the podcast. So I'm looking forward to that conversation. I have her book and read it many years ago. Um, and I think that it's just so important to consider the emotional process

because this is hard stuff. You know, there can be mourning involved, and I talk about that in my book, and I don't use that word lightly, but I think there's a, there is a lot of, you know, loss and, and hopefully acceptance on the other end of that. But that we have to process as we digest this. And I, it's interesting too how many parents I'm hearing from who are also discovering through their child's diagnosis that they too are differently wired, maybe have the same symptoms, the same diagnosis, or they just discover it as an adult and it's very complicated stuff to work through.

Devon: And can be harder to work through with your own neurodiversity involved. If the parent is ADHD, it might be harder to organize your child's plan. And one of the recommendations for parenting a child with ADHD is to try to have more structure in their life and more sticking to schedules. Well, how easy is that for a parent who has ADHD? You know, it's, um, it's tough all around.

Debbie: Yeah, absolutely.

Devon: We have to be nice to ourselves as parents.

Debbie: It's so important. It's so true. We're so tough on ourselves. And I do hear from parents about guilt that they didn't recognize things earlier and they regret wasted time, you know, and getting a later diagnosis or just years that their child may not have been thriving. But that is not really helpful and it's important to just kind of move on to those, those solutions. So let's talk more about that. You know, you said it was in the bargaining stage. How do we even begin, again, we have all this information and it can be hard to even know where should we focus our energies. How do you support parents in thinking about or figuring out where are the things that we should focus on and how do we even figure that out?

Devon: Right. A good neuro psych or psych ed report will have a pretty detailed list of recommendations and I advise parents to look at that as a menu. You're not going to eat everything on the menu on your first meal. You're going to choose those things that are most important now. And I would recommend choosing one from column A and one from column B or two from column A and two from column B. Column A being developing skills that are weaker, addressing the problems, and column B being addressing the child's interests and strengths, and that too often is neglected in the whole process. Too often, it's all about working on the weaknesses. But, but let's just stay with the weaknesses side for a moment or the, the, the growth opportunity side, which is how I like to describe it to the children I work with because that's what it really is.

These are things that you can grow in. There's an opportunity there. There too I would, I would suggest that families choose those, to focus on those things that are most important to them and their child now. Not necessarily the thing that their mom thinks is most worse, that is making the child not fit into that particular school. But the things that are really important to the family that the child develop. And when I say the family, I'm including the child in the process, even little kids. Even an eight, nine year old, um, their voice can be helpful in deciding what's a priority. Maybe you want to do handwriting without tears to

improve graph and motor coordination or maybe you just want to discuss it all and say, hey, let's get keyboarding going. You know, maybe it's not that important to have handwriting that's that readable. So, so together you can make better decisions on what the priorities are given what you think your child might want to do later.

And it can be a little hard to make that judgment. I had one family where there was a child who was absolutely good at every single thing from creativity to sports, to the arts, to English to reading, except for math. And, and with a child who's in high school, I think it would not be inappropriate to decide that math is not going to be emphasized anymore if the student isn't that interested in it and isn't planning a future that, that is going to necessarily require that they be super strong at math. Um, so even something as basic as math I think can be up for grabs as something you decided whether to emphasize or not.

Debbie: I really like that and it feels really freeing to hear that, you know, to even consider, you know what, this actually isn't a priority. And realistically this math is not going to be part of your future and how you spend your time. So why don't we just take that off the table? I'm wondering is there some reprogramming almost of the parents that has to happen here? Because I think we get caught up. And even just with the handwriting, right? There's this idea that your child has to know how to write. That's just a life skill. Um, and I think it can be hard for a lot of parents to take that step back and realize, you know what, in the big picture, this doesn't actually necessarily matter for who my child is.

Devon: Yeah, that's so true. We get these ideas of what's, what, what is required in a, in an education. But these are very antiquated notions in many respects. I mean, even reading books with our eyes, you know, how far away are we from a world where we can absorb information in different ways. I think the best way we can prepare our children for the future is to have them be, be able to think and to be able to flexibly problem solve. And things, basic reading, writing and arithmetic skills like, you know, showing your work and um, handwriting are perhaps going to become much less important. So we have to challenge our assumptions of what we think it's about.

Debbie: Yeah, constantly. Showing, showing your work is just painful for so many of our kids who are just, they're just figuring it out in their head in a whole different way. And it seems very tedious for them to have to demonstrate how they did that.

Devon: Who made those rules?

Debbie: Exactly. Well, so I know that a big focus for you and the work that you do is about helping a child understand their strengths and, and nurturing those strengths. Can you talk more about that? Because that's, I'm imagining where we want to put most of our energy.

Devon: Yeah. Um, and, and I think that's the critical piece that needs to happen after an assessment. Because a child spends a couple of days with the psychologist and you know, doesn't really sometimes get feedback that explains to them in an

empowering way, um, what their brain is like and what the next steps are. So, so I recommend that the psychologist and the child sit down and spend as long as the child is interested in understanding the child's brain, but emphasizing all the strengths and interests and things that the child is good at. And I often call them superpowers, um, to relate to the kids. And then having a few areas or one or two that are development areas that can be grown and having a growth mentality about that, explaining that the brain is kind of like a muscle in your body and you know, if you want to build your muscles, you, you need to exercise. Same is true of your brain. So there are exercises that can be done to build your strengths in areas that may benefit from that. Whether it's a, you know, a behavioral sort of a thing or dyslexia or ADD, whatever it is, there's always a strategy, a program, a therapy, an intervention that can be helpful.

Debbie: So you bring something up in terms of sitting down with the child having this empowering discussion. And you know, when, when Asher went through this process with you, that's the first time that someone who was assessing him sat him down and talked with him and, and really explained how his brain works and where his areas of strength are, and some of his, his areas of lagging skills. And I, and I also know that a lot of parents don't know whether or not they should disclose. Some of them don't want to tell their child anything is going on. They want to try to covertly, you know, slip in supports. Can you talk a little bit more about looping the child in? Is that something we should do from any age? What do you recommend?

Devon: Well, I'm in terms of, I always feel the child should be looped in in terms of a discussion with the psychologist, with the parents, because almost all of them, almost any child who is being assessed thinks there's something wrong with them. Not necessarily because they're being assessed, but because they're having more difficulties than their peers at something and they know it. They are typically not oblivious. Sometimes they are, but rarely and most often they know there's something going on and they may think they're stupid or they may think they're bad and you don't want your child thinking either of those things. So I think it's really, really important that answers be given to them, that include you're not stupid and you're not bad so that they can let that go. And it's a very therapeutic thing. I've, I've had little, I didn't know when I started out doing this, how impactful it was.

And I had a case where, it was about maybe 12 years ago, the child must've been six. And I'm thinking, this is falling on deaf ears, this kid is six years old, how much are they going to take out of this? And then the parents circled back to me recently as, as the young man was getting his engineering degree and said, he always talks about how you told him x and, and how that made him feel better about himself and gave him the courage to pursue his dreams. And so that's really, really empowering. So even if it's a little kid that you don't think would get it, I think they should. And some parents wonder whether they should use the disability terminology, whether they should say you have ADHD or Asperger's or dyslexia. And I think on that one it's appropriate to defer to some extent, you know, to the parents' values cause they, they may be really nervous about, um, there being some negative connotations that might follow the child into school.

Sometimes, you know, the report is redacted for the purposes of the school if the school's not really enlightened about disabilities and how kids are wired, they may somehow think there's something bad about a kid just because they have ADHD, maybe the terminology would be adjusted so that the teachers don't develop a negative opinion of the child based on that. So, so some of these concerns can be, you know, valid ones. Um, but generally speaking, I think the world has changed enough that there isn't as much negative stigma and that we make there be less negative stigma by being open about these things. And so usually, um, parents do decide to use the terminology, but as long as it's in the right terms so that it doesn't become something that's scary.

Debbie: So I want to switch topics just for a moment and just talk about, you mentioned that in the, in the report there'd be a list of recommendations. There are also so many different therapies and books and resources and there isn't kind of one clearing house that I found, you know, for all of these, um, to get really objective feedback on, on exactly what to do. But there's an interesting book called *Child Decoded*, which I thought provided an overview of lots of different approaches and what might work for different kids. But, and, and even in Facebook groups, right, I see this every day in the groups that I'm in, who's tried this, who's tried this? And sometimes they're controversial and you know, this is pseudoscience, and this is great, it totally changed my child's life. Do you have any best practices for how parents can consider the resources available, the different types of support and determine what is valid, determine what could actually be beneficial for their child?

Devon: Yeah, and this is not, this is work for parents and I, I respect and admire parents who, who will dig in and really try to figure out what works and what doesn't. And the best practice I would recommend is to focus on what are known as best practice interventions. And these are ones that have been supported by, well, the gold standard would be, you know, randomized, double blind placebo control studies, real research. Um, and if, if there's evidence that shows that something works, you can be more competent that it will work. However, a testimonial is not proof. It's not evidence. And, and the fact that somebody's cousin's daughter, you know, they think benefited from, from a particular therapy is, is sometimes, um, really the wrong direction to head. Because I think the reason we tend to go that direction is a phenomenon called belief perseverance where you, you tend to pay the most attention to the facts that support your beliefs while ignoring those that contradict our beliefs.

So if we want to believe something, let's say I'm a, I'm a very natural and holistically oriented person, I want to believe that essential oils will cure my child's ADHD. So I will believe the promotional material from the essential oils company. But that's not putting your, your critical thinking hat on and really questioning what's best for your child. So we have to sometimes step out of our comfort zone of what we want to believe and really look for some evidence. And there, there are sources, um, you know, there are, there are some good resources. I do a blog on that called *Neuromyths*. Um, there are other websites, there's, there's something people might not be familiar with called the What Works Clearinghouse that's actually from the US Department of Education where they

go through and, and aggregate and then analyze the data for different interventions. And not, not everything will be there. I, I've looked up things like the Barton reading system, there aren't any studies showing that it's effective, but the Wilson reading program, there are studies showing that it's effective and it doesn't mean that Barton isn't effective, it just means that nobody's scientifically studied whether it is or not. But generally speaking it would be better to go with ones where there's evidence.

Debbie: Wow. Well I've never heard of What Works Clearinghouse and I'm so curious now to, to check that out later today. If you have any other sources or resources that you recommend parents check out, please, um, maybe send those to me afterwards and I'll make sure they're all included in the show notes page. Cause I know we've got a lot of brain science or kind of science nerds out there, and I say nerds with all the love in my heart, but who, want to kind of dive deeper into this and seeking out the evidence, so that's really fantastic.

Devon: And it won't be everybody's cup of tea to dig deep into finding out the evidence because it's time consuming and it's, it's um, it can be a rabbit hole at times. If you, with some of these topics, you see so many arguments pro and so many con. If that's your mindset to dig in, please go for it. And I'll put a lot of resources that I'll, I'll send to Debbie that can be really helpful in that. But absent that, if you're not the kind of parent who has the time or energy to really delve deeply into the research literature, what I suggest is that you try to find a, a team of people you can trust, a psychologist, a therapist, somebody who you feel they know, and I can believe what they say. And that might take some doing to, it might not be the person that evaluated your child. It might be somebody you find through one of Debbie's Tilt Together groups or through some other Facebook group. Somebody can say, you know, this is the expert who really figured it out for me, or this is the therapy. Take that, if it's an expert you believe, go with it. I mean, if you listen to a Ross Greene podcast and you think, my gosh, he really gets my kid, go with a Ross Greene approach.

Debbie: Yeah, makes sense. So I'm gonna ask you, I didn't prepare you for this question, so, um, but I'm, you know, you've been through this as a parent and now in working with, with so many other parents, any kind of hard won lessons that you would like to share? Anything that, that you experienced or, or went through that helped you.

Devon: Yeah. And Debbie, you, you really nailed it with your approach. Find a community, find a group of people or some group where you can share what you're going through. Because it's not going to, you're not going to just suddenly have the right answer and a plan and you're going to implement it and everything's going to always be perfect. There's, something's gonna crop up all the time parenting differently wired children. So you need to find people you can share the experience with. And it may not be your spouse and it probably won't be your parents. It may need to be other parents who are experiencing a similar situation with whom you can feel empathy and support. Um, so I think that's the number one thing. Can I put in a number two as well?

Debbie: Yes, please.

Devon: Number two is to see the light at the end of the tunnel. It all seems so depressing and devastating at first when you think my child has a disability, what's their future going to be like, you know, will they ever be happy? Um, you know, a productive member of society., Sorry that's my office phone ringing, I forgot to turn it off.

Debbie: That's okay.

Devon: Um, and, and I really feel that even when things are pretty gloomy, if you can just try to see some successful people who have similar issues and even maybe get your child to be mentored by one of them or read a book or biography by an inspiring person like Temple Grandin or any of the others who are outspoken about their disabilities. And realize this is this, you're in the trenches now, but it's not always going to be so bad.

Debbie: Well, I think that's the perfect note to end this conversation on. I think it's important for us to remember, you know, when I talk to groups of parents, there are often many who are really in the thick of it and I can see the pain and, or fear or just the hard place they're in, in their eyes. And that's something I try to remind them as well is it's not always going to feel this hard. And it is inspiring to kind of look at the people who are so successful and whose differences are actually what make them so successful and have enabled them to contribute so much.

Devon: Yeah.

Debbie: Well, Devon, thank you so much. This has been just very helpful. I think this is going to be one of those episodes that people are really going to embrace because it, it kind of helps you feel like, okay, now I've got this information and now I know what to expect, and I have some really good guidelines for moving through this. So thank you so much for sharing all this with us today and for all the resources.

Devon: Well, thank you. It's been a great pleasure.

RESOURCES MENTIONED:

- [Dr. Devon MacEachron's website](#)
- [Dr. Devon's blog posts](#)
- [Dr. Devon MacEachron on Supporting 2e Learners](#) (podcast episode)
- [What You Need to Know About Neurodiversity: Now This Video](#)
- [Dr. Devon on Facebook](#)
- [Dr. Devon on Twitter](#)
- [What Works Clearing House](#): U.S. Dept. of Education. Reviews research on programs and policies. Parents might select the Children and Youth with Disabilities filter. The kinds of programs reviewed are "educational" in nature, and include Orton Gillingham, Wilson Reading, Functional Behavioral Assessments, etc.
- [Website of Science Based Medicine](#): Topics include acupuncture, chiropractic, herbs and supplements, is gaming an addiction. More psychological and medical than educational in focus
- [Pseudoscience in Child and Adolescent Psychotherapy: A Skeptical Field Guide](#) by Stephen Hupp. Critical reviews of Brain Gym, medications for ADHD, cognitive behavioral therapy and more.
- [Neurobollocks website](#): Tagline is: *debunking pseudo-neuroscience so you don't have to*. Seems to have stopped writing articles in 2015, but has good pieces on Brain Balance and Amen clinics.
- [Quackwatch](#): "Your Guide to Quackery, Health Fraud, and Intelligent Decisions." Articles on aromatherapy, supplements, the Feingold diet, etc.