Michael John Carley
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Phil Wagner
Hello from the halls of the Mason School of Business here at William & Mary. I'm Phil, and this is Diversity Goes to Work. Buckle up because we're getting ready to take a deep dive into the real human lived experiences that shape and guide our diversity work in the world of work. Should be fun. Hi, friends. Welcome to yet another episode of Diversity Goes to Work. Today's episode is a quick and deep dive into neurological diversity, a topic that really hits home for me. There's a long-standing joke in academic circles that the best research is, quote, unquote me, search. Indeed, so much of my own journey in the D&I landscape happened because my own quirks. I shared in an earlier size diversity episode that I had some attachment there, but one of the other on-ramps I have personally to doing DE&I work happens sort of underneath the umbrella of this topic. I was diagnosed with Tourette's syndrome in my prepubescent years, and to this day, if you see me walking, talking, teaching, or even just eating lunch, you'll likely notice that I twitch sometimes my face contorts. It's the whole thing. It's fine. I'm not embarrassed about it. Who knows, maybe one day we'll talk about it on a future episode. But recently, Forbes put out an article that noted that Tourette syndrome is just about as common as autism. An autism or autism spectrum disorder, as we largely talk about it now, is the conversation that we're going to have today. So today, we're focusing on that spectrum. The spectrum as we know it is sort of this neurological continuum upon which a broad range of social skills and speech patterns, and nonverbal communication behaviors and beyond exist. And we've changed a lot about how we talk about the spectrum. And today's guest has a lot to offer as it relates to this topic. He himself identifies as someone with ASD after being diagnosed in 2000 at the exact same time as his four-year-old son, which came as a big shock to him. Michael John Carley is an author, school and business consultant, and the former executive director in the autism, neurodiversity, mental health, disability, and DE&I world. He has published or spoken at length in a variety of outlets, including for the New York Times, The Washington Post, The London Times, HuffPost, Newsweek, ABC News, BBC, Fox, The Chronicle of Higher Ed Psychology Today. Oh my gosh and beyond. He is everywhere. In 2012, he was one of two people on the spectrum to address the United States Congress and their first-ever hearings on autism. He's addressed the United Nations, he's
written books, and he was kind enough to join us for today's episode. Michael, my friend, it's a
delight to welcome you. Thank you for joining us. Before we begin, I want to ask something
that we've asked on a few other episodes as well, and I think it's important. It's related to
language. As we have our conversation today, are there words or phrases that we should or
should not say as we talk about living life on the spectrum today?

Michael John Carley
That's a great and very large first question there, Phil. I would say that there's no real short
answer because I think when any marginalized community is suddenly liberated to the extent
where they're actually convinced that they can start having conversations amongst themselves
about the words they like or dislike that are used to reference to themselves, that conversation
takes a while to progress. And I think with the word neurodiversity, we're still sort of trying to
figure it out ourselves. There was, I think, an initial reaction of, oh, well, it's just the brilliant
Aspies. And then I think we all quickly realized how not inclusive that was. And now I think
we're starting to realize that if we are really going to be inclusive, that we have to start looking
at really all neurologies or all diagnoses that present with behavioral differences and
understand that much more heavily stigmatized diagnoses like schizophrenia, borderline
personality disorder. If we're going to be true to the concept of inclusivity on this, we have to
invite them as a seat to the table. And that shouldn't be so threatening because those of us that
have been working so hard to improve the iconography of words like autism or before that
Asperger syndrome, they know that you can improve the stigma on all of those diagnoses. And
it's time for, I think, a lot of those folks. But I would go even further that at the end of the day,
if we are looking at behavioral differences that, let's say, poverty-induced trauma or financial
anxieties. Qualify you as neurodiverse and from an intersectional capacity, as far as, especially
race is concerned that makes the word neurodiverse ever more inclusive. So great question.

Phil Wagner
And this is not in the pre-slated questions. So sorry to throw one out here. You talk about a
seat at the table. Until recently, neurodiversity has really been scaffolded, particularly in a lot
of diversity and inclusion work under disabilities. Are we seeing that change? Do you think
that that still scaffolds underneath that larger domain, or is this something inherently
different?

Michael John Carley
No, I think it's still under the umbrella of disability, especially if we're talking about the world
of work because the world of work has to compartmentalize things. That's how they bridge.
That's how they learn. However, I think the definition of disability at least has been, at least in
my mind, redefined from the old days of looking at it in two ways, which was physical
disabilities and non-apparent disabilities, another not apparent. You could break that down
even further into psychological disabilities. Neurological disabilities like the autism that I have,
learning disabilities, and all that jazz. Now, I think we've, or at least I certainly subscribe over
the last at least seven years, to a three-way look, which is accessibility, neurodiversity, and
health. And I think that if we're going to have to do the Darwinist thing of
compartmentalizing, that this is kind of the way to go, especially because if you don't break it down this way, you get so many different contradictions and disability. The main problem with disability in the workforce has been that out of all the elements of D&I. It is by far the more intimidating to those corporate cultures that need to incorporate us. And we got to remember most of those are for profits. They don't care about doing the right thing. They're beholden to their shareholders. And so they got to cut it right. And if you have this giant contradiction that needs to be explained between neurodiverse populations that will fare so much better in this world and help each other out when they're more open about their diagnoses and proud of it and can talk about it without shame. And yet, from the health space, if you're open about your HIV diagnosis, your cancer diagnosis, you're exposing yourself to civil rights violations up the wazoo. And so, therefore, that need for privacy goes in direct contrast to the neurodiversity needs. And therefore, that's why that separation, I think, really helps to frame overall disability. But I will say to close the question that anything with a prefix of dis is bound to have a psychologically negative effect.

**Phil Wagner**
Yeah, that's so good. That's such a great perspective. You've teed us up perfectly. And I'm really excited to hear more on this next question. But how you personally, Michael, have come to experience the terminology they're talking about today has likely changed over your life. Do you mind sharing just a little bit about your story with how you came to understand what it means to be on the spectrum in your own life?

**Michael John Carley**
Sure. Absolutely. I was one of those weird kids in growing up that, luckily, once I found my way to a wonderful high school run by hippies who just loved everybody and they accepted me for who I was, even though they didn't understand who I was, they just assumed positives in the unknown as opposed to negatives, like the school I'd gone to prior and that I was one of the lucky ones because I was thought of as being really inherently talented, especially in the arts. And I can look back on those days now and with just as much self-love as I've ever had in my life, tell you that I wasn't anywhere near as talented as people thought I was. But I'm certainly grateful for that because it opened up the door to opportunities. And I found myself in a community in the arts, which it's okay to be weird in the arts. And I had a really great stupid day job as this minor league diplomat doing work in romantic places like Bosnia and Iraq. And when there's lives that are at stake, it's okay if you offend the boss with what you said every once in a while because the work is just that urgent, and not everybody can do your job. So it was another atmosphere that I had luckily found myself in, which it was okay for me to be a little weird and a little rude. And I'd always known that there was this sense of confusion about who I was to other people. The people that didn't really like me just thought I was. Can I say the A word on your podcast?

**Phil Wagner**
You can absolutely.
Michael John Carley
Okay, thought I was an asshole. And the people who liked me thought, oh, Carley is tell it like it is, guy. And I'm thinking both sides are equally wrong. But I'm going to go hang out with the tell it like it is crowd because why would I hang out with people that don't like me? That just doesn't make any sense. And then comes that day when and in my case, it was one week apart from my then four-year-old son that you find out through a diagnosis that you're not an asshole. And I don't have the words to be able to tell you what a biblical weight that is that's lifted off your shoulders because suddenly now all of your differences with the rest of humanity can be lumped into the idea of different wiring and not about your character. It explains so many things, but it also sometimes explains things in which ways in which I didn't want. I took a month after I got the diagnosis, I took my kid. We lived very close to the Brooklyn Botanical Gardens at the time, and we went for a walk every day for a month after that. And he was four years old. He would trace the stream that runs through the Brooklyn Botanical Gardens. And what I would do is I would basically look over every incident that had happened in my life prior with this new lens and with this new prism. And it was quite a revelation because I would think back to all those people that I thought really liked me. And sometimes they did like me. But other times, I had to realize now they were keeping me at arm's distance because they didn't want anything to do with me. They were being polite to me because they didn't want anything to do with me. And then I would think of the people that I thought had been mean to me, and some of them had been mean to me, but others, I had to realize, oh, my God, they were the ones that believed in me. They were the ones that were saying. You can do this. I'm challenging you to do this. So it's a world rocker. But I would also say that as I think we were talking about before we hit the record button is that 20 years ago, when I was diagnosed, you were mud even with Asperger's syndrome. And suddenly, we started changing the dialogue about how that looks. And suddenly, the iconography surrounding Asperger's syndrome got a lot better quick. But autism was still negatively thought of. And then, we started to get to work on the iconography surrounding that word, and we improved the iconography about that one as well. So it has been quite the journey, which is where we now are starting to see those other diagnoses of neurodiversity finally having an opportunity to improve the iconography surrounding those words. And I will share with you, just to close on the subject of personality, I mean, there's one story that I did have to realize, however, which was when a couple of days after I had gotten diagnosed, I was at work, and I took an elevator with a colleague, and I was sharing with her my son's diagnosis, but I wasn't going to share mine. No way. And she threw me because she knew more about this stuff than I thought she did. And she said, well, isn't that genetic? And I was just caught. Caught dead. And I'm sputtering out words like, well, no, I don't really think so, no. Elevator reaches the ground floor. She gets out of the elevator in front of me, and the image of her back just as I'm exiting the elevator and she's a few feet outside the elevator in the lobby is emblazoned in my memory because I knew that at that very second I had stabbed my son in the back. What garbage would it be for me to ever say to him, you should be proud of who you are if I was going to be such a coward?
Phil Wagner
Wow, that's huge. I'm riveted by your story. I'm riveted also, not just from the professional angle but from the parenthood angle as well. Fascinating. So you mentioned this briefly in your last answer, but how we've come to understand what it means to be on the spectrum has changed a lot, even in the last 20 years, even in the last ten years. When you think about the challenges associated with the definition in the here and now, what are some of the challenges people on the spectrum face in the modern world? 2020 and beyond?

Michael John Carley
I would say that we're still figuring out the right paths to take, but we don't know necessarily how to walk on those paths or how fast to run on those paths. We have all these concepts like neurodiversity, like inclusion, like even the subject of things like emotional intelligence and microaggressions, all of these catchphrases and these pseudosciences sometimes, dare I say it, that kind of gets in our way. And I'll talk to especially the concept of emotional intelligence, which is something I've written about and not in a very favorable way more than once. And this is an element in which I think; obviously, people are under the impression that they're helping people who are neurodiverse by embracing. But honestly, if your career track is going to be influenced or you're hiring by this particular unrecognized, quote, unquote science, I find that to be actually a violation of the Americans with Disabilities Act because it is a very diagnostic staple to be behind in your emotional development if you have many different non-apparent disabilities, including autism. Like what I have. A lot of times, I think that people think that I've learned to adopt a lot of neurotypical ways, and sometimes they're right. But at other times, I'm just brilliant at hiding my cluelessness, and that's a very different animal. But again, emotional intelligence is literally penalizing you for your behavioral and your emotional developmental differences. And so it's just stuff like that that we're just not thinking straight about and that we're not being clear-headed enough about. I've spent a large part of my career, not the biggest part, but a large part as the school consultant. And I can tell you that, especially when we did a little bit of a stopover to take care of some in-laws in the Midwest where you see these hey, come see our inclusive classroom, the inclusion buzzword. Okay, great. Wow, you've got an inclusion classroom. So ergo, the rest of your school is exclusive?

Phil Wagner
Right.

Michael John Carley
How is that inclusive? And it's going back to the old euphemism of 70% of the people that are broadcasting that they're inclusive. They're holding a dance where they've invited people, let's say, on the spectrum, to the dance. But in 70% of those situations, the person goes to the dance, and they stand against the wall, and nobody asks them to dance. That's not inclusion. We've got stuff to work out. I think that we get what the road should look like right now, but how we figure out what the rules of the road are, we're still figuring that out.
Phil Wagner
And it really goes to show the necessity of conversations like this. For instance, I teach communication and soft skills when we talk about emotional intelligence all the time. I will never see that word the same way. And I've been doing D&I work for the better half of a decade. And so I think that's what can be so frustrating about inclusion work, and I mean frustration in a good way, is that it's iterative it's constantly moving forward. We're constantly tweaking our thinking, and that's beneficial for us. But I think it burns so many people out. That's why we wanted to have a podcast like this where we can do those deep dives. It's so fascinating. So we've done some extensive work on being employed and also unemployed while on the spectrum. Can you share some of that work with us? What is that work revealed?

Michael John Carley
Yeah, I think that. Well, it's so tough because one of the things that I have to keep in mind sometimes is that none of us, whether we're on the spectrum, whether we're part of any marginalized community or not, that we're not experiencing a world like my uncle who spent his whole career at IBM, or my stepfather who taught geology at the same college for his entire career. This is now a community of people that constantly shift and constantly change jobs and the turnover rates. We know what if you're a good HR department. You know exactly how much it costs to have a turnover in the mailroom or have a turnover in senior management. It's always been helpful to me to make sure that when we start talking about the employment question that, we do frame it within a larger employment versus unemployment dilemma that we've been having in this country off and on. And part of the issue also, I think, is that it's really tough for us to get a really accurate picture on where we're at when our unemployment statistics lie like no other statistics on the planet. If you have, for instance, that person that has finished their six months of unemployment benefits and they're still unemployed, but they're not taken into consideration in the unemployment numbers. If you have somebody who, let's say, was disabled but had a good gig and was able to work it in an able-bodied position, and then because of, let's say, the housing crisis, they lost their job or financial reasons, they had to get some insurance, so they went on disability, those folks are often not taken into consideration of the statistics either. And it's just very hard to track when there's so much movement going on. So that's kind of a long-winded prelude to your question. But for me personally, I've just had to accept the fact that no one is ever going to give me credit for how willing I was to sell out to the man all my life. I've just been kind of forced into either creating things for myself or taking on temporary assignments just because the nature of the work that I do is so all over the place. And I'm not complaining, but it's just a different work situation when you have these diverse incomes coming in from, at least for me personally, either from consulting, the old days when I ran non-profits, speaking gigs. I won't say book sales because I don't really think any of us make money off our books. We make money off speaking gigs that come from the books. But that's sort of a halfway around the question. I will say this, though. I always worked. When I was ten years old, I was getting up at 04:00 in the morning to deliver papers, and when I was 13 years old, I was working for two and a half hours in a jewelry shop polishing jewelry. I've worked at a bunch of different jobs, and the subject of labor fascinated me during those years in the Midwest because we were in Wisconsin, which, if you know, the situation that was happening there with Scott Walker, where they've destroyed public
education and organized labor at the same time. And I made all my money out of state. I
would get paid infinitely more than I was worth as either a speaker or a consultant outside.
And so, I had a lot of time on my hands in Wisconsin. And just because the whole place was
confusing, me and New Yorkers with autism diagnoses who don't drink probably should never
move to the Midwest anyway. It's just going to be a bad fit. And it was just all confusing. I
couldn't get it. It was Trump country, too. So the whole Trump thing is, and I'm taking on the
state's educational apparatus and getting my ass kicked every day. And I'm saying to my wife,
who grew up there, what's going on here? I can't figure this out. And what I would do that gave
me actually much more of a sense of what that place was like was that nobody checks because
everybody is so desperate for labor in certain aspects. I created a completely BS resume which
just had the most minute and small accomplishments possible on there, like mowing lawns
like fudging everything I've ever done into the most blatant lie, high school diploma. That's all
that's on the resume and everything like that. And I'm Mike, and I submit that so that I can
work all these horrible jobs that everyday Americans, we just saw Nomad land. I was working
all those jobs, maybe two days a week. But just as a way to educate myself, not undercover boss
or anything that silly or dramatic, but it really helped for me to frame just the sort of
employment troubles that all of us are in this country. Back in the day, you could graduate
with just a high school degree and have health insurance and have a pool in the backyard of
the home that you owned. Nothing but gone. Absolutely gone.

Phil Wagner
So your story speaks a lot to the power of personal resilience, and I think that's very inspiring.
But I question whether there's opportunities unmet opportunities that the world of work is
not yielding or presenting to employees who are on the spectrum. So do you have any
thoughts on ways in which the world of work can make itself more inclusive to people like you
who share your experience framework?

Michael John Carley
Well, number one, they should be motivated. And I think that they don't actually understand
that yet. I don't think they read enough Harvard Business Review statistics that prove that the
more diversified your company is, the more that you will outperform your peers. And that's a
culture change. That's a culture change. That is an issue that is getting completely in the way of
the success of the company. So at the end of the day, I'm sure they're going to realize because
they do have to report to their shareholders that they are going to have to diversify, and they're
going to have to get better at the onboarding process. They're going to have to teach their
managers better about how to handle emotional regulation challenges in the workplace. And
right now, they're still very much intimidated by those factors. I will say this, though. It's not
because they don't want to. It's not because they're bad people. It's just because they don't have
the confidence. And the reason why they don't have the confidence is because they don't have
the training. And two of the reasons why they don't have the training is that number one, I
find that in the employment consulting I've done, and when I was running ASTEP all those
years ago, the hardest thing was to get them to make their managers commit to training time
because they just wanted them doing all the things. Any break like that was going to be a

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productivity halt of some kind or interpreted that way. And that was the real minutiae of where I think a lot of the inability stemmed from. But it's also any kind of cultural change is also always going to be hard. And I also think that especially when we're talking about neurodiversity, we're talking about those behavioral differences. And one of the things that doesn't get talked about enough is that behavioral differences sometimes do not mesh with what we think of as quote-unquote professional behavior. And that's a big elephant in the bathtub that nobody seems to want to address. Everybody wants to be able to talk in corporate-speak terms. In corporate speak terms. I'm sorry, corporate people. It is not transparent. You talk around issues. You do not talk directly to issues. And one of the aspects that in the most successful neurodiversity onboarded companies, where they have a large population of folks like us, I guarantee you that in every single one of those companies that those neurotypical employees are communicating ten times better than they ever did amongst themselves, thanks to being forced to not use the soliloquies, the euphemisms, the sarcasm, the corporate speak language, and to actually have to deal directly with people and talk directly to people in a transparent and humane and non-way.

**Phil Wagner**
Yeah, I get it. Cutting technicalities and not resting in the nuance. I think if your story shows anything, Michael, is that you can go through a million microaggressive trainings, you can go through a million inclusion trainings. But there's so much at the intersections of nuance here that's so important to slow those trainings down and really cut through and speak to the humanity behind it all.

**Michael John Carley**
Amen. You say the word microaggressions right now. I mean, we have very lively conversations at NYU sometimes about the concept of microaggressions, that if they're not based in race, that really needs some reframing, because sometimes I think everybody's getting the idea that the concept of microaggressions mean that if you were offended by somebody else's behavioral difference, then you're absolutely right to have been offended. And no, that's not the case. In the case of different neurologies, there may be emotional regulation challenges happening with that individual that caused them to overstep or be more dramatic in their language, and therefore, the intent to offend you was not there. You're wrong. So this is the sudden nuance to exactly what you're talking about, and you couldn't be more right?

**Phil Wagner**
Yeah, it's uncomfortable. That's the thing because there's no black and white, right or wrong. It's everything gray right in the middle.

**Michael John Carley**
I think the solution, too, that's really helpful for everybody to understand is you can acknowledge the impact that that person's statement had on you and how it felt. You can't deny that, but don't trust your instincts. We're just not smart. Yeah.
**Phil Wagner**
That's good. I have one more question for you, and it's like a super hypothetical. Right. We don't have a magic wand to give you, but if we did and we handed you a magic wand that you could wave and fix the most pressing issue facing neurodiverse people in the world of work right now, what would you waive that magic wand to do.

**Michael John Carley**
Phil, it's not one thing. There's one thing that's a wonderful problem to have, which is there's now such a glut of unqualified and just really inept, quote, unquote neurodiversity consultants that are just capitalizing on the popularity. I wouldn't have any other way. We both know what it was like ten years ago. We didn't have that problem. We had the opposite problem. But oh, my gosh, it's pretender land out there. That would be one thing. But it's really taking the absolute top shelf viewpoint of everything that's been going on, you know, getting rid of the whole interview concept. If you have to work so hard to get through an interview with somebody at a company because of all the traditional the eye contacts, the shaking hands, and stuff like that, you're not going to last very long at that company if it really took you that much to get through, if that kind of culture permeates in the interview if you look at how people write their job descriptions and I can show you examples that are hysterical, where a company has written will do data input in a cellar with no windows, no human contact for pretty much all of their day and at the bottom, it says strong leadership skills required.

**Phil Wagner**
Right.

**Michael John Carley**
People just don't think sometimes. And it's because of the obligation to the cultures that existed 30 years ago that just do not work really for anyone today.

**Phil Wagner**
Has COVID changed that at all for neurodiverse people, or has it made it better? Has it made it worse? Has it changed it at all?

**Michael John Carley**
That's a great question, and I think the answer is only going to come after COVID.

**Phil Wagner**
Yeah.

**Michael John Carley**
When we see whether or not if we're approaching this from an all-over disability field, I can relate you to so many people that will, especially for accessibility and transportation needs, have said I've been waiting for this all my life. All my life. And yet, at the same point, are we going to be allowed to record Zoom lectures if we have, let's say, processing difficulty and need
to hear the material over and over again. But there's an intellectual rights issue with the person that gave the presentation. So all of this stuff, that's a question that I think is yet to be answered afterwards.

**Phil Wagner**
More to come. More to come. Well, Michael John Carley, it's an incredible pleasure speaking with you. I really appreciate you taking your time to inform our approach to diversity and inclusion work, making sure it's really inclusive for all. Thanks so much for your time and your energy today.

**Michael John Carley**
Thank you, Phil. I really had a great time, and your questions were fabulous. So anytime.

**Phil Wagner**
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