



Transcript of episode 085

“Pathological” Demand Avoidance? Words Matter

Emily Kircher-Morris: [00:00:20] Welcome to episode 85. I'm Emily Kircher-Morris, and I am the author of the books *Teaching Twice-Exceptional Learners in Today's Classroom*, and *Raising Twice-Exceptional Children: A Handbook for Parents of Neurodivergent Gifted Kids*, both scheduled for release this year.

Today Kristy Forbes will be joining us. Kristy is an autism and neurodiversity support specialist, and she is also the founder of inTune pathways, which is an organization based in Melbourne, Australia. We'll be talking about PDA, or pathological demand avoidance, and the difference between PDA and other types of demand avoidance. We will also talk about the language of autism and how Kristy views the terminology surrounding autism. That's all coming up.

If you haven't been to our website, we invite you to go there to learn more about the podcast and browse some of our past episodes. If this topic is interesting to you, you might want to check out episode 54, when we chatted with Harry Thompson about his experience with PDA and his book, *the PDA Paradox*. We'll include a link to episode 54 in the show notes for this episode. It's all at www.NeurodiversityPodcast.com. Also, we invite you to join the Neurodiversity Podcast Advocacy and Support Group on Facebook. To join, go to facebook.com/groups/neurodiversitypodcast.

On today's show...

Kristy Forbes: [00:01:42] I'm Kristy Forbes, and I'm an autism and neurodiversity support specialist.

Emily Kircher-Morris: [00:01:47] And when we recorded our interview, it was early in the morning in Melbourne. And as we know, Australia is famous for its diverse wildlife. You'll be hearing a sampling of that in the background. Kristy explained the local birds to us...

This time of the morning, because it's early morning here, they are everywhere. And hopefully they won't do what they like to do at about 9:00 AM, and that's flying over sounding like the monkeys of the Wizard of Oz.

That's all straight ahead.

(break)

Today we're speaking with Kristy Forbes of inTune pathways, and Kristy is joining us from Melbourne, Australia. Uh, Kristy, thank you so much for taking the time to speak with us.

Kristy Forbes: [00:03:21] Thank you so much for inviting me.

Emily Kircher-Morris: [00:03:24] So let's start off by giving our audience just a little bit of background about why you're the expert in the area that we are talking about today, specifically autism and demand avoidance.

What is your connection to the neurodiversity community?

Kristy Forbes: [00:03:41] So I am autistic, ADHD, PDA. Uh, I have four children who also share those neurodivergences. Uh, and I'm married to an autistic, ADHD, PDA man. Um, but my background is in education, early education, primary and secondary teaching. And I did work with families for a really long time, uh, supporting families who were raising autistic children.

So yeah, I've kind of been in all different perspectives and, um, I wouldn't say I'm an expert. I would never call myself an expert, but I think lived experience coupled with my professional experience has been really helpful for me.

Emily Kircher-Morris: [00:04:33] It's interesting. I can relate to your pathway. I started as an educator before I got into the mental health field and we're a family full of ADHD specifically, and I work with ADHD and neurodivergent kids and families, and I think sometimes people think that that would be too much, but I kind of love it.

Kristy Forbes: [00:04:53] Yeah.

Emily Kircher-Morris: [00:04:54] It gives me a real purpose.

Kristy Forbes: [00:04:55] Yes, me too. I absolutely love it. And when people say, gosh, you worked so much because I'm always doing something with my business, but it doesn't feel like work to me. It's, it's my joy. It's just. I love it so much.

Emily Kircher-Morris: [00:05:13] I think the thing that, especially working with, I have a lot of clients who are autistic and a lot who deal with demand avoidance. And I think the minute that all of a sudden they feel understood or their parents get that, "oh, all of a sudden I understand what has been happening." it's just such a relief. They take a big breath and it's really empowering.

Kristy Forbes: [00:05:40] Yeah, absolutely. And I think, you know, before I, within the last couple of years I worked in consultation, so I did private consultations with hundreds of families. And by the time I'd get to see them they'd been to so many different professionals, tried so many different programs, been given really unhelpful parenting advice, where it was about their parenting approaches not being adequate, which is just so inaccurate. And because a lot of the time our children, we know our children are autistic before we know that they're PDAers, we're looking at all of the approaches and supports on offer to autistic children.

If a child has a PDA profile of autism, a lot of those approaches are not helpful for our PDAers. And so then parents think that they must be doing something wrong or it's their

fault. And yeah, families, by the time I got to see them, they had really hit rock bottom and we're in crisis. So. The relief... absolutely

Emily Kircher-Morris: [00:06:50] I want to start off before we dig into a lot of the stuff of, of, uh, you know, the meat of our interview, and I want to talk a little bit about the language that we use surrounding neurodiversity, because I believe it's really important. And it greatly influences how we perceive specific traits of neurodivergent folks.

So for example, we're talking about "pathological" demand avoidance, and autism spectrum "disorder." And I'm curious about how you view language and its impact on the neurodiversity community.

Kristy Forbes: [00:07:26] Yeah. This is such an important topic. And it's also unfortunately, so controversial. Um, for me personally, it is so... language is everything because I use identity-first language. So I say I'm an autistic person. The reason that I say that is because I'm not a non-autistic person with a side of autism that can be treated or wished away or rewarded or punished away. I am a completely autistic person. Autism is central to my being. It influences how I sleep, how I think, how I feel the depth and range and intensity of my emotional experiences, how I process my environment, how I take in information and analyze it and dissect it and put it back together, how I love, the foods I choose, everything about my neurobiology is autistic. So I think that's really important for people to understand. And at the same time, I'm absolutely respectful of autistic people choosing what is okay for them in terms of how they identify.

So some people will say "I'm a person with autism." The reason I don't say that personally is because, just as I was saying before, I'm not a non-autistic person with autism. It's not something I pick up or put down. It's not separate from me. And when we use language like that, that's when we hear things said such as, autism doesn't define me, or person-first, make sure, you know, they're a person. And this comes from academia. So when we're studying allied health or psychology or any of those fields, because a large part of those professions involve working with people who are disabled, it has been considered respectful to refer to people as people with disabilities or people with autism. And so this is why that rolls out and people speak like that.

But the thing is me saying I am autistic is a reclamation of something that ended up being used as a slur or something that was negative. And it's important for the stigma and the shame to be taken away from that. A lot of families, including myself before I knew I was autistic and I believed that I was a non-autistic parent raising autistic children, I would hear people refer to autistic people as autistic, and it would trigger something in me. But then when I really sat with that discomfort and challenged and explored why I felt that way, it's because I was saying autism is something that wasn't good. Something that was negative. Something that I wanted to wish away because I didn't understand it at the time.

And+++++ for many families, their initiation into their children being identified as autistic is doom and gloom. It's very seldom a positive experience from the time they're

assessed and diagnosed moving forward. So, I like to say I'm autistic because I promote positive autistic identity.

The thing about PDA is, yeah. Pathological is not a great word. I don't even think it's an accurate word. It's really not. I mean...

Emily Kircher-Morris: [00:11:35] I agree.

Kristy Forbes: [00:11:36] We could be saying pervasive or something like that. But the other challenge here is when I hear people say autistic with demand avoidance, or just demand avoidance, which is something that I've often used as well, but there are so many different origins and types of demand avoidance as well. There's demand avoidance that comes with ADHD. There's demand avoidance that comes with autistic inertia or burnout. So when we're talking about PDA, that is a complete neurobiology as well. So yeah, I think language is really, really important and it is everything. I don't like to be referred to as disordered.

I definitely agree, autism is a disability, according to the social model for me. Which means how well supported and understood and accommodated I am across environments means my level of disability will fluctuate, but I am certainly not disordered. And I don't believe any autistic people are disordered at all.

Emily Kircher-Morris: [00:12:48] You touched on something that I've actually been reflecting on lately. Specifically, I've heard ADHDers start to use that term demand avoidance, and sometimes even pathological demand avoidance or PDA. Or sometimes I've heard people talk about... how can I put this? It comes from a certain place and like, you have to support it in a certain way that isn't the same as what other individuals might be experiencing. For example, like burnout. Right? To me, that might look on the surface similar, but you address it really differently.

Kristy Forbes: [00:13:24] Yeah. I think the reason I've, I'm so aware of how this plays out is because inside of the autistic community, there are pockets in our community of people who do not accept that PDA exists. And that's often, I guess, because people who experience demand avoidance are very quick to assume that it's the same as having PDA or pathological demand avoidance.

And sometimes it's not, and this is really important. And this, it's also important to me that I don't invalidate or dismiss people's experiences, but also I think there are also many PDAers in the autistic community who believe that their experience is autistic experience solely, and so when they hear about the characteristics of PDA, they think that it's not a thing, we're just talking about autism, which is... reminds me of when I was not aware that I was autistic and I was studying teaching, and I went to a lecture on autism. And I remember sitting through the lecture and looking at the notes and listening to the lady and thinking, "what? How is this a thing? This is normal, this isn't..."

Emily Kircher-Morris: [00:14:55] Right. Doesn't everyone experienced this??

Kristy Forbes: [00:14:59] But I do this. Everyone does this. And of course, you know, no, they don't, but I see a very similar parallel playing out in the autistic community. So yes, I always

say to families and individuals and professionals, this is why it's so important to tune into the individual experience rather than basing the supports or approaches we use off the back of a label or a diagnosis. This is so important to understand why working with the individual and seeing what they respond well to always wins. Always wins. So whether somebody has an identification or a diagnosis of something or not, it's about just tuning into what works and what doesn't.

Emily Kircher-Morris: [00:16:00] Let's dig in a little more specifically about pathological demand avoidance. Can you describe what this might look like in kids? And also as those kids get older, how autistic adults might experience PDA?

Kristy Forbes: [00:16:17] Yeah. So I think there is a stereotype, which I would probably fit, and that is a child... well, you know, this is really interesting too, because there are so many PDAers who are not what I would refer to as fighters, they're fawners. So they are more introverted and more subtly demand-avoidant. And then there are people who are unapologetically, sometimes maybe aggressively, outright fighters. "No, I won't do that. Stop forcing me."

And here's the thing. There's a few, there's a few key ways of knowing with children because it starts very young, the language that they use. There's one liners. It's almost predictable to me now. I mean, I've, I've seen it so much, but children who struggle to comply with everyday demands, which might be putting on their own clothes or brushing their teeth, or having a shower, eating when everybody's eating, it can be different for every single person what the brain perceives as a demand. Saying "no." Saying, "you're forcing me. Stop trying to force me. I feel pressured. You're pressuring me." Um, that might be a child who lives a lot of their time in fantasy, in role-play as characters, very common for them to be villains or bad guys.

And the other is a child who appears to be compliant all the time and agreeable, but behind closed doors, or quietly, is resisting demands and doing things their own way. So in a classroom, they might be asked to write a sentence and they'll spell all the words incorrectly, even though we know they can spell perfectly, because they have to find a way to come back into balance, which most people would describe as being in control.

For adults, you know, this, I find this depends too, on the awareness of the adult, whether they have the understanding of their neurobiology or not. Before I knew that I was a PDAer I was very controlling and I could not cope with things going, you know, not according to my plan. But not in an autistic way, in a 'completely consumed with anxiety and anger' kind of way. So I would project that onto my children, and onto my colleagues, and I was very difficult to be around. And it was painful to be that way. Absolutely excruciating.

I can't work for other people because I require extreme amounts of autonomy and flexibility. So even when I was teaching, and I absolutely loved teaching and I miss it all the time, because there were so many, I guess, rules around time, and reporting to people, and all of that stuff, I couldn't do it.

And the important thing for people to understand about PDA is that it's not just a person going, "uh, that feels too hard so I'm not going to do it." Or, "no that's not in my control, so I'm not going to do it." It's a neurobiological response. It's not conscious thinking, it's not will, it's not intent-driven. So my brain is in threat mode consistently. And PDAers operate from threat responses to our environment, to people, places, and things. We don't get a lot of choice or say over how our brain responds to things, over what our brain decides is safe and not safe, and so often we're held hostage to our own demand avoidance.

So I can get really excited about my own hobbies and my brain will confuse the excitement for danger and I will not be able to engage with those hobbies because my brain believes I'm I'm at risk. So it's, it's really, really tricky and complex and challenging to explain to people, but it can have the impact of people confining themselves to their rooms and really struggling to come out, especially teenagers, because they don't understand why they can't. And well-intentioned people in support roles and families will be encouraging and encouraging and encouraging, but the PDA brain perceives that as pressure. And so it reinforces that need to hide away.

Emily Kircher-Morris: [00:21:47] One of the things that I've learned through my, the families that I work with, is how important not only that autonomy is, but the time it takes to bring that threat level that you're describing down. And it's so difficult. I think you mentioned the social model of disability. Our society is not set up for kids to take the time that they need to work through those things. I'm thinking of a, uh, situation, and I'll, I'm going to kind of change some of the details, but you know, a, a young college age student who was pretty traumatized through high school by the things that they were... situations that they were kind of forced to do. Extremely bright, and now kind of has retreated to their room, and the coping skills that they used to have - the reading, the writing, the, you know, artwork, those types of things - just can't really even initiate those activities. And will say, "oh, well, I'm experiencing writer's block." And when you mentioned needing that level of awareness, that's so true. And, and when I'm working with this person, I'm just trying to help them build that awareness of themselves because I think that is such, that is the key to a lot of it. To be able to kind of unwind some of that past trauma and work through a lot of that.

Kristy Forbes: [00:23:13] Yeah. And it's important to be able to let go of our own self-loathing. And people don't understand how much we turn on ourselves as young people, because we don't want to disappoint people. We don't want to be rejected or disapproved of. So it's, it's challenging because we want to be doing otherwise, but we have this powerful, inherent, protective drive that requires so much autonomy, flexibility, and freedom.

You know, I often have to work with families to understand that once we're in that space, more often than not there's trauma, and it sneaks up, it sneaks up on us while we're pushing through, because we're determined people. And then the amount of time and space that we require as PDAers to recover, to deescalate that threat response, to deescalate that heightened anxiety, that takes time. Sometimes it can take months, years, and you know, you're talking about a society that doesn't accommodate that. It's also a society that doesn't support parents who are doing the very best they can to love and nurture their children

through really, really difficult times. The amount of pressure placed on families who are supporting young PDAs is just phenomenal. It's phenomenal. And it does so much harm.

Emily Kircher-Morris: [00:25:08] My understanding about PDA is that it's generally seen in autistic individuals who are generally both intelligent and pretty good at masking their autistic traits. Has that been your experience as well?

Kristy Forbes: [00:25:24] Um, people say that. I think that, I dunno. I mean, how do we measure intelligence, really? I mean, I think that everybody is intelligent in their own way and there are so many autistic people, non PDA autistic people, who have had their intelligence undermined because of not having the opportunity to explore their learning pathways, different learning pathways, and masking is an interesting one because PDAs are generally, very socially motivated.

And so that's why our children sometimes are desperate to be at school, but that neurobiology won't allow them to be there. We're desperate to be there, to be with our friends and to see people and to be a part of it. There are characteristics about PDA that may be different to non PDA autistics, and that is our eye contact. Our ability to socially connect. We still have challenges there though, but what happens there is, the autism is often missed because we don't present - and I'm doing little quote fingers - in the way that people have been conditioned to believe autistic people present. And so this means that so many people have been misdiagnosed with other things like Oppositional Defiant Disorder is a really good example of that, don't even get me started on that...

Emily Kircher-Morris: [00:27:10] No, no. I'm sure we could both rant for a while on that one.

Kristy Forbes: [00:27:12] Yeah, but I think previously in the past DSM, PDD NOS - pervasive developmental disorder, not otherwise specified - meant you're kind of autistic, but not enough that we can diagnose you. So a lot of people today who are identified as PDAs would have fallen under PDD NOS, and that's because we do present a little bit differently in the fact that we tend to be able to socialize really well. And, um, I think that's more about the fact that we train ourselves to be in control, to take control of a situation so that we deescalate our anxiety.

Emily Kircher-Morris: [00:27:55] I've heard you use the term radical acceptance.

Kristy Forbes: [00:28:00] Yeah.

Emily Kircher-Morris: [00:28:00] Which is a term I love, I feel like it's really powerful and I use it in my counseling practice, but I'm curious to hear you describe what that term means to you.

Kristy Forbes: [00:28:11] Yeah. I reflect on this a lot actually. Because is it really radical to accept somebody unconditionally? Because that's what it means to me. It means unconditional acceptance of a person. And I kind of feel sad that we're calling that radical, but that's, that's the language that we use. I mean, it says a lot about our social and cultural conditioning when we're calling unconditional love and acceptance radical.

Emily Kircher-Morris: [00:28:45] Right.

Kristy Forbes: [00:28:46] So when children are diagnosed or identified neurodivergent in any way, usually the initiation process is, "sorry, but yes." And the prognosis is that they're going to need occupational therapy, speech therapy, psychology, and one of the other therapies. And when that is a family's introduction - that their child needs this plethora of therapies that puts them into a system that continually rolls out social skills interventions, and just the word intervention. I mean, the language is so alarmist. We're calling characteristics of autism red flags. How can a family ever feel positive about neurodivergence? So when I talk about radical acceptance, I'm talking about challenging current paradigms. So, when my, when the first of my four girls was diagnosed autistic, I felt like it was the end of the world.

What, what are our lives going to be like? I had to give up work and I saw it all as really, really awful and negative and bad, and our lives were over. And I could, it couldn't have been further from the truth. It completely changed our entire family and all of our lives for the better, just turned it around 100%.

And then when the last of our children was diagnosed autistic, it was nothing. We already knew she was going to be autistic before she was born. And we were cool with it and we live inside of autistic identity and culture now as a family anyway, so that is radical acceptance. And not going, "okay you're autistic so you need all these therapies." Therapeutic approaches and supports are wonderful when they're necessary, just because the word autism or ADHD or whatever it is, comes up, that's not an instant prerequisite for a whole heap of therapies.

And you know, a lot of OTs I've heard, say they have clients come in who have been referred to them and they have to ask the, the families, "so what is the actual problem here? Or what kind of support are you looking for?" And the families don't know, they just say, oh, our child autistic so we've been referred to you. It's not always necessary. Radical acceptance means looking at how we can adapt our environment. To support ourselves and our children to thrive, knowing that we can do life differently in a way that supports us. That's radical acceptance.

Emily Kircher-Morris: [00:31:42] You mentioned earlier a little bit about burnout. Neurodivergent burnout. And I'm curious about the overlap of burnout and pathological demand avoidance. And also some commentary from you about the critique... some people would say that PDA doesn't exist. I've heard, I've heard people say, you know, that it's just, yeah. It's just a manifestation of burnout, like you were mentioning, even within the autistic community.

Kristy Forbes: [00:32:09] Yeah.

Emily Kircher-Morris: [00:32:10] Can you elaborate a little bit on, on specifically how you would tell the difference between the two?

Kristy Forbes: [00:32:16] I mean, PDA exists even when someone's not in burnout. It exists in children. It exists in, I mean, some of the research is even reflecting that children as young as six months old. I know with one of my children, they would not reach for toys. They would

use their mouth. And we actually thought... we went through the whole process of taking her to a pediatric neurologist because we thought there must've been some kind of, um, neurological condition or something that needed to be seen to, and it was just... it was PDA. And I think this is really important too, for people to understand that there's such this cemented understanding for people who just make assumptions, I think, that it's a person who is making a choice. "I'm in burnout so I can't do that." Or "I'm in burnout so no, I can't get up and write." It's not about the avoidance of demand specifically. It's about how we go about avoiding the demands. And burnout? I mean, gosh, no, I don't even know how people are tying the two together. PDA is lifelong. Burnout isn't, burnout fluctuates.

And then the other thing I hear is, it's trauma. It's a manifestation of trauma. That's difficult because the way that we respond to our environment absolutely mimics trauma. It mimics somebody who has experienced significant trauma. I guess what I would say is, in the same way, I feel really disappointed when it comes from the autistic community, because as autistic people, we know what it feels like for non-autistic people to look at our behavior and make assumptions about it.

That's how the DSM comes about. That's how all the textbook stuff about autism comes about. Non-autistic people observing our behavior and then going away and doing a write-up or making, coming to a conclusion about it. It's dismissive, it's invalidating, and it's ableist. So when I hear about other people who are autistic looking at PDA specific behavior and going, "that's not a thing, that's autistic behavior, I want to remind them that it is possible for two people to display the same behavior and its origin be completely different. So that's really important to remember.

Burnout is really common in PDA, but that's because our brain is consistently activated in threat response. So when you have a brain like that, your body is consistently flooded with cortisol, the stress hormone, adrenaline, and you are exhausted most of the time. So we end up in burnout, but the demand avoidance is always there. It's always there. It doesn't just come about when we get into burnout, it is always there. So it is not a manifestation of burnout, and that's why I think it's important to differentiate between PDA and demand avoidance, because demand avoidance does come with burnout. PDA? It's already there. It's lifelong.

Emily Kircher-Morris: [00:36:04] So I know we're getting a little short on time, so this'll be, we'll kind of wrap up with this. If you were speaking directly to an autistic person who was diagnosed with PDA, what would you say to them? What advice would you give?

Kristy Forbes: [00:36:27] Oh, wow. Yeah. Um, I would say, first of all, be kind to yourself. Be kind to yourself. Self-forgiving, self-compassionate, and know that it is okay... it's not only okay, it is important that we explore what that means for us, what it looks like in terms of lifestyle, and explore ways to support ourselves. And even though those ways may be, they may feel completely unconventional, that's what we're built for. We're built for unconventionality. And there are some serious leadership qualities in there. It takes time, but learn about, learn about what it means for you. And I know it's hard for us to read books and listen to what other people say about it, because that's part of PDA, but exploring what it means for us is really important. Yeah.

Emily Kircher-Morris: [00:37:49] Kristy Forbes of inTune Pathways, thank you so much for your time today.

Kristy Forbes: [00:37:54] Thank you so much for having me, and for asking such amazing questions.

Emily Kircher-Morris: [00:38:04] The language that we choose to use around neurodiversity is an incredibly important part of changing the paradigm surrounding how the world sees and understands neurodiversity. You may have noticed subtle, and not-so-subtle changes in the conversation surrounding neurodiversity over the last few years. Even on this podcast, you'll notice I've dropped the disorder part of autism spectrum, and have begun to refer to ADHDers, instead of people with ADHD. I love the way that Kristy rephrased pathological demand avoidance as pervasive demand avoidance, because it's not only more descriptive, but also less... judgmental?

The importance of understanding person-first versus identity-first language is also an important shift. Those of us who are professionally trained as educators or clinicians may have been trained that person-first language is the best way to talk about people with disabilities. However, recently, neurodivergent people have been reclaiming their identities and insisting on being referred to with identity-first language. Being an autistic person, instead of a person with autism, for example.

Why is this change so important? Well first, using person-first language implies that there is something inherently wrong with the person because of their diagnosis, a student with autism could be just a student if we could get rid of that autism.

Another example about the flip side of language: giftedness is another type of neurodivergence, but we have no problem using identity-first language for this. "A gifted student," because giftedness is considered an asset from a social standpoint, so we don't mind labeling a student as being gifted. When we use terminology that separates a person from their neurological wiring, we're implying that there's something that has to be fixed or something to be ashamed of or something that we want to get rid of about that person.

This implication ignores the qualities of neurodivergence that we need in our world. Nobody is saying that neurodivergence isn't a disability, especially when accommodations aren't made available, but can you imagine a world where we cured every type of neurodivergence? The world needs people who think and see the world differently, and a simple language change - an autistic person an ADHDer, a dyslexic student - can be one of the first steps to changing how the world sees and values neurodiversity.

I'm Emily Kircher-Morris, I'll see you next time on the Neurodiversity Podcast.

Dave Morris: [00:41:05] Thanks again to Kristy Forbes, as well as the birds and wildlife of Melbourne, for getting up early and making an appearance on this episode of our podcast. It made me want to head immediately "down under" for our next vacation. You can check out Kristy's website, www.KristyForbes.com.au, and you can find links to her work on the episode 85 page of www.NeurodiversityPodcast.com. In case you haven't yet, you can listen to us and peruse our YouTube channel at www.Youtube.com/neurodiversitypodcast.

I'm executive producer Dave Morris, Emily Kircher-Morris's personal Uber driver. Stay safe. Stay healthy. See you next time.

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