



[2021's Biggest Conversations - Pathological Demand Avoidance](#)

EPISODE #111

Narrator 0:00

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Intro 0:24

What is neurodiversity? This is the Neurodiversity Podcast.

Emily Kircher-Morris 0:40

I'm Emily Kircher-Morris, and today's episode is the final feature of our best of 2021 series. In this episode, we talk about PDA, also known as pathological, or pervasive, or persistent demand avoidance in autistic individuals. 2022 will hopefully provide a lot of new opportunities for all of us. One that we want to tell you about is called the Neurodiversity University. This is going to be a hub of virtual courses that we are creating for educators, clinicians and families. There will be free offerings, as well as courses that parents can actively go through with their children to develop communication, understanding and strategies to support their neurodivergent household. If you want to make sure that you don't miss any of the offerings, head on over to neurodiversity.university, and sign up to catch all of the announcements that are made available, that's neurodiversity.university. Okay, we go all the way to Melbourne for a chat with one of our most popular guests of 2021.

Kristy Forbes 1:48

I'm Kristy Forbs, and I'm an autism and neurodiversity support specialist.

Emily Kircher-Morris 1:53

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.

Kristy Forbes 2:07

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 9am, and that's flying over sounding like the monkeys off the Wizard of Oz.

Emily Kircher-Morris 2:23

That's all straight ahead.

Narrator 2:28

Previously on the Neurodiversity Podcast.

Harry Thompson 2:31

Hello, my name is Harry Thompson, and I am the author of the "PDA Paradox."

Emily Kircher-Morris 2:36

What is pathological demand avoidance?

Harry Thompson 2:38

They will exhibit differences in communication, social interaction, and also restricted and repetitive behaviors and interests. PDA is best understood, according to the literature as an anxiety driven need to remain in control. And I tell people try not to get too hung up on the demand avoidance aspect, because then it will make understanding how the child's presentation can differ in school more difficult to grasp.

Narrator 3:07

That's episode 54. Look for it wherever you get your podcast.

Emily Kircher-Morris 3:16

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

Kristy Forbes 3:27

Thank you so much for inviting me.

Emily Kircher-Morris 3:30

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 3:47

So I am autistic, ADHD, PDA, I have four children who also share those neuro divergences, and I'm married to an autistic ADHD PDA man. But my background is in education, early education, primary and secondary teaching, and I did work with families for a really long time supporting families who are raising autistic children. So yeah, I've kind of been in all different perspectives, and 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 4:39

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, it gives me a real purpose.

Kristy Forbes 5:02

Yes, me too, I absolutely love it, and when people say, gosh, you work 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 5:19

I think the thing that especially working with I have a lot of clients who are autistic and a lot of 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 5:46

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, being 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 their PDA is 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 6:56

I want to start off before we dig into a lot of the stuff of, 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 7:32

Yeah. this is such an important topic, and it's also, unfortunately, so controversial. For me, personally, it is everything, because I use identity as a 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 you roll 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 seeing autism as 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. 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, 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 12:55

You touched on something that I've actually been reflecting on lately, specifically, I've heard ADHD or 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 13:30

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 experienced 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 and 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 isn't normal.

Emily Kircher-Morris 15:01

This is right, because doesn't everyone experience this?

Kristy Forbes 15:05

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, 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 16:06

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 16:23

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 foreigners, 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, that 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. That might be a child who lives a lot of their time in fantasy, in roleplay, as characters, very common for them to be villains, or bad guys, and the other is 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, oh, 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 or 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 receives that as pressure, and so it reinforces that need to hide away.

Emily Kircher-Morris 21:53

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 about a situation and I'll I'm going to kind of change some of the details, but you know, 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 artwork, those types of things, just can't really even initiate those activities, and will say, oh, well, I'm

experiencing writer's block, or you know, and when you mentioned needing that level of awareness, that's so true, 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 23:19

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 this 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 de-escalate that threat response to de-escalate 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 PDAers is just phenomenal, it's phenomenal, and it does so much harm.

Emily Kircher-Morris 25:14

My understanding about PDA is that it is 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 25:31

People say that, I think that, I don't know, 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 PDAers 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 off.

Emily Kircher-Morris 27:16

No, I'm sure we could both rant for a while on that one.

Kristy Forbes 27:19

Yeah, I think previously in the past DSM, PDDNOS, 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 PDAers would have fallen under PDDNOS, 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 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 de-escalate anxiety.

Emily Kircher-Morris 28:02

I've heard you use the term radical acceptance. 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 28:17

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, says a lot about our social and cultural conditioning, when we're calling unconditional love and acceptance radical. 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 neuro divergence? 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 was really, really awful and negative and bad and our lives were over, and I couldn't, 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 support 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 who have been referred to them, and they have to ask 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, our child's 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 31:48

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. Can you elaborate a little bit on specifically, how you would tell the difference between the two?

Kristy Forbes 32:22

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 have been some kind of 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 this this 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 were 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 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 knowing 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 constantly 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 is already there, it's lifelong.

Emily Kircher-Morris 36:10

So I know we're getting a little short on time, so this will be 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 36:33

Oh, wow, yeah, 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 learning 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 37:55

Kristy Forbes of "Intune Pathways", thank you so much for your time today.

Kristy Forbes 38:00

Thank you so much for having me and for asking such amazing questions.

Emily Kircher-Morris 38:10

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 the autism spectrum and have begun to refer to ADHDers instead of people with ADHD. I love the way that Kristie 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 a person's 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 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. In a simple language, changing 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 41:12

As 2021 comes to an end, we'd like to thank you for making it a year of incredible growth for us, please continue to tell others. Thanks to the musicians who contribute to our podcast. As we move into 2022 we do so with optimism that it will be a better year for all of us, we could certainly use the change. The host of our podcast is Emily Kircher-Morris. The post production editor and executive producer is me Dave Morris, and for all of us here, thanks and Happy New Year. This podcast is a production of Morris Creative Services.

