



[Understanding Pathological Demand Avoidance](#)

EPISODE #121

Harry Thompson 0:00

We're all reacting accordingly to our triggers. We're all reacting accordingly to what we perceive as threats and to pathologize someone is to essentially deem their way of being as defective, or falling beneath the perceived norm, or wrong get simple as that wrong.

Emily Kircher-Morris 0:22

Today, we're talking about a specific profile of autism called pathological or pervasive demand avoidance or PDA. Individuals with this profile can exhibit difficult behaviors at home or school, which are often misunderstood. We're featuring a conversation with Harry J. Thompson, author of the "PDA Paradox. The Highs and Lows of My Life on a Little Known Part of the Autism Spectrum." This is our continued coverage of World Autism acceptance month, and episode 121 is straight ahead. I'm Emily Kircher-Morris, and this is the Neurodiversity Podcast.

Intro 0:58

What is neurodiversity? This is the Neurodiversity Podcast.

Emily Kircher-Morris 1:19

We're talking today about PDA, and if it's something you've never heard of you aren't alone. Let's dig in Harry Thompson, thanks for being here.

Harry Thompson 1:27

Oh, it's my absolute pleasure. Thanks for having me.

Emily Kircher-Morris 1:30

So why don't we start with this what is pathological demand avoidance or PDA?

Harry Thompson 1:34

Pathological demand avoidance is largely accepted as being part of the autism spectrum. So as with other individuals, who meet the criteria for autism, they will exhibit differences in communication, social interaction, and also restricted and repetitive behaviors and interests. So what distinguishes PDA from other presentations of autism is first and foremost, the individual will display a pervasive and extreme tendency to avoid the demands of everyday life. Also, a PDA person will employ social strategies as part of the avoidance so not just ignoring or fleeing from, say, a request, but using social strategy so coming up with a number of excuses using delay tactics, excetera. Thirdly, the PDA individual has what is described as surface sociability. So appearing, sociable and socially driven at first, but perhaps lacking depth and understanding and impulsivity, and emotional lability, and having a tendency to withdraw into fantasy, and to engage in roleplay, and finally, forming obsessions, which are often directed at people rather than things. And the diagnostic ratio is even, so boys and girls, or males and females are just as likely to be diagnosed as each other. Unlike with ASD, where males up to four and a half times more likely to be diagnosed.

Emily Kircher-Morris 3:40

I know that PDA is being discussed a lot more where you are in the UK, much more than it is here in the United States. When did the concept surface? And when did people really start talking about it?

Harry Thompson 3:52

Well, I suppose it goes back to the 1980s when Elizabeth Newson, who was a neurodevelopmental psychologist based in Nottingham, in the UK, observed children who exhibited traits of autism similarities, however, traits that also set them apart from other autistic kids, namely, resisting the ordinary demands of life. So she published a peer reviewed study, which currently features in the archives of childhood diseases and this was back in 2003, the name of the study is called "A Necessary Distinction Between the Pervasive Developmental Disorders", so she pioneered the work I would say, and due to this happening in the UK, I think it's fair to say that the UK are spearheading the PDA movement.

Emily Kircher-Morris 4:54

You actually have this diagnosis yourself, correct?

Harry Thompson 4:57

Yes, that's correct.

Emily Kircher-Morris 4:59

So tell me how have a bit about your path to diagnosis. How did that come about for you?

Harry Thompson 5:04

Initially, I was diagnosed with ADHD when I was 13, following my, quote, problematic, unquote, behavior within the classroom. A year later, I was diagnosed as being on the autism spectrum when I was 14, what was formerly known as asperger syndrome. Now not recognized by the DSM, as a condition in its own right, well now falls under the umbrella of ASD. Four years later, the same woman who diagnosed me reviewed my case, because I thought I was going to give music college a try, and my mentor, with whom I was living at the time, got in touch with the speech language therapist who originally diagnosed me as being on the autism spectrum, so my diagnosis was reviewed and updated to a PDA profile, because it would be no use if I were to attend an institution and they were implementing strategies, which are often used for autistic kids to ensure that the teachers would adopt a more flexible and collaborative approach to educating me. So that's my diagnostic history.

Emily Kircher-Morris 6:18

I see a lot of kids who have been diagnosed with ASD, but were originally diagnosed with ADHD. For you, was that a missed diagnosis? Or would you say that it is concurrent?

Harry Thompson 6:30

I'd say concurrent I'm, I'm very much ADHD, perhaps with the exception of asperger syndrome, to be honest, I am an ADHD and I am autistic with a PDA profile.

Emily Kircher-Morris 6:41

How accepted is that PDA diagnosis in the UK and Europe? Would you say that it is pretty well understood?

Harry Thompson 6:48

Yes and now, yes and no, it depends on whom you speak to, and it depends on where you live, largely. Many clinicians and diagnosticians, pediatricians, speech language therapists, psychologists, psychiatrists, etc, are willing to recognize and diagnose it. However, it still remains a highly controversial topic due to the fact it doesn't feature in either of the diagnostic manuals, DSM, which you use over there in the states and the ICD, which we use over here in Europe. So many people will still claim that it doesn't exist, or there are alternative explanations for the behaviors, which are part of that

constellation. But due to the fact I interact with many people overseas, I think I'm in the position where I can see how, how much more difficult it is in other countries, because I, I might tell my UK clients look, at least here we have a PDA society, at least here there are numerous clinicians who are willing to recognize and diagnose it, which just isn't the case overseas, at least not to the extent it is here in the UK. So it's a tricky one, because the situation here is not perfect by any means and a lot more work needs to be done. I suppose if you are a family whose child meets this profile, and you do live in the UK, you need to be somewhat grateful, that's that's all I can say.

Emily Kircher-Morris 8:34

We kind of talked about those symptoms, kind of what those characteristics are like at the very beginning. What does that look like in daily life?

Harry Thompson 8:41

I mean, my simple explanation is this is a child who is unbound by human confinements. That's my short description, and that in itself indicates how any type of system or way of life imposed upon this child is going to be met with extreme resistance. So because it's a relatively, I'd say newly recognized condition, it is thoroughly under researched, so we don't have prevalence rates. We've got a study, which was carried out a couple of years ago, as to how many children who have this profile are unable to access school, and that is 70%, and over, I'd say. Universally, these kids have problems with school, but perhaps some children might mask at school, then they may be able to hold it together during the school day, but due to the nature of the mask, which, you know, exhausts and drains the person by the end of the school day when they return home to their kind of safe space, the parents get the brunt of it. So the child that the floodgates are open by the time the child returns home, and a meltdown is likely to ensue, and the parents report that the child's behavior is often not consistent with the teachers report of the child's behavior. So the teacher often often places the blame on the parent and saying, well, we don't see this type of behavior at school, the child is relatively well behaved. So these nightmare stories, which you recount at home, must indicate that it's a problem with your parenting. So that's a huge problem. The types of issues you'd see at school would be home, excuse me at home, would be resisting more or less everything from eating, bed time, to leaving the house for a family outing, anything you can think of, could be a demand, so the child is likely to resist a heck of a lot.

Emily Kircher-Morris 10:58

You mentioned how kids mask at school, I wonder if as kids get older, if that becomes more difficult for them, to mask and to appear not to struggle?

Harry Thompson 11:11

Well, I suppose it depends, I mean, one could, one could also make the claim that the older the child gets, the more efficient they are at navigating the neurotypical world and observing how neurotypical people would conduct themselves and search certain situations an autistic or PDA person would find very stressful, so they may hone their masking ability as they continue to develop. And due to the traumatic element involved with the child, quite simply, who is unable to be themselves without repercussions, I suppose that would motivate the child to bolster or strengthen the mask as they get older. And the PDA child often has good acting skills, good thespian abilities, so masking is quite prevalent, and I say this in my talks, you can have 100 different reports about a single child and they could all say something slightly different so, and it's difficult because I mean, 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. I describe the kind of "locus of control" whereby the child feels quite safe at home because what you see, when you're PDA, you often scan people, you're scanning people's innermost feelings, so you notice how mum dad has unconditional love for you is unwavering, and therefore, this provides a sense of safety within a environment such as home. So because it's safe, and because there are no costs, and because there is no impression in your mind, other than mom and dad loved me and will not abandon me, the behaviors can take a very extroverted form. You only need to place the child in an environment which isn't so safe and that anxiety driven need to remain in control will shift forms. So at school people don't love you unconditionally, and there are more risks, and therefore, holding it together may be a new control tactic. I call that inverted control, which is when you lend people in your environment, the upper hand, in order to probably keep them close or keep things the way they are not draw attention to yourself, because mom and dad don't abandon you, all of these friends at school may do if you act the same way you do at home. So sometimes, it's helpful to view it as this hyper controlling that can take on different forms.

Emily Kircher-Morris 13:55

Looking very compliant, just so not to rock the boat.

Harry Thompson 13:58

Absolutely, the compliance is illusory, it's likely being driven by a foreign response, the least known of the five F's fight, flight, freeze, flop, all of which are self explanatory, and then falling excessive people pleasing as a way of retaining one's safety. And sometimes you have to ask yourself, which behavior is more likely to guarantee my survival? Do I avoid demands here? Will that be safe? Or do I fall in here? Will that be safer? And one may prevail over and over another depending on the context.

Emily Kircher-Morris 14:33

When I'm talking to my clients and my families about understanding how that all ties in, like you mentioned earlier, it's very anxiety based, and how that ties in with that ASD diagnosis. Some of the black and white thinking or having difficulty with unexpected transitions or those types of things, I feel like it all kind of ties into that. And as I've learned about this, I'm like, man, that term pathological is such a turn off I think, this is coping scale, it's kind of like to make an analogy. Sometimes if I have clients who are using self injury as a way to deal with anxiety or depression, that is a coping skill, it's not a healthy coping skill, but it is, you know, it's a way that they're trying to get through that.

Harry Thompson 15:15

Sure, it's, the word is deeply problematic, and there are various attempts to justify its use, such as, it's the fact that the demand avoidance is so pervasive and extreme I mean, some people would much rather refer to it as extreme demand avoidance, because many autistics take issue with the fact that non autistics attempt to pathologize our experiences. So I believe the word pathological is problematic for that reason, it does not acknowledge the mismatch of experience, how the experience of the autistic differs vastly to that of the non autistic. So I take issue with the language, of course, because from my standpoint, that part of it does feel quite reasonable, you know, because I suppose I'm detecting threats, where another person may not, and there's confusion as to what constitutes a threat. So from my vantage point, and I will, I suppose even I recognize a threat and I won't go anywhere near it, it's a threat to my level of control my level of freedom. Anything that is designed to swerve me out of what I call the PDA current has to be discarded, anything useful can be incorporated into the PDA current. See, I often talk about how there's no such thing as an overreaction. Many parents or teachers might be, might describe the child's meltdown or extreme, quote unquote, behavior as an overreaction to simple requests, without realizing that the child perceives these requests as inherently dangerous and in some aspect is not able to distinguish a minor request from a genuine threat. So there's a mismatch of experience worth acknowledging and when you acknowledge how the two experiences are different, then the word pathological becomes redundant words like overreaction become redundant, because we're all reacting accordingly to our triggers, we're all reacting accordingly to what we perceive as threats. And to pathologize, someone is to essentially deem their way of being as defective, or falling beneath the perceived norm, or wrong, yeah, simple as that wrong.

Emily Kircher-Morris 17:45

You know, you mentioned about perceiving those things as threats. Would you associate that with some of the, like, you mentioned at the very beginning, talking about some of the symptoms with interpreting social situations and appearing to understand them, but not necessarily at a deeper level? And so would you say that some of that threat is like, okay, I hear what you're saying, but I'm not quite sure what's beneath that, or what this means for me?

Harry Thompson 18:10

In social situations, as far as the PDA experience is concerned, one often finds that the child will, at an intellectual level get by, so learn the very rudiments of non autistic interaction as a way of getting by perhaps even as a way of manipulation in some cases for some of these children, as a way of staying one step ahead of their interlocutor or primary caregiver or teacher. So, you know, difficulties with grasping sarcasm and irony, are often noted, as to the social ability of the PDA person. I can recall, struggling with things like that myself as a child, sometimes I probably suddenly failed to recognize sarcasm, but interestingly, I would use sarcasm quite fluently, but when it came to receiving sarcasm, it didn't seem to land smoothly inside my brain, but I was able to deploy it. And speech and language therapists often pick that up actually, where expressive language is quite fluent, and apparently able, receptive language not so much, so I can I can recall that as a as a much younger person. And I suppose I don't have as many problems with sarcasm now, I'm not sure if that's because I'm older or I'm not sure I get it now, and it seems to be a very useful tool and commodity so I'm grateful that I have.

Emily Kircher-Morris 19:49

Like I said, I have several of my clients who just fit this profile so perfectly. And one of the things that I know that is the most effective way to help them is to just take a collaborative approach to most anything. Or like, hey, this is kind of our goal, what do you think are the best ways for us to work towards that? Or what's going to work for you? Or if there is a little bit of that pushback, just backing off for a while, and then maybe coming back to it when they're more ready when they indicate that they're ready.

Harry Thompson 20:18

Yeah, what you just described sounds like a beautiful experience, I'd relish, I'd relish that, as a child, I'd relish it now, so a collaborative approach is always very important. Reciprocity and fair exchange is our language, we need to be on the same level as people in order to relate to them, recognizing authority is of great difficulty to us. It's not so much a rejection of authority. it's more of a, as I said, it's a blindness to it. it's a blindness to authority, it's like a pecking order seems to be invisible. So seeing everything as equal, which I think sounds kind of nice, but other people seem to think

that's a problematic way to structure society. So there's a there's when a parent or teacher presents an activity, which benefits both the PDA child and the teacher or parent, then that's more likely to elicit a positive response from the child. There's often this hypersensitivity to separation, so if I feel separate to a person, I'm less likely to trust them, and cooperate with them. If I feel they're on my level, and I feel that we can work together towards something, then they're on my level, which means they are visible, the person whom they are becomes visible, and therefore I can interact with them. I sense distance between myself and people which creates this kind of unbridgeable gulf.

Emily Kircher-Morris 21:49

You mentioned that hierarchy of like authority, if anybody takes a step back and looks at that questions, just for a moment, why as a society, we have these rules about, you know, authority, in the school system, or at home, or, you know, it's like, well, you do this because I'm the parent, or you do this, because I'm the teacher, and I told you to do it. Anyone who's perhaps neurotypical, we don't question it, but if we just question it for a second, it's like, why is that? That doesn't necessarily make sense, why do we have to do that? And if this is what works for this, kiddo, let's do that. We all want autonomy, we all want that sense of, of ownership, that's good for all kids.

Harry Thompson 22:29

You know what? That's it's interesting you say that, because I was having a debate with someone not so long ago, and their argument was, at the end of the day, all of the PDA friendly strategies would work for all kids. Yes, exactly, I agree with you, I think in a sense, there's nothing unique to the PDA profile other than less tolerance, in fact, zero tolerance for the, to put it crudely b*****t life, and extremity in presentation. So the extremity in presentation combined with zero tolerance draws our attention to these things that we never really question. And one can't help but realize, who really likes being told what to do? You know, who wouldn't benefit from a flexible approach to life. So, I think that's one of the gifts of PDA if you asked me, it's a signal to the rest of the world, that perhaps it's time to have a spring clean of the system.

Emily Kircher-Morris 23:36

So as I was doing some prep work and research about PDA for this interview, I came across some opinions that would be described as, I guess, skeptical, maybe, some people who question the diagnosis or say it would be better described as more like burnout or executive dysfunction. I'm curious about what you think about those critiques?

Harry Thompson 23:58

Well, of course, there are going to be critiques, because research is limited. It's all you know, very, very limited scarce, so that opens the door for people to swoop down and look at PDA through a more skeptical lens, which I don't mind per se because at the end of the day, I want to get to the bottom of what this really is. So I will address those two phenomena, which you listed, executive dysfunction and burnout. PDA is not burnout and it is not executive dysfunction. Though burnout can definitely arise as can executive dysfunction, to be honest, but the demand avoidance of the PDA kind is unique in that it can't really be explained by anything on the outside, which may, there's there's there lacks a kind of rational explanation for why demand avoidance occurs, for example, it occurs even when the child or person likes the thing that they do. So I recall a time when I was 18, and I was on a kind of retreat, let's say, and I take my guitar with me to most places, especially if I'm going to stay overnight anywhere. And by the time I was 18, I had some considerable experience in performing publicly with my music. So we were sitting around one day and the kind of organizer of the retreat, said, Harry, didn't you bring your guitar? And immediately the anxiety sets in, and I said, yes, and he said, do you think you could bring it over here and play us a song? So my immediate reaction was to not say no, say yes so that I wouldn't cause a scene, but then I went back to my room and tore the strings off the guitar. And even though I'm a musician, and a guitar player, I have never learned how to restring a guitar, I don't know why, perhaps, because I refuse to, but I have never bothered learning how to restring a guitar, it doesn't faze me and I, so I ripped the strings off, and then I was unable to use my guitar for the remainder of the retreat. And immediately after doing so, you can't help but feel, why did I do that? What a terrible idea that was, and I wanted to play, I wanted to be able to just do it because I've done it many times before, and because music is so important to me. And many people might say, oh, hang on, is it because you were feeling embarrassed or shy or reserved, and it had nothing to do with that because I had experience in playing. I can remember when I first played, there was an element of shyness there, but maybe within the shyness, there's a demand not to play, there's a demand not to play, so then you avoid that and end up playing it. So demands are all over the place, they're fluid, they're not static, they pop in and out of existence, and they can just pop up anywhere in your life. But in order to explain it, it's because I was asked to play it because the request violated my sense of who I am. It impinged upon my sense of freedom and control, and if it does, that, it has to be avoided at all costs. So burnout, demand avoidance following from burnout would imply that the child is exhausted, the child's mental energy reserves are low. And with PDA, it's got nothing to do with that the child could be willing to do anything, the child could be as energized as they've ever felt before, and if the demand is detected, it will be swiftly avoided. So demand avoidance following from burnout is rational demand avoidance, it's a reasonable response to exhaustion. So demand avoidance of the PDA kind is, essentially it's my way or the highway, I refuse to compromise my freedom, in order to

meet your request. And to executive dysfunction, you know, you know, having difficulty with beginning a task, seeing the task through completing the task, running into distractions, and you know, essentially requiring a lot of mental energy in order to engage with a task and carry it out. You can have two kids who refuse to do their homework or don't do their homework, I should say, for completely different reasons, let's say you have a PDA kid and an ADHD kid. Perhaps the ADHD kid doesn't do their homework because maybe they maybe they forget about it, maybe they bring it home and just forget to do it or maybe they sit down to do it, but the amount of stamina and dedication and commitment it would take to focus on the task at hand would be immense. And therefore, the child may lack the ability to focus on the task and essentially, becomes beset by many, many distractions and they're gradually dragged away from the task by distraction and whatever else. The PDA child may not have any of those issues at all, ADHD doesn't necessarily have to accompany PDA though it's often seen in PDA kids ADHD and PDA often exist together, but it doesn't have to. Maybe the PDA child has no problems with lapses in concentration whatsoever. The fact that someone asked them to do it is enough of a reason not to do it, and perhaps they'd struggle to meet their own self imposed demands. Whether they have the ability to do it or not, has no bearing, perhaps they have the ability to do it and do it so well, perhaps they have the ability to do it better than anyone in their class. But if it is a demand, if there is a demand to do the homework, it doesn't matter about the child's ability to do the work, it could be far beneath them intellectually, but they will not do it because it is a demand.

Emily Kircher-Morris 30:35

What advice would you give the student, the child who is struggling with this something maybe that you would have wished that someone would have said to you, when you were really kind of going through this as a young as a younger individual?

Harry Thompson 30:53

Ah, well, it's difficult to answer, because I look back on my experiences, and each of them were pivotal, very important in creating the person I am today. But there were many times when, obviously, I could have just done with a friend I could have just done with someone who was willing to understand me, maybe they wouldn't have understood me immediately, but who are just willing to understand me. In my book, I talk about how I went to a home from homeschooling organization, a woman, an ex headmistress, an ex principal, I should say, for American audiences ran a school from within her farmhouse, ideally, for kids who didn't quite fit the system. And she accepted the fact that I found life difficult, I suppose, because I was perhaps what you'd call a gifted academically, teachers and family members always thought that my behavior arose from perhaps laziness, stubbornness, unwilling to cooperate, blah, blah, blah. But she

just saw right through that and said, I can see that you have problems with life, and that was the biggest compliment anyone had ever given me, and it was so important to have someone who really acknowledged me, so community is so important, if these kids just have one friend who gets them, that's so important to have. But as to relating it to their future, sometimes it's helpful to see the demand avoidance as a guide through life. I describe, I've got a you know, little concept I have right now a little metaphor, I call the PDA current, and I always have to ask myself, am I inside the current? Inside the current I can flow smoothly through life, and everything is possible, and that is my identity. You know, this, obviously, this role I have now I don't call it a job or a career or anything like that, because that will jinx it, and I won't be able to do it, so whatever I do now is just a lifestyle that is in total and blissful harmony with my brain chemistry. So it's, it's asking oneself, and I would have asked myself, I would have noticed this as a child, occasionally, I found that I could do things when I was able to do them myself without any pressure, and I could define the terms in my life, that was me being inside the flow. So I still ask myself that now, am I in the flow? Am I out the flow? When I'm out the flow I run into old habits, let's say, and I have to, I have to say, okay, how do I get, every time the child avoids a demand every time they carry out an extreme impulse, is essentially a knee jerk reaction, is an attempt to steer themselves back into the flow, back into their autonomy, back into who they really are. And resisting everything and rejecting everything is part of rejecting things which fall outside the flow, because you're hypersensitive to a way of life other people want you to take. School? No, that seems absurd, that seems ridiculous, that does not resonate. So having that kind of helpful metaphor has really aided me. You've found a way to make it work. Yes, now, I don't like speaking in absolutes, because anything could jinx anything, you know, it's I'm on a knife's edge all the time. I'm tightrope walking, I'm tightrope walking.

Emily Kircher-Morris 34:19

I'm just really hopeful that this conversation will help people understand what is going on inside our kids just a little bit more.

Harry Thompson 34:28

You and me both, you and me both.

Emily Kircher-Morris 34:31

Harry Thompson, author of "The PDA Paradox", thanks for the chat.

Harry Thompson 34:36

Hey, I loved it.

Emily Kircher-Morris 34:41

Demand avoidance is a very real and a very misunderstood occurrence. Not all autistic people experienced demand avoidance, but for those who do, it can lead to unnecessary and inappropriate discipline, academic underachievement and learned helplessness. If there's one thing I would urge you to focus on when you're communicating with someone who experiences demand avoidance, it is to focus on the relationship validate their experiences and emotions. Give them the benefit of the doubt that they aren't being difficult for the sake of being difficult. And ask them to help you find the solutions that will work. If you start with a relationship based on trust, you can help to greatly reduce the anxiety of someone with PDA, and that will help them feel safe when they're with you. I'm Emily Kircher-Morris, I'll see you next time on the Neurodiversity Podcast.

Dave Morris 36:27

Thank you to Harry J. Thompson for being a guest on this podcast. This is our continuing coverage of World Autism acceptance month 2022. Thank you for listening. Our host is Emily Kircher-Morris. The executive producer and post production editor is me Dave Morris. More episodes ahead for autism acceptance month so check your podcast feed all during the month of April. Thanks for listening, we'll see you next time. This podcast is a service of the Neurodiversity Alliance.