



Episode #182:

**A Conversation with Autism and
Neurodiversity Support Specialist Kristy Forbes**

November 5, 2019

- Debbie: Hello Kristy, welcome to the podcast.
- Kristy: Thank you so much for having me. I'm really excited to be here.
- Debbie: I'm thrilled that we were able to make this work despite the fact that we are on opposite sides of the globe. And as I was just saying before I hit record, you have been perhaps the most requested guest that I've had recently for the podcast. Like I've been getting a number of emails, including just yesterday, saying you have got to have Kristy Forbes on the show, so I'm really happy we could make this work.
- Kristy: That is amazing. That just feels like such an honor to me. It's really lovely to hear.
- Debbie: Well, for those of you who weren't requesting and who may not be familiar with your work, would you just take a few minutes to just tell us a little bit about yourself and about the work that you do?
- Kristy: Yeah, sure. So I am an autistic person and I also have a PDA profile of autism, which isn't well known about at this point. But I'm also the mother of four autistic girls. I have a background as an educator. So I worked in early childhood, primary and secondary, and then I worked for a little while as a childhood behavioral and family specialist. So supporting families whose children had a social, emotional or behavioral difference. And now I'm in business for myself, so I work to support families raising neurodivergent children, so children who may be autistic or have ADHD or any form of difference, to create really joyful, balanced lives that work for them. So I work in consultation with autistic adults as well and I run a few programs and webinars. So that's what I do in a nutshell.
- Debbie: That's fantastic. Yeah, you have, I really like your social media presence as well. You've had some really powerful posts that I've seen shared in a number of groups. So for listeners who are new to Kristy's work, definitely check out the show notes page for this episode because I will have links for all of Kristy's work so you can tap into her, just her presence and, and the things that she offers. So I actually just wanted to even talk about PDA briefly because I just did an episode about maybe two months ago on PDA because as you said, it's, it's not something that is that well known, especially here in the U S and I got so much feedback from that episode. People were so grateful to just to have a name for this. Can you talk a little bit about that PDA profile and I'm just curious about your experience with that and even within down under, tell me you're in New Zealand or Australia? If that's an insult I'm sorry.
- Kristy: I'm in Australia.
- Debbie: Okay, sorry, I know that can be an insulting question
- Kristy: No, I'm not insulted at all, but I am an Aussie.

Debbie: Okay, awesome. So yeah, tell us a little bit about PDA.

Kristy: Yeah, sure. So PDA is also not that well known in Australia either, and we have very few clinical psychologists or professionals who specialize in PDA. I think because we have so many other diagnoses to cover different conditions and presentations around our focus on behavior, that sometimes we just completely overlook things when we haven't heard of them before. So I didn't realize that I had a PDA profile until ah look maybe a year ago. And it was suggested to me several years ago by a psychologist. PDA is a subtype of autism. So it's a different type of presentation. And usually when I consult with a family who suspects their child may have a PDA profile, it's based on their behavior being quite atypical from what we have come to understand as an autism expression or presentation. And of course that varies because it's a spectrum, right? So when we realize that a person may have a PDA profile, usually, unfortunately that's because the person has come to a place of distress.

So we see particular behaviors start to unravel and unfold and parents tend to be at their wits end because they've tried all of the regular autism strategies and nothing seems to work. So we see a lot of children having to be taken out of school. They end up traumatized, unable to shower or brush their teeth and look, in all honesty, PDA is quite a spectrum in itself because some people with the profile will actually be more passive and more subtle in their demand avoidance. So it's an extreme form of anxiety that does not present in the same way that generalized anxiety does. And the most predominant behavior that's typically noticed or picked up on is the way we avoid demands. And a demand is not what you would typically expect a demand to be. So it could be somebody making a suggestion or asking us to put our shoes on as children or just everyday life. So yeah, I mean it's a huge topic so I could get lost in it to be honest.

Debbie: Yes. We could do a multi-part series on that, I'm sure. But, but I just appreciate your perspective on that and it's definitely something I wanna bring more onto the show because in my experience and from what I've heard from my community, there is a dearth of practitioners who understand the profile. There's a lot of resistance to the label, both within and outside of the autistic community. And so I just find it really interesting and it's something I want to bring more attention to on the show.

Kristy: Yeah. Excellent. And you're right, even within the autistic community, there are a lot of autistic people who may not have had direct experience with somebody with a PDA profile. So the assumption is made that, well, most autistic people are demand avoidant to a point anyway. Yes, we are, but PDA is a totally different level of demand avoidance. It really is. And you really have to sit down with the, you know, there's an insurmountable collective of families who are hitting crisis point because there's nobody out there to say to them, actually this isn't just autism, there's more to it than this. So they're not getting the support and the help that they need.

Debbie: Yeah, I mean that's absolutely what I'm hearing from people and there are so few people trained in understanding this profile. So, hopefully that is going to change

over time and be part of this sea change of providing more support. So there's so many things that I could talk with you about and you do have so much experience in this area, and I'm curious to know in your work with families who are on the spectrum or with ADHD, I'm curious to know from your perspective, what are some of the most common beliefs or things that are standing in the way of these families thriving? Like when they come to you, what's not working for them?

Kristy: Trying to live a life that isn't aligned with being neurodivergent. And I mean it's really, really difficult for families not to be working toward normalizing their children because unfortunately as a society, this is what we do. I mean many of our early intervention and therapies are geared toward having, say an autistic child, present as indistinguishable from their peers. So our goals are typically set around teaching our children social skills to match neuro normative standards. So there's little value placed on the neurodivergent brain and there seems to be still more value placed on conforming and fitting in and getting along in the same way that everybody else does. And the problem with this is that if this was working, then there wouldn't be so many families in crisis and there wouldn't be so many autistic adults burning out and ending up with other co-occurring conditions, mental illnesses and chronic health conditions. So, you know, when our children are diagnosed, our first point of contact is typically a professional who is trained in all the ways that we really need to take a deeper look at. So there are some wonderful professionals out there, but we tend to work toward compliance rather than acceptance-based and supportive therapies. So knowing the difference between awareness and true acceptance of neurodivergence is crucial.

Debbie: Yeah, I love that you shared that and I'd like to go a little deeper there. So one of the things that I talk about in my book and when I'm exploring these topics and in front of parent groups is that it's important to get clear about the intention behind any intervention. And if the intention is to, you know, for a child to quote unquote fit in better or as you said, to, you know, normalize their behavior, then that's the wrong intention. You know, but then there are areas where a child getting some supports could really serve them. So can you talk about that, like distinguishing those two sides and how can parents suss out where they, where they are and how to move forward?

Kristy: Yeah, so another part of this problem is that I don't, I mean my experience and what I observe a lot in other families is that we can become disconnected from our intuition as parents. So when the first of my four girls was diagnosed with autism, even though I had this extensive background and professional development and I'd worked with families, you know, I'd worked with autistic people and around autism for a really long time and I thought I knew so much. And when I became a parent of an autistic child, I realized, gosh, I know nothing. But my focus was on, I have this child who's different, completely different from me and I feel inadequate and disempowered, and I don't know how to parent her, and I don't know how to connect with her. And the reality was that I just really needed to listen to my intuition and tune into her as an individual.

But what I did was went off to professionals and I got some really great advice and I got some other advice that wasn't so great, but I wasn't to know that at the time. So you know, we enrolled her in the one evidence based therapy that we found and it wasn't working out and my gut was screaming at me every day telling me, this doesn't feel right. This doesn't feel right. This isn't right for our family. But those pressures, those outside pressures that families contend with from well-meaning family members, friends, professionals, society as a whole, that I needed to keep my job and work. I needed to have my child in therapy. I needed to be parenting in conventional ways. I was just so disconnected, so disconnected from myself as a woman and a mother. Disconnected from what felt right.

And I would drive home sobbing every day feeling like there's something wrong here, but I don't know what it is. And look, eventually we took her out of that therapy and it took a number of years for her to recover because it wasn't the right therapy for her because it was compliance based. So we were taking this beautiful child and not even really exploring the many beautiful gifts that she was born with and just completely overlooking that and going, okay, we have to make her like everybody else. This is what we need to do so that she will survive in the world. And in doing that, we completely shut her down. So, you know, she started speaking at eight and demonstrating how intelligent she is at the age of eight. But before then she wouldn't speak, she wouldn't engage with learning activities because she'd had this experience of a therapy that wasn't right for her. That doesn't mean it's not right for others. And she was terrified, terrified of demonstrating who she was inside in case we then presented her with more expectations that she wasn't sure she could meet.

So I think, I see a lot of families being given the advice that we need to make sure our children will get along in the world and survive. And this is a fear as parents that we want our children to be okay. We want them to be happy, we want them to be thriving, we want them to be functioning members of society. But what we don't explore for some time is that this very well may look different for our families. It doesn't mean that our children won't be happy or thriving if they aren't like everybody else. We changed as a family from compliance therapies into supportive therapies. So then we had a beautiful occupational therapist come into our home who had a beautiful nature and energy, who connected with our children, because that's really important. She saw who our children were as their beautiful organic, innate neurodivergent selves, with no intention to change, just to support them. So I think families need to be supported to tune into who their children actually are, and look at what their challenges are and find supportive ways of assisting them to get the help that they need that way. Rather than just taking this entire human being, not even looking at who they are, and just going, okay, autism means we have to make them something they're not. Because it traumatizes them.

Debbie: Yeah, it's so true. You know, as you're sharing that story, and I'm sure there are many listeners who are going to relate to that, you know, we get this information and then suddenly it's almost like there are checklists, you know, this is what you need to do for this and you need this for that. And it never is, or very rarely is it

about really understanding who your child is. So I'm wondering, when you work with parents, you know, this idea of really tuning into your intuition might be a foreign concept for a lot of people. And do you have any strategies or ways to help parents learn how to better listen?

Kristy: Yeah. I mean, it's already there. That intuition is there. It's this primal innate ability that we have as human beings and we can be disconnected from it through a series of events. However, it doesn't completely go away. It's always there. And I believe that there are many signs in our bodies that let us know whether something feels right or not. And if we're not able to tap into that straight away, our children let us know via their behavior. So whilst we may have a child who is non-speaking, they are not non-communicative, they still communicate with their bodies, with their behavior. They're still communicating with us in a myriad of ways. So I encourage parents to, you know, it really depends on the family situation, where they're at in their journey, sometimes it's important to just let everything go and come back to basics. To sit on the floor with your child and watch how they play. To parallel play with them if they're not comfortable with engaging with you in play. To allow them the freedom and the space and the respect to play in ways that feel good for them and to join them over time because we need to be prioritizing connection with our children and that will look different for every single family. Once we have that connection, that trust, and our child feeling safe with us, they will begin to show us more of who they are. And I believe that our intuition, the muscle of intuition is strengthened through the connection we have with our child.

Debbie: You know, I talk a lot about this idea of becoming fluent in your child and that does take time and observation. Is this something, you know, you shared in your own journey that you went down this one path of more compliant based support and then realized that that was not actually the right solution or the right direction for your family, for your children. And so if there are parents listening to this and they're shaking their head and saying yes, you know, we are, this hasn't felt right and I've just been doing it cause that's what the experts told me to do. Can you talk a little bit about making that change? I imagine a lot of parents feel guilt or regret. And then what is that quote unquote recovery like for a child, you know, is it ever too late to make those changes?

Kristy: No, it's never too late. And I want to say first and foremost that there is never any blame. You know, as parents it's like we are preprogrammed to feel guilt anyway. I mean, show me a parent who doesn't feel some form of copious guilt in, you know, where we may have gone wrong or made mistakes, but we are human beings and we are only ever doing what we believe is best for our children. And again, under these circumstances, when we have a child with a diagnosis, it's such a new experience for so many of us that we just put all of our trust and faith in other people and we do what we have been told is the right thing to do. So I believe that the majority of us, everything we do for our children is out of a place of love. And how can we go wrong there?

You know, I just, it hurts me to think that parents are feeling guilt and regret and shame. There is always, always possibility for recovery and to start again, and this is the beauty about being a human being. We all have this innate resilience,

form of resilience, and the ability to overcome with the right supports. The transition for me was difficult because I actually felt I'd failed my child and I did feel that overwhelming sense of guilt and I felt lost and like I was just whistling in the dark. What do I do now? I've got no idea. I ended up having to leave my job. I ended up chronically ill. I couldn't get out of bed because I was so ill and I was forced to only be able to sit on the floor with my child and to observe her. And I'm so grateful that that breakdown occurred in my life and in our family because it led to a breakthrough and I was able to learn about my child without any outside influences, without any preconceived notions.

I just let it all go. I still didn't have any ideas about where we were going to go, what kind of therapy, what kind of support would we engage in next? I couldn't even think about that because I was also somewhat traumatized from the experience. Our children let us know when something's not right for them. It shows up in their behavior. It shows up in changes in the way they handle daily life. It shows up in their sleep, it shows up in their toileting and all I could do for a number of months was to just be with her. And that was my form of amends. That was me making amends to her, making peace. And I had a moment where I sat on the floor with her and, and I at that stage had no idea. I was still at the point of believing that a person's intelligence was congruent with the way they moved their bodies and the sound they made.

So because she had a diagnosis of, and I don't like to use functioning labels, it's not usually a part of my vocabulary. But she had been diagnosed with severe autism. And at that point I had no idea whether she knew what I was saying. I really had no clue. But I said to her, I am so sorry. I'm so sorry I haven't seen you. And I did what I thought was right and it wasn't right and we're going to do differently now. And she got up and she came and sat on my lap and leaned back onto me. And up until that point, we'd not experienced a lot of affection with her. So it's a moment I will never forget. And everything changed after that and she really heard me. So this, her sense of safety began there. I think it was a number of, maybe two years after that that we felt ready to engage with other supportive therapies. And that was an occupational therapist like I mentioned before, her speech therapist, and sometimes we had to make the decision that this person wasn't right for our family and seek somebody else. And that may be a process and that is okay as well.

Debbie: Thank you so much for sharing that story. It's a, it's really moving and also, you know, again, I think that I, and I hear this from parents in my community, regret and guilt that they didn't realize something earlier or maybe didn't realize, recognize, that something was even going on with their child. And I love the time that you took and it sounds like the universe conspired to give you that time and to allow you to, you both had that time to heal.

Kristy: Yes, absolutely.

Debbie: So you wrote a really powerful post on Facebook about trauma and demand avoidant children. And I'm wondering if you could just talk with us a little bit about that cycle of being in survival mode, which a lot of differently wired kids are in some form of, you know, fight, flight or freeze, and then needing that

recovery time once a change is made to get them out of that situation. Can you talk a little bit about that cycle?

Kristy: Yeah, it's a really difficult, difficult cycle to spot, to be honest because I mean, as you would know, you can have two children who may behave in exactly the same way and their behavior can mean two completely different things. So we tend to, as a society be focused on behavior. And I think, you know, the beauty is that we are changing and growing in the way we understand behavior. But when we think about demand avoidant children, the difficulty there is again that it's, there's still so you know, there's so little known about it and it's not well recognized. So just that alone means that there are children with demand avoidant profiles who are going through life in survival mode. They're either masking and fawning, which means in survival mode we adapt to situations in order to protect ourselves. It's a form of self preservation.

And just thinking about the demand avoidant brain, that hypersensitive neuroception, so the part of our brain that's receiving information for our environment, from our environment, sorry, and deciding how much of a threat it is. Well the PDA brain just finds so much more of our environment a threat. So you know, our fight, flight, freeze, fawn situation is just that it's constantly going. It's constantly going. We are consistently in fight, flight, freeze or fawn. And when our adults don't know this, when we don't know this because we've never had any other experience, it's not a nice way to live. We're constantly in survival mode. And you know, by the time those behaviors start showing up or the school refusal shows up and our children are absolutely adamant that no, I can not survive in the school environment, for a number of reasons, because PDA begins with a foundation of autism. Now autism alone means that we're often bombarded on a sensory level by our environments.

So we have that as a baseline. We're dealing with that already. But school is a cesspool of demands, I mean one instruction after another from the time you get there til the time you get home. Now for a demand avoidant child to survive that environment, by the time they get home at the end of the day, you could just imagine the levels of exhaustion and the way that that may be expressed in behavior. So when families finally get to the point where, and this isn't the experience for every child with a demand avoidant profile, many children do enjoy school because they've been supported in the right ways at school and at home. It really varies. But by the time some of our children have been taken out of school and they're now at home and it's been recommended to the families by professionals that they have a low demand environment.

That's when the trauma catches up. So we know with any kind of trauma, it's when we stop that the trauma starts to filter in and we start to feel it because we've come out of survival mode. So when many families think, okay, now things will improve because my child gets to rest. This is the period where trauma starts to show up. So those children, you know, the thing I see the most is, they're at the point now where they are avoiding most demands. They're not able to shower, they're not able to brush their teeth, they're not able to leave the house, they rarely leave their room sometimes. Screen time is a major, major component of recovery time for many of our kids who are PDA. And so I have

parents coming to consultation with me saying, all right, we need to work out a way to get them out of the house to get them off their screens.

How can I get them to their appointments because they need to go and see their psychologist. How can I get them, you know, brushing their teeth. And it's difficult to communicate to families that well actually, we really need to take a giant step back here and work out what is priority. And it's not going to be what you expect because our children need recovery time now. So sometimes we might be looking at children only showering once a week. And for most people, you know, we would hear that and just go, oh my god, how can we have our children living like this? But if we continue to push them, that's going to be worse, far worse. Their recovery time can take years. They may have taken years to get to the point of trauma that they're at. And when we talk about trauma, most people think we're talking about abuse, neglect, significant events, but for the PDA brain trauma is triggered very, very easily. And when we're talking again about being in survival mode so consistently, we need significant recovery time and to just let go of our expectations and panic around, we have to have a plan to get them back into school. And this is most families' priority. How do we get them back to school? Sometimes we might not get them back to school and sometimes we might, but recovery must be prioritized.

Debbie: Well and you use that word panic and I think that is really appropriate. You know this, it is a fear response on the part of the parent to be concerned about, you know, the showering or you know, just to, to make these things mean more than they actually do. And I'm wondering, and I don't know if there's an answer for this, but if parents are really able to strip away all demands and not kind of listen to that, that ego or that fear self and really give their child the space to recover without demands, I'm assuming that that can help the recovery process move along more smoothly than if we are kind of halfway going there.

Kristy: Yeah. Yeah. And again, it varies for every child. So I think an added difficulty, I mean a huge challenge that families will have and this will not be true for every family, but for many of our PDA children, whilst they're in recovery and that trauma is being processed, they may become aggressive, they may be lashing out physically, they may be self-harming, they may be swearing a lot. You know, their behavior will be very concerning and terrifying and exhausting and devastating for, for their families because they're so loved, you know. And this is the difficulty is that we are conditioned to think a certain way and to feel a certain way about how things should be and what parent would not panic in that situation. I mean, most families would consider this a family breakdown, a crisis point. It doesn't look like recovery. It's not what you would expect recovery to look like.

But this is a form of processing for the child. So there are so many difficulties accompanying that process of letting go and being able to create a low demand environment. But I think a lot of families will find that they don't have a choice about it because their child will just put their foot down after a period of being in that survival mode. There's no willingness to go back into it in any capacity. So they will not get in the car and go to an appointment. They will not brush their teeth, they will not get in the shower, and we have to start working on making changes within ourselves as the adults to be able to help that process. So many

families will be focused on working with the child, but this is the crucial time for us as the adults and the parents to start learning more about how we can help our child.

Now, if we don't know our child is PDA, this is where we can run into trouble because many people will say, oh, well you must have expectations for them. You must have a plan of recovery for them. Or they won't even recognize it as the child being traumatized and needing space to recover. So it's really important and the way that I work with parents is we work on letting go of assumptions, expectations, fears, panic, dread, and we work on changing our language to be non-directive for our children. We work on seeing who our children are and loving them and identifying their most wonderful parts because underneath this are these beautifully intuitive, incredible little people and big people. The children that we know, they still are the children that we know, those sweet, kind, compassionate, deeply empathetic children. And this is part of their difficulty. Those qualities are their greatest gifts, but they're also their greatest challenge because it leads them into burnout so often. So it's difficult to feel assured that your children are still your children when they become somebody else in recovery. So I work intensively with the adults around that time because that's what's most important.

Debbie: Yeah, that is certainly the, you know, when I hear from parents about the rage or the meltdowns and when behavior starts to get scarier to parents because maybe their kids are getting bigger, you know, it's so challenging for parents and I'm so glad that you're, you're working with them through this process because it just really does trigger us so much because we want the behavior to stop. It can be scary and we also need to hold a space for a child to go through this process. So if there are parents listening to this who are in that state right now, and this is the reality of their day to day life, I don't know if you have like one strategy or word of wisdom for them to think about. Something they can noodle on to even kind of start a reframe in their mind about how they're experiencing this.

Kristy: Yeah. First of all, I just want to send so much love, so much love to those families because they really, really need it. They need unconditional acceptance and love and understanding. And I want them to know they are not failing their children. They have not failed their children. They've loved them. They've done what they have felt is best. And I know I've said this, but this is so important. It's so important for parents to know that this isn't anybody's fault. We can only know what we know and when we know better, we do better. And this is a difficult journey for the children, for the families, and there's so much trial and error and we're all in crisis. We're all in either a trauma state or a recovery state, not just the child, the entire family. So my advice is to find adequate support from somebody who accepts and listens in a way that feels right for the family.

If you source a professional who, you know, appears to be encouraging you to implement demands and you know in your heart and your intuition tells you that that doesn't feel right. If you try things and it's not working out, it's okay to say no. It's okay to step back from that. And I know that sometimes it's easy for us to get to the point where we throw our arms up in the air and we think, I just don't know what to do now. I don't know what to do. Someone else needs to take over.

You know, just because somebody has studied at university or is in a position of authority around particular fields doesn't mean that they know the child better than you. I mean, we are the people as parents who are most equipped to give our children what they need because they need love.

They need unconditional love, but so do we, so it's important for us to have a support network too. Connect with friends and family who will be there for you, even if, if you're unable to get out of the house, even if you can be on the phone for two minutes just to have somebody tell you they love you, just to have somebody say, we're here for you. We're thinking of you. You know, even just a text message. And I want you to know that this will not be your forever. Everything changes. It won't be forever and to hang in there and please do reach out and ask for help because there are people out there that can help you.

Debbie: Yeah. Wow. Thank you so much. I know those are words of comfort for many people listening and yeah, I just really, really appreciate that and I actually would love to close by if you could take a few minutes to share some of the resources, cause though you are in Australia, I know that there are ways that listeners can work with you through some online programs and webinars. So can you talk a little bit about what you offer through InTune Pathways and how parents can connect?

Kristy: Yeah, sure. So I offer online consultations and I do that because I know most of the families I work with are often in a point of crisis where they're unable to get out of their home. So I offer online consultations, telephone consultations, email consultations. My families lead the way and I follow along and support them in whatever way they need support. Sometimes we put together a plan of action. Sometimes they just need to know, to be reassured that what they're doing is okay. Sometimes I share strategies with them, I connect them, refer them on to other professionals that I think may be helpful. I also run a 12 week online program called InTune Families, and that is targeted toward families raising autistic children. So it's a series of modules that looks at autism from an autistic perspective. So we're putting aside the medical model of autism and looking at it as an identity and a culture.

So we're breaking down what behavior might mean, how to connect with and guide our children, how to take their lead. We basically look at everything. I've taken everything I know about autism and put it into this program, basically. It's, you know, people have lifetime access, they work at their own pace. We have a beautiful little Facebook community where parents are connecting and sharing wins and sharing challenges and helping each other out. It's a respectful space. There's no judgment. And I also have a number of webinars online and I'm really excited, next year I'll be touring Australia with Harry Thompson, another fellow PDA-er from the UK and Raelene Dundon who is a clinical psychologist here in Australia who has practiced with children with a PDA profile. So we're doing a tour to get the word out there.

Debbie: That's awesome. Okay, so listeners, I will have links to all of Kristy's information on the show notes page so you can check that out. But um, oh my goodness. I just feel like there's so many things we could talk about. So we'll have to discuss a

part two. But I just really appreciate the work that you're doing on behalf of our kids and the way that you show up. I just, again, I think just following you on social media and, and your sharing of your own journey and your vulnerability and authenticity, I know that just reaches and connects with so many people and I'm just really grateful for you showing up that way.

Kristy:

Oh, thank you so much. And I am equally as grateful that people allow me the space, you know, that little pocket in their lives where I have the honor of being a part of their family journey and you know, in, in offering a support network, I've been given a beautiful, beautiful support network by literally thousands of people from all over the world. So I'm also really grateful and thank you so much for having me.

RESOURCES MENTIONED:

- Kristy Forbes' website InTune Pathways
- Kristy Forbes on Facebook
- A Conversation with Dr. Melissa Neff About Pathological Demand Avoidance (PDA) (podcast)
- In Tune Families (12-week program)
- Kristy Forbes on Instagram
- Harry Thompson