

SEN

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A tipping point for PDA?

Sally Russell looks at the shift in the diagnosis of pathological demand avoidance

It takes time for ideas to spread and when it comes to understanding of medical conditions, this is a good thing. Reasoning needs to be robust and sit well with the clinicians' experiences. More importantly, evidence needs to be explored, data tested and replicability confirmed before professional leaders detail protocols.

In the field of neuro-diversity, diagnosis places labels on clusters of traits and replicability is ensured through use of particular tests that have been rigorously researched. These are combined with observations and developmental histories along with a dose of professional judgement. The purpose of diagnosis (apart from allowing financial resources to be made available) is to further understand the individual, their specific needs and any requirements for support. These days therefore, the diagnostic label is only one part of the process which seeks to give a more helpful and holistic assessment.

This leads to a question: how can clinicians deal with new ideas in an ever-developing field, when at the same time being constrained by a need to work with evidence that may be some years old?

A developing understanding

Pathological demand avoidance (PDA) is one such new condition that has come to prominence in the past few years. Professor Newson first described PDA in the 1980s as a pervasive developmental disorder and sitting alongside Asperger's syndrome and classic autism (Newson et al. 2003),

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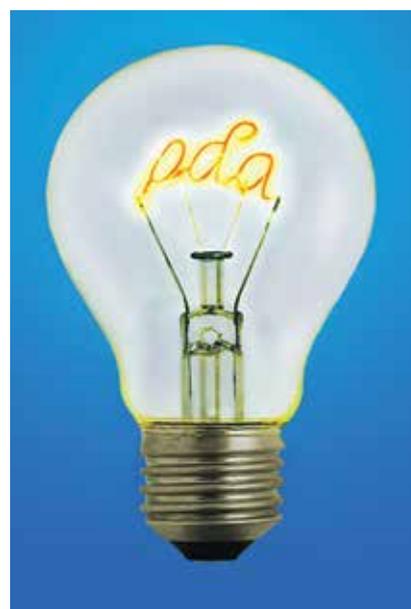
but changes in terminology have led PDA now to be considered part of the family of autism spectrum disorders or conditions (ASD/ASC). Those with the condition have traits in common with others with autism, but there are a number of differences, the key one being an anxiety-led need to avoid everyday demands.

Although identified in the 1980s, it has taken time for further research to be funded and although it is now going on apace it will still take time for all the data to be in. In the meantime, the diagnostic tool known as "internet search engines", has led families, schools, specialist teachers, therapists and so on to look at the early research, combine it with the anecdotal evidence and draw their own conclusions.

A recent survey of 52 professionals by the PDA Society (2016) showed that half of the clinicians who were responsible for diagnosing ASD were prepared to diagnose PDA. Those who didn't do so contend that further research is needed or that differentiation of sub-groups of disorders within ASD is unnecessary.

Experience counts

In addition to a lack of detailed research evidence, there are a number of issues



making this a difficult area for clinicians. The condition is relatively rare with perhaps only one in 25 of the most complex cases of ASD being described as PDA; what's more, the strong desire to avoid demands is quite common as a trait amongst other autistic people, and indeed those with conduct disorders. This means that even the most experienced clinicians probably haven't seen very many young people who they would describe as having PDA, and they may have seen rather more individuals who exhibit demand avoidance which has other causes at its root.

At the same time, the experience of parents and schools is that, for those with the condition, knowledge of PDA gives a clearer understanding of what is driving behaviour and how to manage it. Differentiated strategies use techniques that would not normally

be used for others with ASD, such as using negotiation, flexibility and variety. In the eyes of practitioners and families, the success of management techniques confirms their “search engine diagnosis”, and has left many wondering why clinicians aren’t keeping up.

The application of the medical model

We are in an imperfect and changing world, with unfinished research. So where does all that leave clinicians, where all their training and practice is defined by a medical model with diagnosis sitting within the DSM or ICD frameworks?

In fact, even within the boundaries set by those frameworks, individuals may adopt different approaches, colloquially termed “lumping” and “splitting”. Lumpers will use a more general diagnostic term and still hopefully consider needs within that and “splitters” may provide a more differentiated diagnosis. But whichever approach is used, all agree that the key is to focus on the problem that is causing most difficulty and for the diagnosis to highlight it so appropriate resources may be brought to bear. Underlying this is the need for “profiling” which makes sense when working with neuro-diversity, and also leads to the view that diagnoses aren’t necessarily life-long descriptors, but can change over time.

It can be argued that this sort of innate flexibility also allows for PDA as a type of ASD to be recognised more explicitly, while not undermining the role of the diagnostic manuals. Would this be considered a minor adaptation of the medical model? If so, it would seem to be helpful in coping with the ever increasing pace of change while not forgoing the importance of detailed research in the longer term.

A tipping point

It should not be the case that every “new condition” is integrated in this way, but with PDA there is an increasing body

Detailed research is essential to ensure replicability and clarify details

of evidence available. PDA is already a common topic of conversation in ASD professional meetings across the country. There are books published, educational guidelines in place, expert groups established, and schools and charities focussed on PDA. It is widely recognised by speech and language therapists and outreach workers. Indeed, it appears that we are reaching a tipping point, with increasing numbers seeking training; more than 1,800 professionals, including diagnostic teams, will have been trained this year alone by Phil Christie, a national expert who has worked on PDA since those early years with Newson.

Nevertheless, the PDA Society (2016) study showed that two-thirds of the professionals surveyed may give incorrect management advice to families and were not aware of the most recent research. More than anything, this shows that it isn’t simply a paucity of research that is creating barriers, but also simply the slow spread of the work that has already been done.

Gillberg (2014) explained that “PDA is already a very real clinical problem... It is one of the most ‘difficult to treat’ constellations of problems in the whole of child and adolescent psychiatry. Strategies developed for ASD, ODD and ADHD are often ineffective and parents, teachers and clinicians may be driven half crazy by the child’s stubborn refusal to cooperate and by avoidant... behaviours”. As a result it needs all hands on deck. It is to be hoped that more clinicians will look at this area carefully and consider how they can best help parents and young people come to terms with their needs and find appropriate solutions through the marrying up of profiling and diagnosis.

The spread of ideas takes time, and this is necessarily so. Detailed research is essential to ensure replicability and clarify details. But as we wait for this to come through, young people still need support. Understanding what that support looks like, why it is different, and being able to explain it to others, is leading clinicians into a slightly uncomfortable but necessary interim position without standardised terminology. But of course, from the autistic person’s perspective, it isn’t the standardisation of terminology that counts, it is simply about everyone understanding how they can help. **SEN**

References

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Further information

Sally Russell OBE co-founded the charity Netmums and is a former Chair of the Institute of Health Visiting.

She is now a carer and a volunteer with the PDA Society.

Information on PDA and the Society’s updated *Reference Guide for Practitioners* can be found at: www.pdasociety.org.uk