Autism Learns

Online learning for parents, carers and professionals

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Navigating the CAMHS Minefield

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Aim

* To explore why it can be difficult to access an assessment for the PDA profile
* To consider possible difficulties/obstacles and how to overcome them
* What you can do to prepare for the diagnostic process

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Acceptance of PDA as a specific behaviour profile

* Perhaps a more accurate title for this slide might be 'lack of acceptance' rather than 'acceptance'
* Addressing the elephant in the room – PDA remains a highly controversial topic
* Not every professional in a CAMHS context will (a) have heard of it or (b) accept it as a valid description
* There have been a number of challenges to its specificity and validity as a stand-alone concept

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Acceptance of PDA as a specific behaviour profile

* Although there is growing evidence about PDA, a strong social media support network and the 'lightbulb' moment that so many parents and individuals recognise when they first read about PDA, the fact remains that it does not appear in the 'diagnostic manuals' (These are the DSM 5 and the forthcoming ICD-11)
* It is also a fair critique that currently there are no absolutely clear, and agreed diagnostic guidelines for PDA.

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Acceptance of PDA as a specific behaviour profile

* Although many people now accept the term PDA and it has become a recognised identity for many, some clinicians continue to object to the use of the term 'pathological' as they feel the term is not helpful or fair on either children or adults
* Whilst some areas across the country are happy to acknowledge PDA, many are not, although they may be happy to identify 'demand avoidance' or 'extreme demand avoidance' as part of a diagnostic formulation.

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Not all demand avoidance is PDA

* Some of the types of behaviour challenge seen in individuals with the PDA profile (rapid mood swings, 'meltdowns' reluctance to follow guidance and instruction, high levels of anxiety and strong need for control etc.) are also seen in other conditions, which some clinicians might be more familiar with. It is important not to forget that in terms of absolute numbers, the PDA profile is relatively rare and some clinicians may not have come across it before.

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Waiting lists and referral routes

* Another reason why it can be challenging to access a diagnosis is because areas vary in the ways they deal with referrals. Some have dedicated Autism teams, some have neurodevelopmental teams, some areas have a pathway through the Child Paediatric service.
* Many teams will only accept a referral if this is supported by the child's school

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Waiting lists and referral routes

* On occasions where the child's school does not see any problems, it can be difficult or even impossible to access a referral for a specialist assessment.
* This is not helpful and more people need to understand the concept of 'masking' or 'camouflage'
* If problems are not seen at school, it can often be assumed that there must be a 'parenting' issue and parents may be offered a parenting course

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Waiting lists and referral routes

* There is also the sad fact that many teams across the country were unable to carry out face-to-face assessments during the COVID-19 pandemic and now face a huge backlog of referrals that need to be processed and children and adults who need to be seen for assessment.

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So – how can some of these obstacles be overcome?

* Barrier one:

  'PDA doesn't exist, it is not in the manuals and this trust does not recognise it'

* PDA may not be in the manuals, but 'demand avoidance' can certainly (and should certainly) be acknowledged in any diagnostic assessment, especially if it occurs to the extent that it significantly interferes with the child's wellbeing and his or her family's functioning.

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So – how can some of these obstacles be overcome?

* Try not to be too hung up on the name if you live in an area that is less familiar with the concept of PDA, but do insist that extreme avoidance of demands can be a 'red flag' which needs investigating, acknowledgement and inclusion in any diagnostic report.

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So – how can some of these obstacles be overcome?

- Barrier Two:
- 'There are no clear guidelines for diagnosing the PDA profile'
- Whilst this is currently true, these are being worked on and in the meantime, the PDA society website has a good summary of the key features.

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So – how can some of these obstacles be overcome?

Barrier Three:

'My child is said to be 'fine in school' and they will not support a referral to CAMHS'

- This is a worry – both that so many CAMHS teams refuse to accept a referral that is not supported by school and also because with all due respect, school staff are not clinicians or necessarily experts in the area.

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So – how can some of these obstacles be overcome?

As a first step, try to make an appointment with the SENCO or a senior person within the school and take information with you (again from the PDA society) about 'masking'. Point out that there is lots of emerging evidence about this, particularly in relation to Autism.

If this fails, point out the NICE guidance recommends gathering information from a third party. However, this does NOT have to be school.

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Preparing for a diagnostic assessment

* Gather together any previous reports that have been prepared about your child (if you have dozens, a brief summary of each might be helpful)
* Look out your child's 'red book'. You will be asked about early milestones and what your child was like as an infant. None of the questions are deal breakers, so do not panic if you can't remember exact details. The assessors will be most interested in the general developmental profile of your child.

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Preparing for a diagnostic assessment

* The primary focus of the assessment is likely to be Autism (very few places will assess specifically for the PDA profile), so, to help the process it can be useful to think about how your child meets the diagnostic criteria for Autism first.

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Preparing for a diagnostic assessment

* Taking each part of the DSM 5 criteria for Autism you can see what kind of examples you might need to provide:

A Social communication and interaction

* Social and Emotional reciprocity:
  * Can your child engage in a two-way conversation? Do they interrupt or talk over other people? Can they listen to others and empathise with another's point of view. Can they 'read' when someone is bored or wants to move on to a new topic of conversation?

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Preparing for a diagnostic assessment

* Non-verbal communication:
  * Does your child struggle to interpret tone of voice and facial expression? Do they use gestures and eye contact appropriately (note – some children over-use gestures or use exaggerated, copied gestures)

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Preparing for a diagnostic assessment

* Developing, maintaining and understanding relationships:
  * Does your child struggle to make and maintain friendships? How do play dates go? Is your child over-controlling of others? Do games have to be played their way? Does your child have a tendency to become obsessed by certain people?

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Preparing for a diagnostic assessment

B **Restrictive, repetitive patterns of behaviour, activities or interests**

* Stereotyped and repetitive behaviours
  * Have you noted any repetitive behaviour? Lining things up, or repetitive movements (stims)
  * How does/did your child play with toys?

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Preparing for a diagnostic assessment

* Insistence on sameness and routine:
  * Does your child prefer a routine? (in a child with the PDA profile, this can often manifest as the child wanting to set their own routine and do things their own way, but it's still a need for sameness and control over the environment)
  * How do they respond to unexpected change or manage transitions?

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Preparing for a diagnostic assessment

- Highly Restricted or fixated interests:
  - Does your child become fixated on certain topics or activities (more than other children of the same age). Does this lead to them talking about them all of the time and being insistent upon having/doing certain things?
  - In the PDA profile, many children become fixated upon a particular person, rather than an activity.

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Preparing for a diagnostic assessment

- Hypo- or hyper-reactivity to sensory input?
  - This includes the usual senses such as taste, touch, smell and hearing but also proprioception (knowing where the body is in space) and interoception (the perception of feelings and bodily sensations).

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Preparing for a diagnostic assessment

* If you wish to explore the PDA profile, it might be helpful to print off the key features and provide examples for the assessors of how your child fits the profile.
* Try if possible to avoid videoing your child in a meltdown – everyone knows what a child having a meltdown looks like and all they will see is a child in distress. Explain how a meltdown happens and tell the assessor what the triggers are and how long they last.

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Preparing for a diagnostic assessment

* A note of caution – although it is hard if you feel you are being judged or disbelieved, it is helpful to try and remain factual and calm.
* If someone tries to suggest that your child has a Reactive Attachment Disorder, ask for evidence of where exactly they feel the child experienced early neglect or trauma.
* If your child is the 'masker of all maskers' and the assessors claim not to see any problem, once again point out the literature that provides support for your case.

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Final thoughts

* Demand avoidance is a human construct – everyone avoids demands they don't want to comply with or are not interested in
* The challenge is to help people understand that the type of difficulties experienced by children and adults with the PDA profile goes beyond simply not wanting to put your shoes on, or not going to school

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Final thoughts

* When I mentioned earlier that perhaps it is best not to get too hung up on what CAMHS teams call the PDA profile, this was mainly because ultimately, the main purpose of any assessment is to secure the understanding and support that a child or adult needs. That does not mean that it is not important to continue to work towards a better and shared understanding with multiple professional groups of exactly what the PDA profile is.

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Final thoughts

* I know from having worked with so many families and young people, just how debilitating PDA can be, how often it leads to misunderstanding and the impact this has on the young person's self-esteem and identity.
* I have witnessed the trauma and mis-diagnosis that occurs when young adults with the PDA profile find themselves in inpatient or adult services (who often have even less understanding than the CAMHS services)
* Happily there are people out there spreading the word and continuing to gather information for research purposes.

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Any Questions

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