

# Research into PDA Factsheet

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## **1. EXPLORING THE BEHAVIOURAL PROFILE IN PDA**

Research into PDA is currently in its infancy. To date, we have conducted a questionnaire study looking at behaviour in PDA, before we start projects to examine what is driving behaviour. We collected information on questionnaires measuring autistic like traits, social interaction problems, difficult behaviour and anxiety from parents of 40 children with PDA (8 females, 32 males) aged 9–16 (O’Nions et al., in preparation).

The new data we collected from parents of children with PDA were compared to data from over 5,000 12-year-old children from an existing database of children representative of the general population. This allowed us to examine how severe are the difficulties in PDA compared to the levels of these behaviours seen throughout the population.

Within our existing database, 39 children had an Autism Spectrum Disorder (ASD) diagnosis, and 28 had very high levels of “conduct problems” (CP), behaviours associated with “oppositional-defiant disorder” (ODD) and “conduct disorder” such as impulsivity, aggression, and a tendency to lie or cheat.

We compared our new data from parents of children with PDA to these other clinical groups to see how the behavioural profiles differed. The four children in our database who had high levels of conduct problems plus an autism spectrum disorder were left out, as we thought they may resemble PDA.

### **Co-morbidities associated with PDA:**

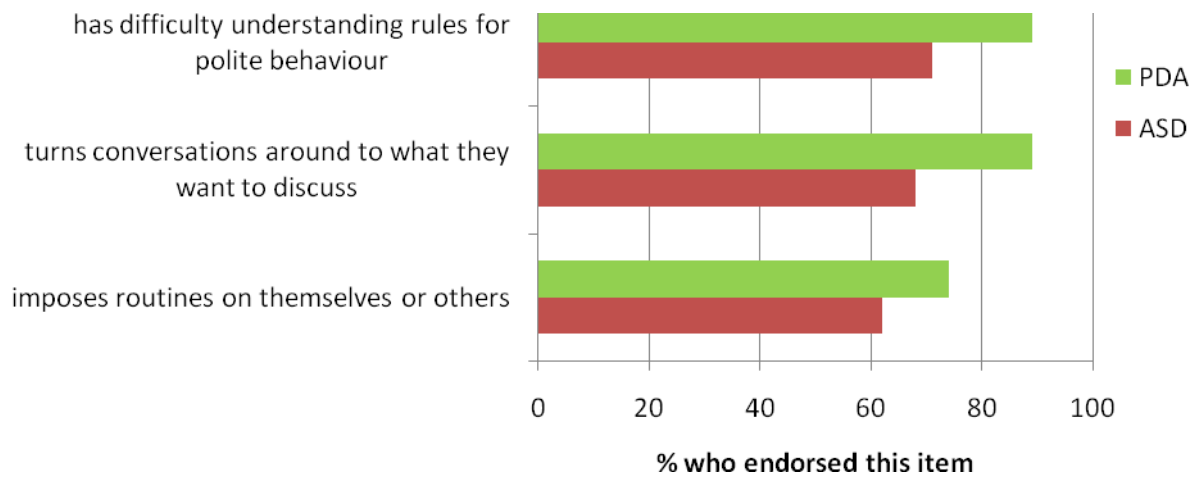
32 parents provided information about the co-morbidities of their children with PDA. This list does not include the number who reported autism as a co-morbidity, as this was often part of the PDA diagnosis (e.g. “atypical autism with a PDA profile”), and may not have referred to the presence of behaviour more typical of ASD than PDA.

Notably, one individual had an Interstitial Duplication on Chromosome 15, a genetic disorder associated with autism.

<b>Disorder</b>	<b>Count with co-morbidity</b>
<b>ADHD</b>	6
<b>Asperger</b>	5
<b>Anxiety problems</b>	5
<b>Sensory processing disorder</b>	3
<b>Mild learning difficulties</b>	2
<b>Dyslexia</b>	2
<b>ODD</b>	1
<b>Tourettes</b>	1
<b>Interstitial Duplication Chromosome 15</b>	1
<b>Epilepsy</b>	1
<b>Severe learning difficulties</b>	1

### **Behavioural profile in PDA: Autistic like traits**

We used the Childhood Autism Spectrum Test (“CAST”, Scott et al., 2002) (for an updated version of this questionnaire, see [http://www.autismresearchcentre.com/tests/cast\\_test.asp](http://www.autismresearchcentre.com/tests/cast_test.asp)) to measure autistic like traits in our PDA group. Out of the 18 in the PDA group for whom we collected full data on the CAST, 14 had a high enough score to meet the “clinical cut off” for autism.



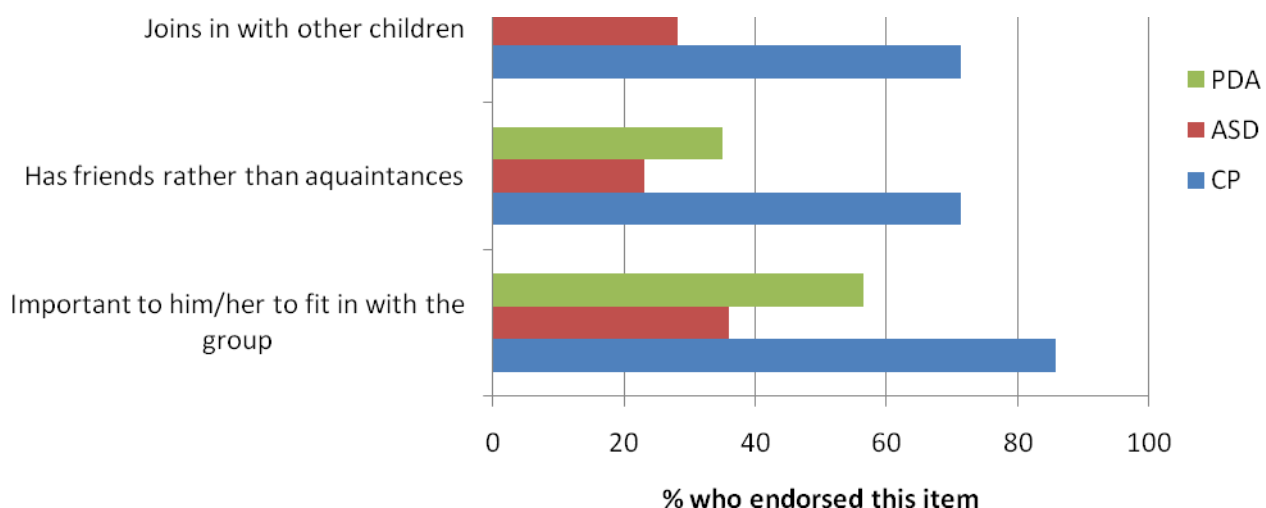
The figure above illustrates several items from the CAST that were more endorsed in PDA than in ASD. We speculated that parents of children with PDA may have had different reasons for endorsing the CAST items compared to parents of children with ASD.

For example, for the item “Doesn’t understand the rules for polite behaviour” may reflect social naivety in both PDA and ASD, but in PDA, it may partly reflect the child testing the tolerance of the person they are interacting with. Similarly, “turns conversations around to what they want to talk about” and “imposes routines on him/herself, or on others” may have reflected a need to be in control in PDA, but special interests and a need for routine in ASD. Children with PDA were reported to have better eye contact and conversational skills than children with ASD.

### **Behavioural profile in PDA: Social interaction problems**

We next compared our clinical groups on items reflecting difficulties with social interaction, such as finding it hard to interact with other children, or not caring about how they are viewed by peers. The social interaction problem items came from the CAST questionnaire and the Strengths and Difficulties Questionnaire (SDQ): (Goodman, 1997, [http://www.sdqinfo.org/py/doc/b3.py?language=Englishqz\(UK\)](http://www.sdqinfo.org/py/doc/b3.py?language=Englishqz(UK)))

Like children with autism, children with PDA were in the worst 1% of the population sample for difficulties with social interaction. As you can see from the endorsement rates for the following items, difficulties with social interaction were much more severe in children with PDA compared to children with conduct problems. This indicates that PDA is not just another term to describe children with conduct problems, but that problems with social interaction mark PDA out as separate, and may point to a different cause behind their behaviour problems.

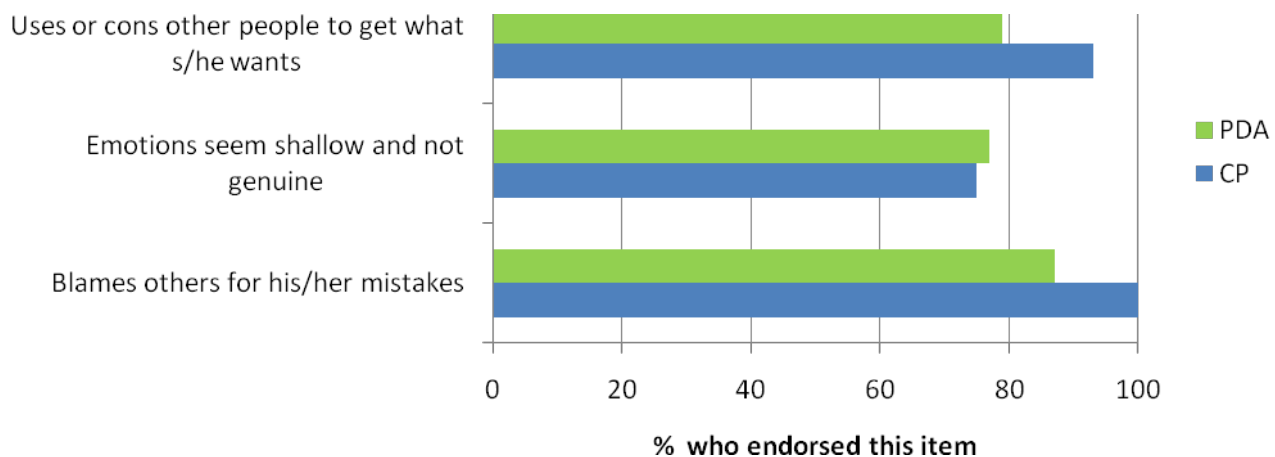


### **Behavioural profile in PDA: Difficult behaviour**

We next compared children with PDA to children with conduct problems in terms of the severity of their difficult behaviour, with items measuring impulsive behaviour, lying, temper tantrums, and poor

planning. The items that made up our difficult behaviour measure came from the SDQ, the Anti-social Process Screening Device (Frick and Hare, 2001), and the Conners parent rating scale (Conners, 2001).

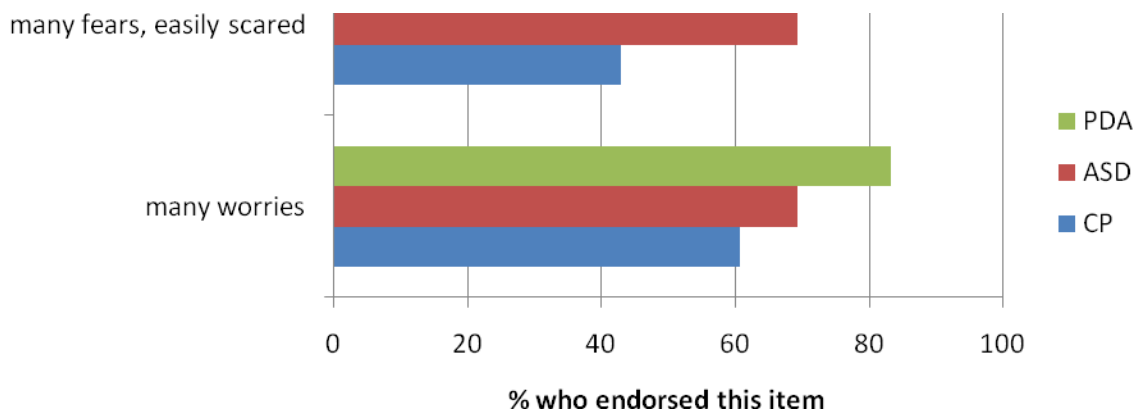
Both children with conduct problems and children with PDA scored in the worst 1% of the population cohort in terms of difficult behaviour. The figure below illustrates comparable endorsement rates for several items that formed part of the difficult behaviour composite measure (counting the item as “endorsed” if parents responded “somewhat true” or “very true”).



Again, we suspect that parents may have been reporting on behaviour that was slightly different in the different groups. For example, for the item “Uses or cons others to get what s/he wants”, the word cons was sometimes crossed out by parents in the PDA group, as if “cons” implied more pre-meditation and underplayed the compulsive element of the behaviour in PDA.

### **Behavioural profile in PDA: Anxiety**

Based on the above findings, it might be tempting to conclude that PDA should be viewed as a “double hit”: an ASD accompanied by personality traits associated with conduct problems. However, the PDA group had higher levels of parent rated anxiety (measured using the SDQ anxiety items) than both ASD and CP groups, and were in the top 2% for anxiety across the population sample. The figure below illustrates the endorsement rates for anxiety items in PDA compared to both ASD and CP groups.



### **To summarise:**

Children with PDA resemble those with ASD on questionnaire measures of autistic like traits and social interaction problems, and resemble those with conduct problems in terms of difficult behaviour. Research using experimental tasks to measure the underlying causes of behaviour (e.g. “Theory of Mind” stories that measure awareness of others’ points of view) is needed to establish whether there really is continuity between ASD and PDA.

Of particular note is the severity of difficulties experienced by children with PDA, in a variety of areas, translating to an imperative for access to appropriate support. Children with PDA were in the worst 2% of

the population for all of the aspects of behaviour described above (autistic like difficulties, social interaction problems, difficult behaviour and anxiety).

## **2. UNDERSTANDING WHAT CAUSES PDA: How heritable are PDA related traits?**

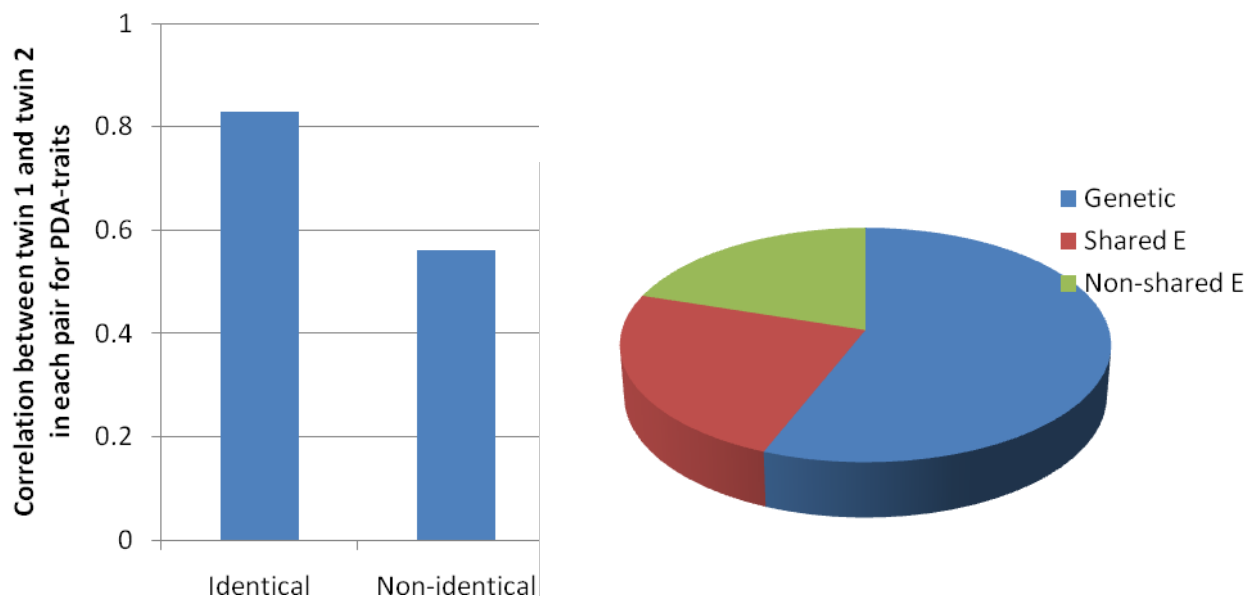
For most disorders, it is thought that both genetic factors and environmental influences play a role in the developmental pathway. For example, in ASD, a gene may cause disruptions in brain development, which translate to problems understanding things from others' perspectives (impaired "Theory of Mind").

However, environmental factors can impact on how severe the difficulties are. These could be biological factors, familial environments or events and experiences outside the family. For example, if parents are very supportive and provide opportunities for the child to learn compensatory strategies, children with ASD may get better at working out others' perspectives than they otherwise would have been.

Neuro-developmental disorders such as autism are considered to be among the most heritable of all disorders. Researchers came to this conclusion by studying twins. Just as identical twins, who are 100% genetically identical, look physically more similar to each other compared to non-identical twins; identical twins also resemble each other more in terms of autistic traits compared to non-identical twins. This suggests autism (as well as physical appearance) is heavily influenced by genes.

To explore the heritability of PDA related traits, we used data from twins who took part in the Twins Early Development Study (TEDS, <http://www.teds.ac.uk/>), a study conducted with twins born in the UK between 1994 and 1996. Here, instead of using twins who had PDA (who are probably extremely rare), we used typically developing twins, and looked at how heritable the behaviours associated with PDA are. We also looked just at twins who had high levels behaviours characteristic of PDA, and found similar results. We measured PDA traits using a composite measure of questions from the database that matched the diagnostic criteria for PDA very well.

If PDA related traits are heritable, we expected greater similarity on our PDA measure for twin 1 and twin 2 in an identical pair, compared to twin 1 and twin 2 in a non-identical pair. The findings suggest that PDA related traits are substantially influenced by genes. Scores for twin 1 and twin 2 in identical pairs were much more similar to each other than for non-identical pairs (reflected in the higher correlation in the figure below). However, both shared environment and non-shared environment also have a role to play, suggesting that there is room for educational interventions and support to have a beneficial effect.



### **Summary**

Though research into PDA is still in its infancy, we hope to make progress towards answering questions about what is driving difficult behaviour in PDA in the future, as well as developing tools to help

clinicians identify it. Research is necessary to raise awareness of PDA among clinicians, and promote better provision for those diagnosed with PDA.

If you are interested in participating in further research, please follow the link to the new questionnaire and information sheet about the study. The aim of this new project is to develop a questionnaire purpose built to measure PDA behaviours, which could in the future be used by clinicians and researchers to help identify PDA. To do this, we need to see how children (aged 6–17) with PDA, children with another diagnosis, and children with no disorder score on it.

Information sheet:

[http://www.iop.kcl.ac.uk/iopweb/blob/downloads/locator/I\\_10\\_Parent\\_information\\_sheet-FINAL-electronic.txt](http://www.iop.kcl.ac.uk/iopweb/blob/downloads/locator/I_10_Parent_information_sheet-FINAL-electronic.txt)

Questionnaire:

[http://www.iop.kcl.ac.uk/iopweb/blob/downloads/locator/I\\_10\\_Parent\\_questionnaire\\_EDAQ\\_black\\_white.doc](http://www.iop.kcl.ac.uk/iopweb/blob/downloads/locator/I_10_Parent_questionnaire_EDAQ_black_white.doc)

If you participated in the previous questionnaire study about PDA, you will notice the first few questions (from the Strengths and Difficulties Questionnaire) are the same. If you wouldn't mind filling them out again that would be really great!

### **Acknowledgements**

We are extremely grateful to all of the parents who participated in this research, or helped distribute questionnaires through parent support groups. Without their help, none of this research would have been possible. Margo Duncan's help has also been invaluable, and her information sheets have provided inspiration for some of the question items from the new measure. We are also very grateful to the clinicians who have helped with developing the questionnaire and other aspects of the project, particularly Phil Christie and also Dorinda Miller, Rukhsana Meherali, Lorna Wing, Judy Gould, Francesca Scanlon, Rosalyn Proops, Betsy Brua, Liz Savage & Jacqueline Morgan.

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