



Stronger Together



2015 Parent and Carer Conference





Introduction from Margo Duncan of The PDA Society

On September 23rd 2015 we held The PDA Society's first ever conference for parents and carers, in Northampton.

240 people came along and it was a great day. We are grateful for all the positive and kind feedback we have had since then. This booklet is both a reminder of the day but also includes the results of all the feedback we received before the conference where 138 people were kind enough to share their experiences of living with a child with PDA and to offer their own insight on the challenges, rewards and strategies that worked for them.

Our theme for the conference was “stronger together”. We hope that when you read this booklet you will realise that you are not alone and that with the support of others we can nurture our children, and ourselves, to be the best we can be.



The conference ran from 10am to 5pm. There were 4 main speakers and a range of 9 workshops for delegates to choose from. In whatever spare time was available the hotel kept us well watered and fed and delegates had the chance to browse a range of stalls, offering everything from books to sensory equipment.



Here's a summary of the day by Steph Curtis



PDA Society Conference;
Truly Inspiring!



Wow, wow, wow. Yesterday the [PDA Society](#) held their first ever conference for parents and carers of children with Pathological Demand Avoidance (PDA).

Over 240 adults attended, from all walks of life, but with one thing in common; the desire to learn and understand more about Pathological Demand Avoidance. The hugely positive feedback received by the team all day during and after the event suggests that the objective was achieved, and in style!

Lucy (my roomie) and I arrived the day before the event to help out, but to be honest everything had been organised so brilliantly, from the individualised planner check-in sheets, to the table plans (genius to try and group families from the same geographical areas together!), and down to the lovely finishing touches such as ribbons at every place setting, that we knew there wouldn't be any major problems on the day.

The conference kicked off with a slide show of PDA family pictures along to the music track by Kelly Clarkson - 'what doesn't kill you makes you Stronger'. The theme of the conference was 'Stronger Together'. Committee members came up with the great idea to provide paper chains on all tables; attendees were then asked to write on them anything which made them stronger. Examples such as family members, or coffee and biscuits were given - hubby of [Living Life Our Way](#) blog writer suggested 'days like these' which I thought summed the day up beautifully.

Founder member of the PDA Society, Margo Duncan, took to the stage to introduce the first speaker; Phil Christie, the man who worked with [Elizabeth Newson](#) and who knows all there is to know about PDA. His speech theme was the 'State of the Nation' and he talked through a short history of how we have got to this conference, followed by discussing where PDA sits under the banner of Pervasive Development Disorders* (now known as Autism Spectrum Disorders, although this is not a term which is in the manuals) and then onto looking at diagnostic criteria for PDA (listed here on the [PDA Society](#) website). He noted how the National Autistic Society has recently updated its information, agreeing that PDA is best understood as one of the Autism Spectrum Disorders. (*that diagram can be found in the list of extra resources [here](#) or on my last blog post discussing [PDA and ODD](#))

He was followed by a very positive presentation on Collaborative and Proactive Solutions by Dr Jo Clarke, who is apparently the only person in the UK who is trained and licensed to present [The Explosive Child](#) Strategies. I suspect she will be in huge demand for a long time to come!

Other speakers included Jane Sherwin, who wrote the book *My Daughter Is Not Naughty* and Neville Starnes, producer of the *Blue Millicent* videos which have helped so many. Both of these individuals are experts in PDA; I heard so many comments saying each of them was inspiring and that sharing their stories has really helped others. A special shout-out (did I really just use those words?!) from me to Max who appeared on the *Born Naughty* programme recently; I applauded her loudly for also sharing her story very publicly and it was such a pleasure to meet her finally. In between these speeches there were nine different workshops running during three different session times. They were: Resilience, De-escalation techniques, Education Law (thanks to the wonderful Evelyn Ashford), Sensory Issues, Siblings, Sleep, Working with schools (mainstream) and working with schools (specialist). From what I could see, nearly every session in every time slot was full, and I think thanks to some careful planning, most parents were able to see the ones they had the most interest in (resilience and de-escalation featuring highly at the top of people's lists!). At the end of the day, the 'Stronger Together' paper chains were linked together and a second video was shown, showing comments from people who wanted to thank others who had helped them along their PDA journey. The paper chains were then sent over heads from the front to the back of the room; an inspired touch which I know lots of attendees will remember for a long time.

Well done to the venue (Park Inn by Radisson in Northampton) which was another great choice; plenty of tea, coffee and snacks, delicious hot and cold buffet and the hotel conference staff were all very willing to help set up exactly as needed as well as deal with last minute matters quickly. All the committee names and those who helped to start the PDA Society (formerly PDA Contact Group) were mentioned in the video several times over, and all the speakers, but also others such as Jo Jones, Cathy May and ADD-vance, even CAHMS Doncaster which is pretty amazing! It's so good to hear that several professionals are already on board with PDA and after the conference I'm sure more will follow suit. 'It's so good to just be in a room with other parents who get it' is a phrase that has been repeated many times. It may sound dramatic but to not feel alone and to not have your parenting skills challenged but to have them accepted by so many others who understand and who are in the same position is actually life-changing. The whole event was so inspirational, especially considering the PDA Society is entirely made up of parents who are volunteers and who share the stresses of having children with PDA. I think we should give the team a few days rest before they are asked to start planning the next one..... Special thanks to the committee members who all worked so hard to make this the truly amazing day that it was.



Our pre-conference questionnaire

Before the 2015 conference 138 parents filled in an online survey to help us identify common themes amongst their personal and family experiences.

We asked questions both of a factual nature (e.g. age, gender, diagnosis) but also of a more subjective type (e.g. satisfaction with different services).

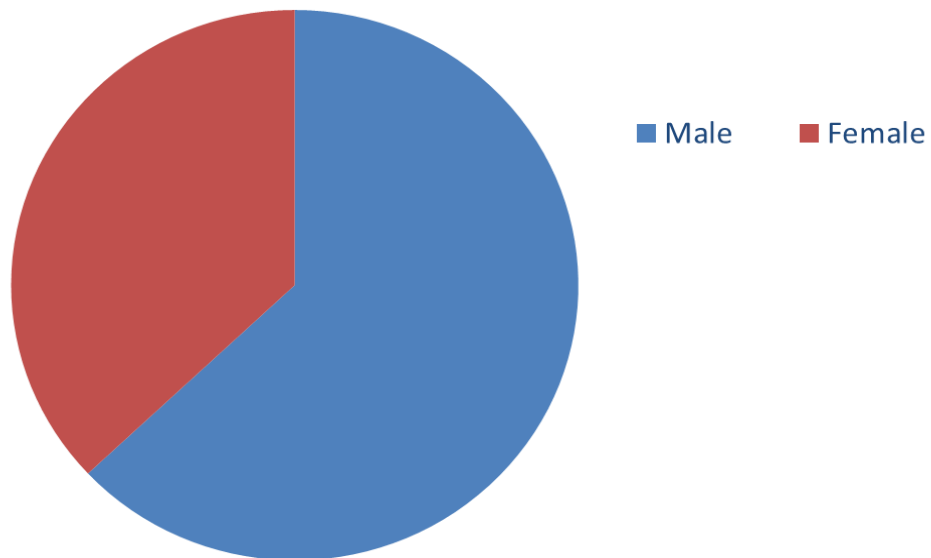
Thank you to everybody who took part and to Jasmine James who has analysed the information

We've analysed your responses and wanted to share our findings with you. All quotes are verbatim from parents. However any names have been removed.

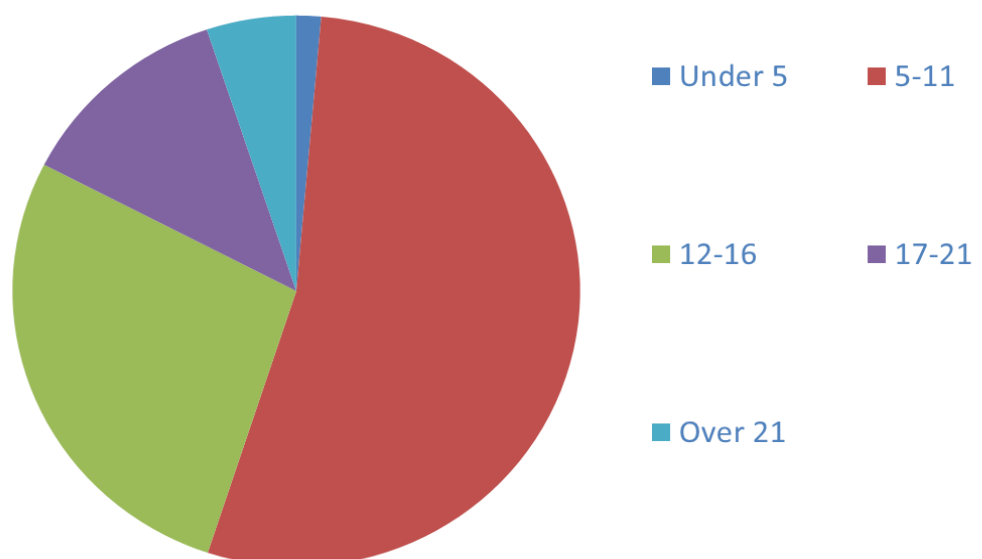
A separate report is available at www.pdasociety.org.uk that details all the advice shared by parents.

About the children and young people

Just under two thirds of the children represented were male

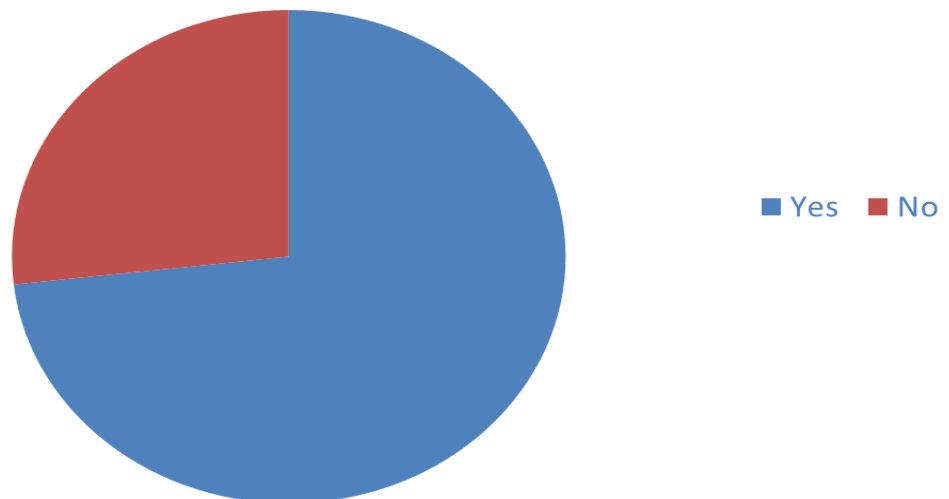


.. and most were of primary school age

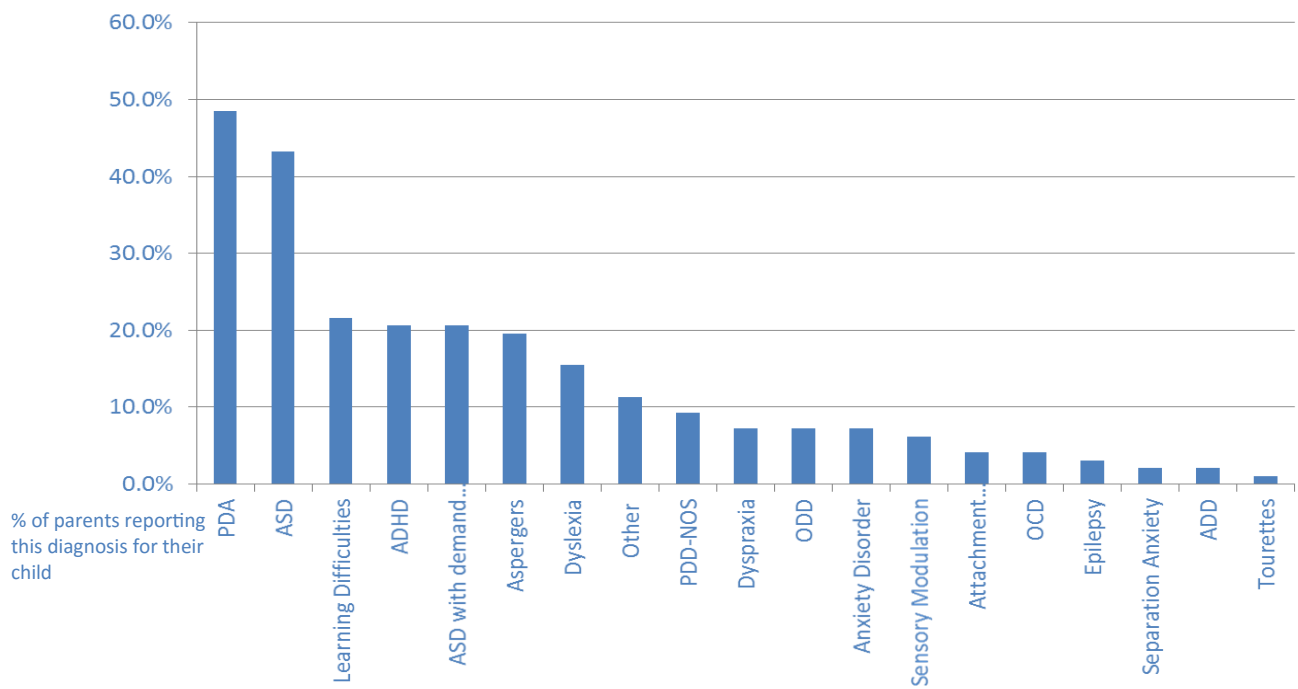


Diagnoses

Around three quarters of children had some formal diagnosis



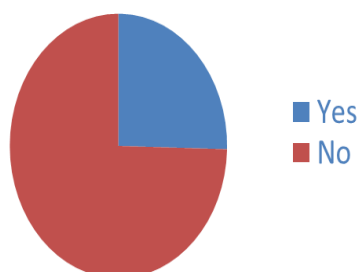
Parents reported a wide range of diagnoses having been given



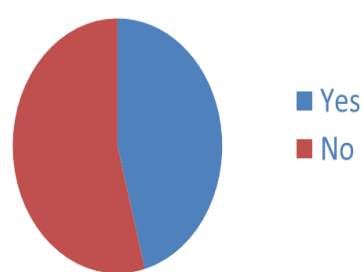
CAMHS

The majority of children do not currently receive CAMHS support but many have had it in the past

Does your child currently receive support from CAMHS?

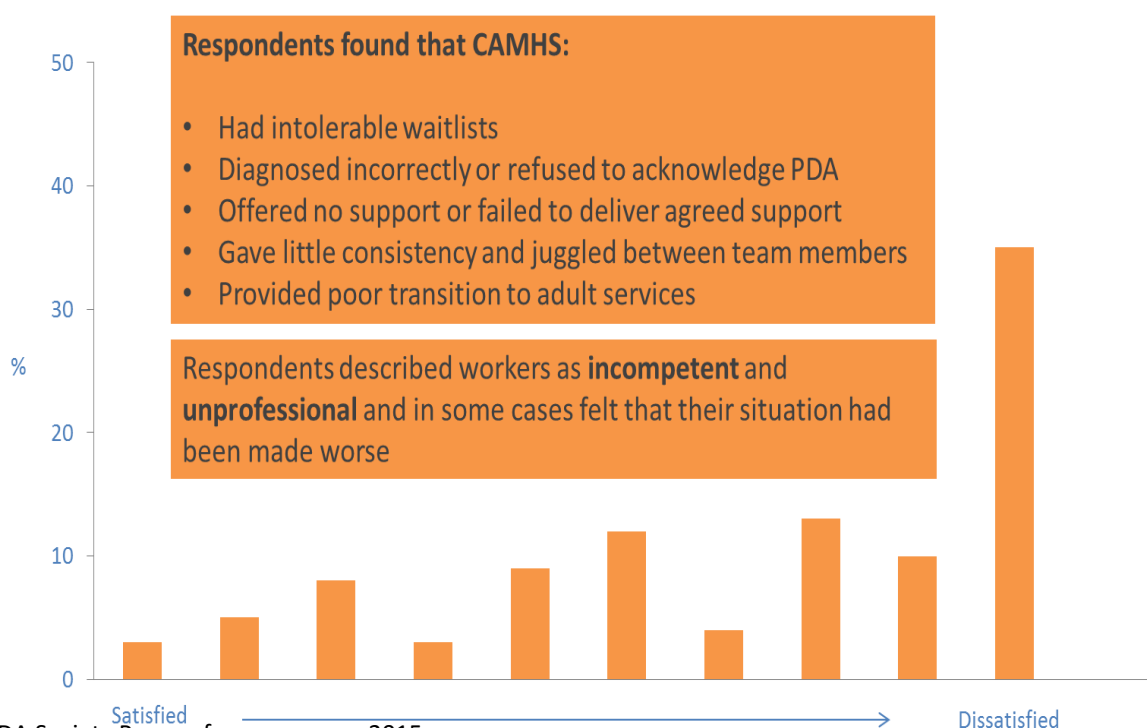


Has your child previously received help from CAMHS?



.. But many parents are extremely dissatisfied

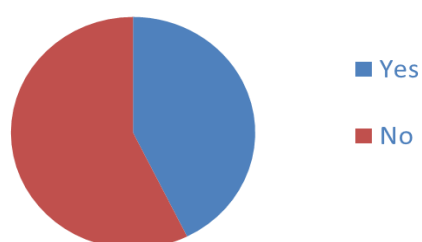
“the service is failing children all over the country”



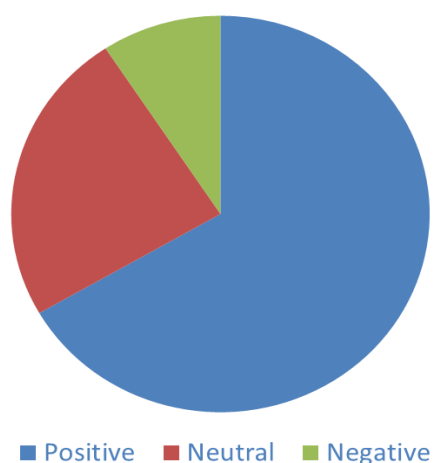
Medication

Just under half the children take regular medication and on the whole parents think it has made a difference

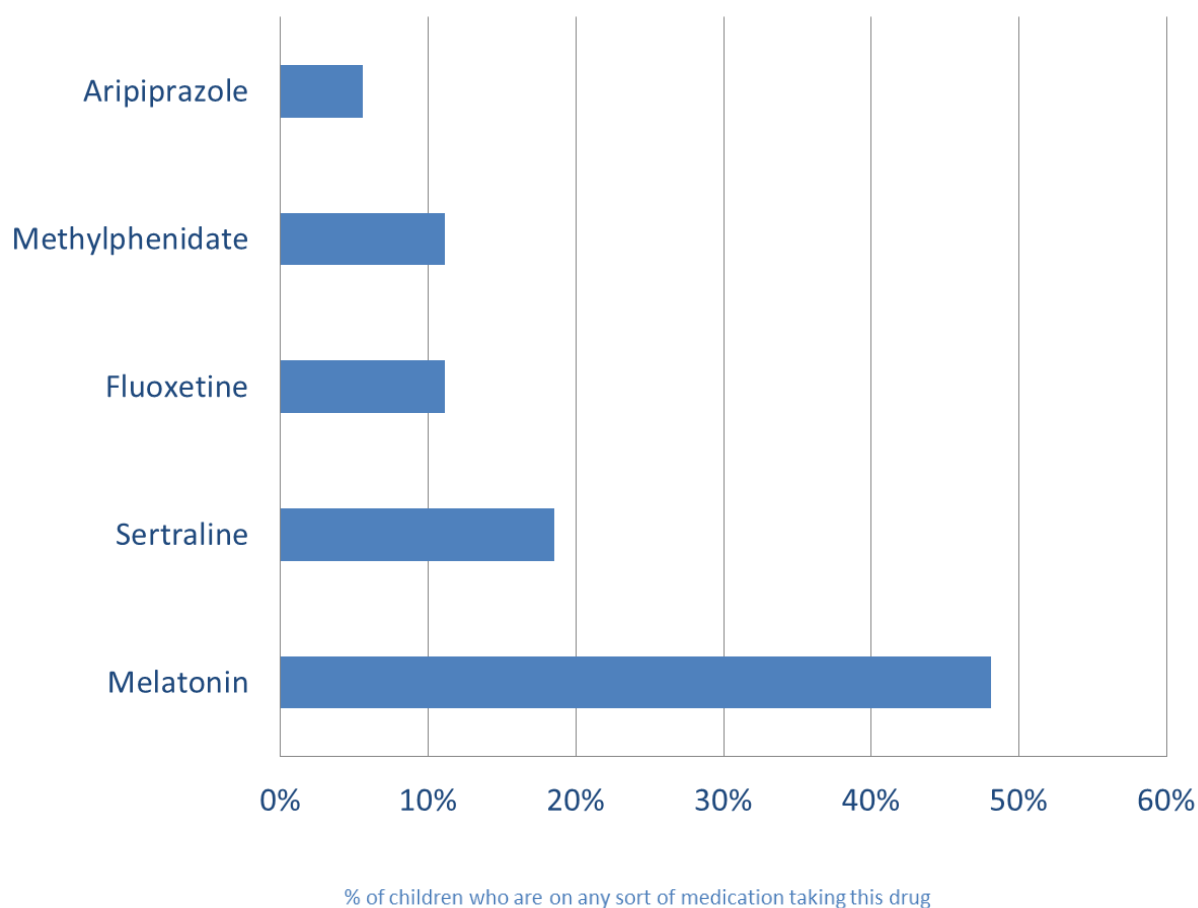
Does your child take any regular medication?



Do you think the medication has made a difference?



There are a small number of medications that are mentioned most frequently



Medication can transform bedtime

👍 Medication helps to calm my child and gives her a **deeper** and **longer** sleep, which helps my sleep too

👍 My child's mood and behaviour is improved because she is not sleep deprived

👍 Medication makes a huge difference in lowering anxiety, improving concentration and stifling anger and impulses

🗨️ My child is often non-compliant when it comes to taking his medication

🗨️ When my child is feeling particularly emotional then the medication has no effect

Z

Z

Z

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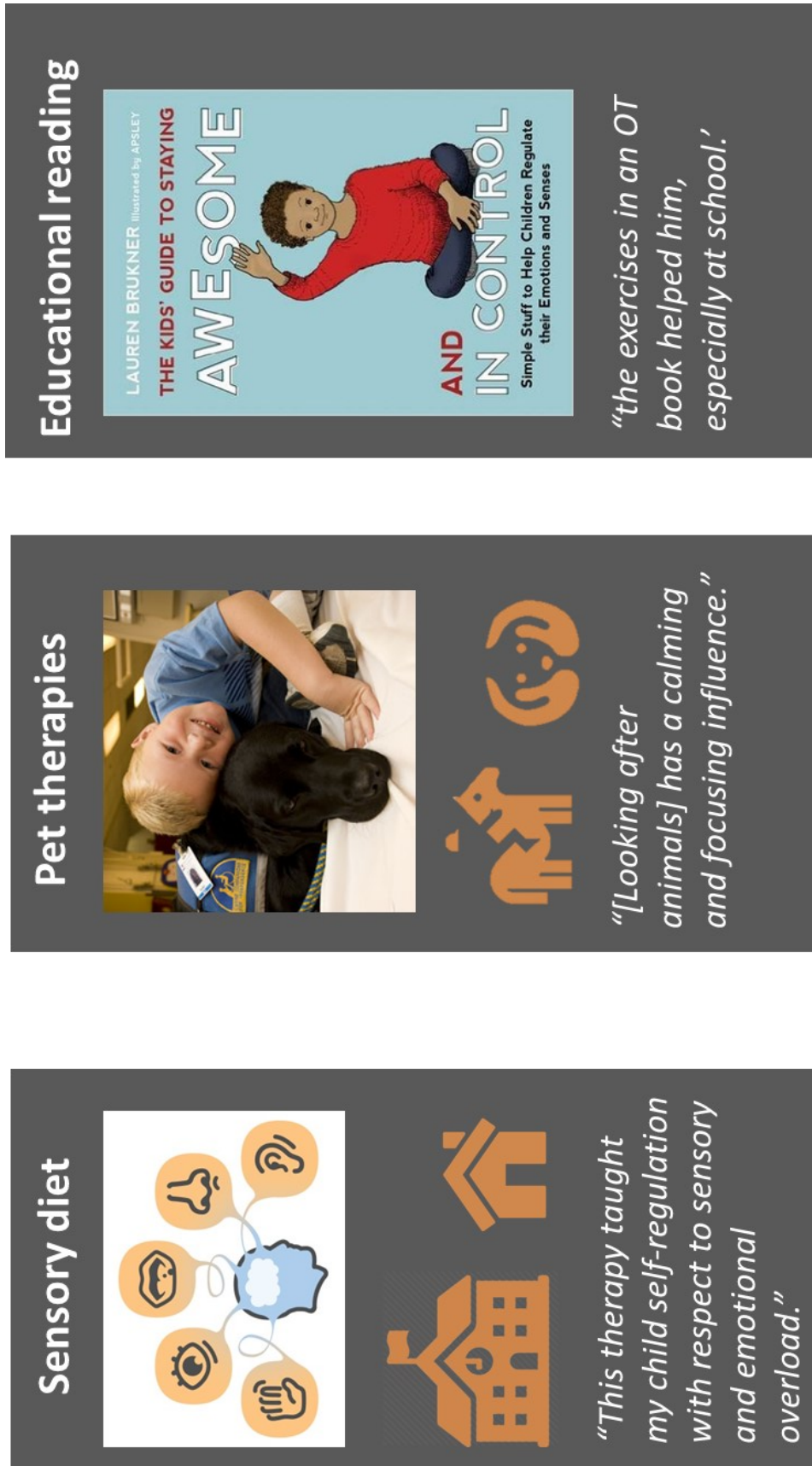
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Health

There are a number of other approaches that some parents say have been helpful



And some others mention these therapies positively

Cognitive behavioural therapy

CBT can be modified to address specific needs (e.g. "emotional literacy") before focusing on thoughts and behaviours

Music and art therapy

"helped with expression and communication"

Homeopathy

"helped enormously with anxiety and anger"

Occupational therapy

"OT greatly improved her gross and fine motor skills and balance"

Sleep clinic

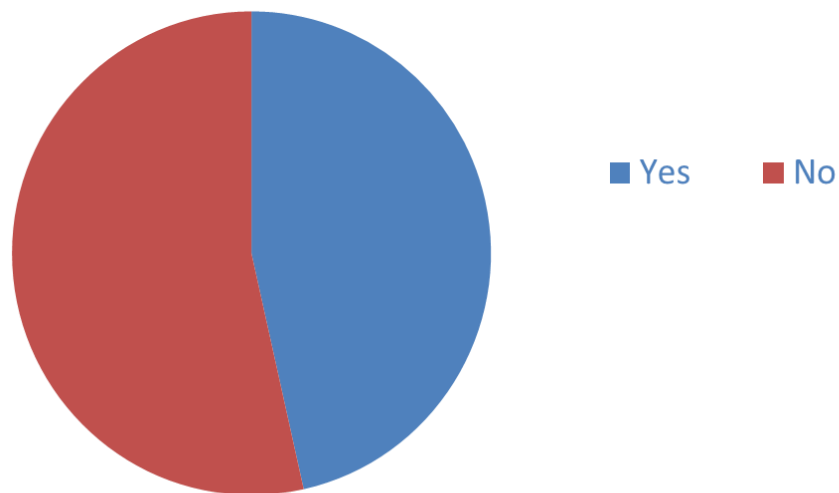
"teaches techniques to relax and fall asleep"

Integrated family support

"advised us of structures and boundaries and we still use these techniques – they were a big help"

Education

Just under half of children have a statement or EHC Plan

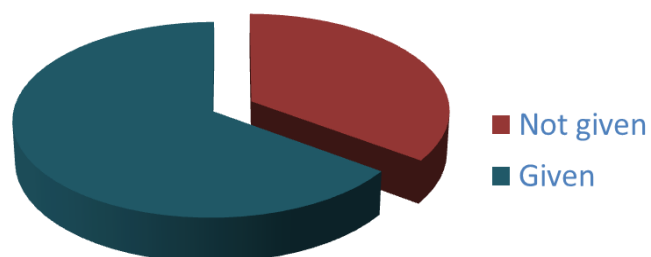


..but 35% have been refused a plan

The data showed that generally, schools are supportive when it comes to issuing Education, Health and Social Care plans or statements

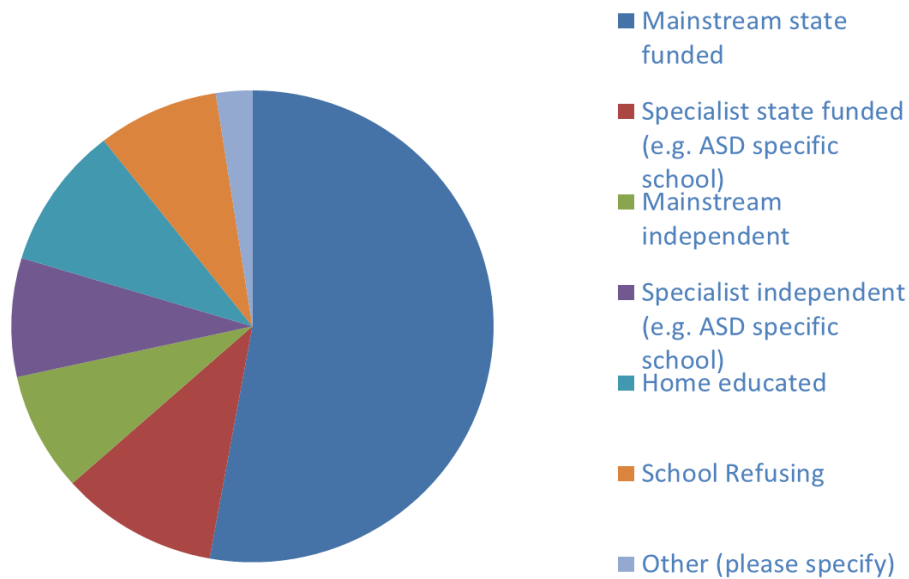
In the cases where a parent was denied a plan, the school:

- Said that the child was too intelligent
- Did not recognise PDA
- Required more evidence
- Considered themselves to be meeting the child's needs



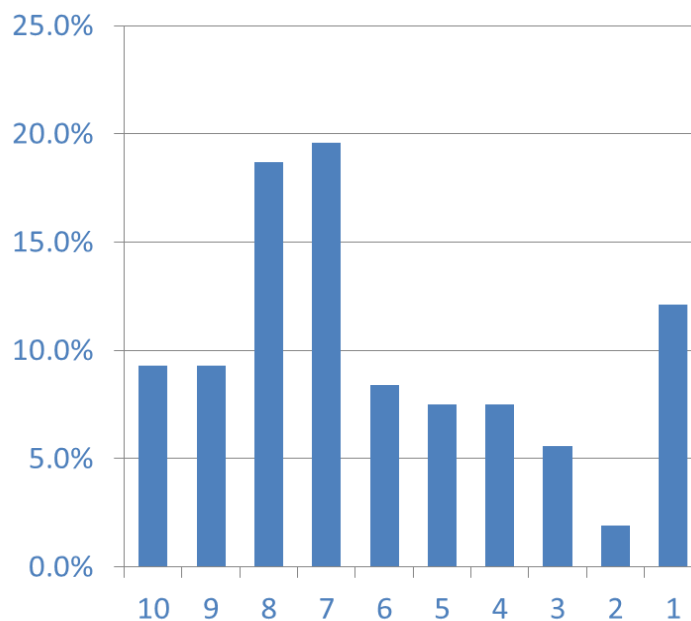
Children attend a wide variety of schools, with a significant majority home educated or refusing school

What type of school does your child attend?



Parental satisfaction is very varied

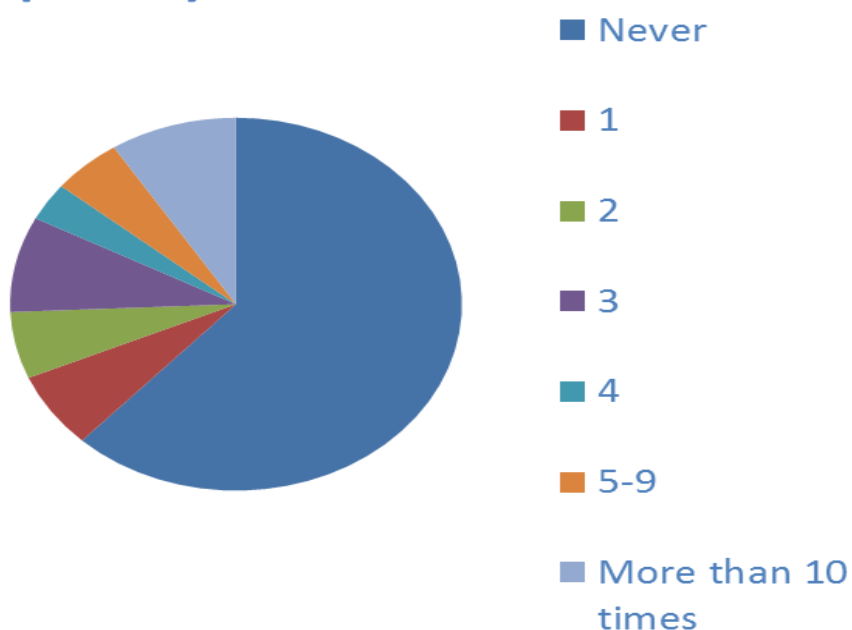
On a scale of 10-1 where 10 is highest and 1 is lowest please indicate your level of satisfaction with the educational provision made to your child in their current placement



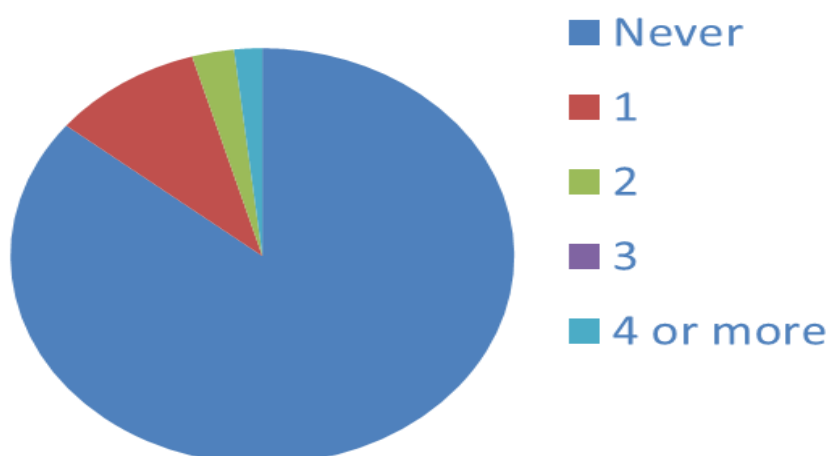
Education

A significant minority of children have experienced exclusions

Has your child ever been temporarily excluded from school?



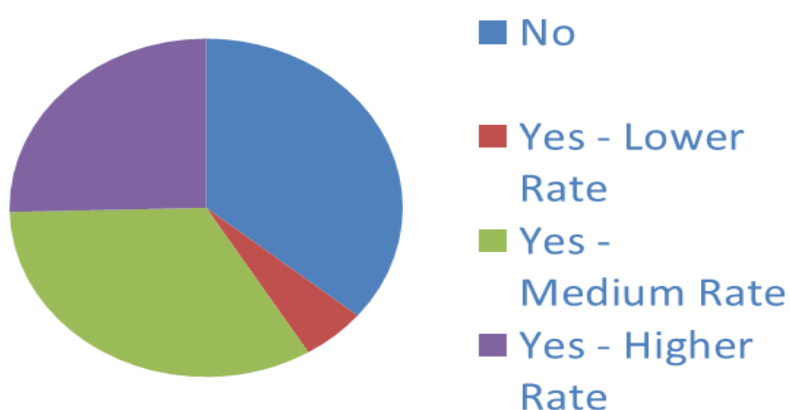
Has your child ever been permanently excluded from school?



Welfare Benefits

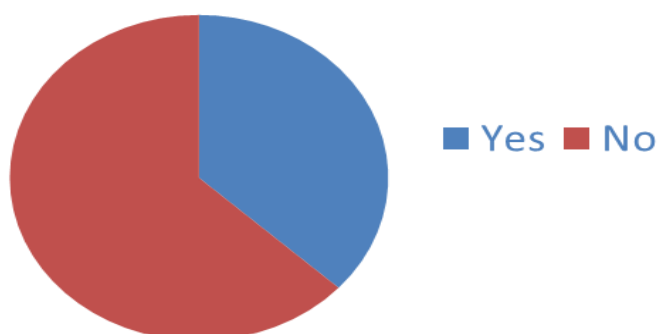
A majority of children receive other benefits

Does your child receive Disability Living Allowance (or Personal Independence Payment)?



..but a minority of parents/carers

Do you receive carers allowance?





We also asked some general questions on topics ranging from what you felt your greatest personal challenge was to what was the best piece of advice you have been given.

Turn to the next page for the key themes from your answers.

We asked what were the biggest challenges of being a parent of a child with PDA.

Here are the main ones.....

- A lack of recognition and understanding from professionals
- Having parenting skills doubted by others
- The constant fight for support
- The abandonment of career opportunities and personal time
- Dealing with the unpredictable symptoms of aggression, anxiety and meltdowns



Meet “Sarah” - a typical mum

Sarah’s son, Jack, has PDA

After waiting months for an initial CAMHS appointment, his symptoms were not recognised as a diagnosable disorder. Jack was not offered support nor recognised as special needs by his school



Having given up career opportunities to look after Jack, Sarah struggles to find the money to pay for his private therapy where he was finally diagnosed

On the outside, Sarah has to fight to be understood and defend her parenting skills to others

On the inside, Sarah feels **isolated**, **misunderstood**, and **frustrated**. Meanwhile, she struggles to find the patience to deal with Jack’s challenging behaviour and the enormous strain on family life

Can you relate to Sarah?

What advice would you give to Sarah?

Here are your top five....

1. You know your child best
2. Trust your instincts, pick your battles, and never blame yourself
3. Reduce and rephrase demands when tolerance is low
4. Start each day afresh - do not carry over negative attitudes
5. Never stop fighting for support, for your child and for yourself



And here are your top 5 rewards of being a parent.....

When they say they love us

Our strong bond and understanding my child like nobody else

Moments of progress and insight, however fleeting

**It makes the affection and positive moments even more
treasurable**

**Being able to share advice and
experiences with other parents**



Huge thanks to Paul Carroll for the photographs

www.paulcarrollphoto.com

