Towards a better understanding of Pathological Demand Avoidance

Danish Child Neuropsychological Society
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Professional tradition in…

- Developmental psychology
- Observation of child in play and natural contexts
- Criterion referenced assessment
- Parents as part of assessment team and experts on their own child
- Making clinical and research work accessible
- Assessment as starting point for educational and other interventions
- The importance of dialogue…with the child and the family

Background to Developments…

- **Diagnostic** and assessment service (Elizabeth Newson Centre)
- **Educational provision** in a specialist school for children with autism
- **Action Research** tradition and **collaboration** with other organisations
- Working closely with **families**
- Consultancy and training for schools and other organisations

Some Themes…

- An **evolving** understanding of PDA
- Recent research and clinical developments
- Implications for education, management and support
- Support needs of families
- Insights gained from young people with PDA
- Local Context
- Looking ahead

Outline of Presentation

- Historical and Recent Developments
- Pervasive Developmental Disorders, Autism Spectrum Disorders and distinctive diagnosis
- Defining Criteria
- Where next?
- Some implications for education and support

Some Key Milestones

- Original work by Elizabeth Newson (1980's)
- PDA contact group (1997)
- Archives of Diseases in Childhood (2003)
- GAP publication (2007)
- IOP research into PDA (2010 onwards)
- NAS conferences (2011 onwards)
- Jessica Kingsley publication (2011)
- National Autism Standards guidance (2012)
- PDA society (2014)
- Updating of NAS website(2015)

Some Key Drivers…

- **Increasing contact from parents and professionals 'recognising' child in written accounts**
- **Appreciation of different emphasis needed in educational approach**
- Requests for training, consultancy and support
- Contact from other clinicians and researchers
- More requests to confirm provisional diagnostic opinion
- Wider use of formulation by other professionals

I am a psychologist in Brisbane who specialises in the field of ASD. K… came to my attention early 2005…. I have seen her in her 3 different schools and at home with her siblings… taken comprehensive history and had discussions with school staff.

In the past I have identified what I have felt to be children with PDA. They have looked like ASD on paper but there is a ***quality of relating which reflects a level of social understanding*** not usually seen in the standard ASD presentation - if any of them can be said to be standard!

K….s profile is marked by what can only be said to be outrageous behaviours, exceptional drive to control interpersonal contacts, and a range of milder demand avoidance behaviours, but as I see it **all underpinned** by significant social exposure **anxiety.**

PDA is not well known in Australia but as a clinician, I am convinced that **effective management can only be achieved when you address what is driving these** incredible **behaviours**

Diagnosis and Classification

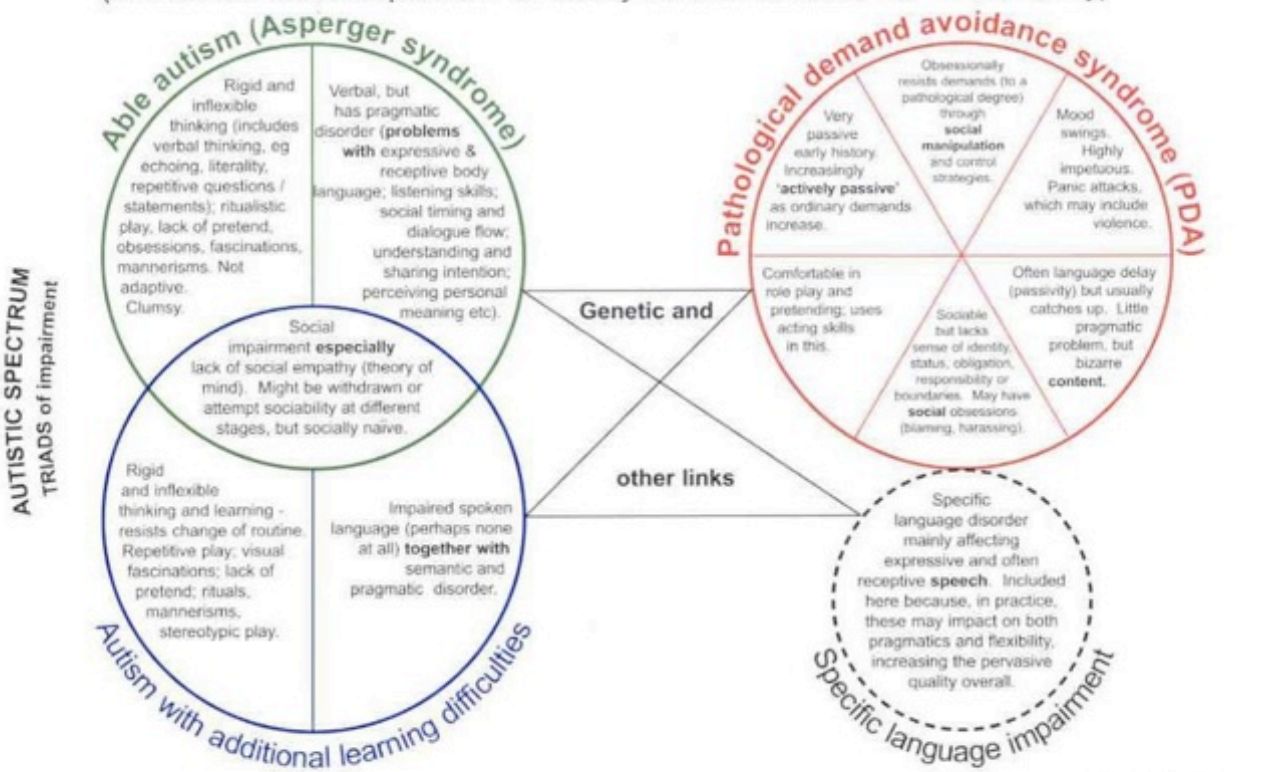
Pervasive Developmental Disorders

- *Pervasive* suggests that the effects can be seen in all of a child's development
- *Developmental* means that the disorder is present at birth, gradually becoming apparent during the course of development
- *Disorder* implies more than straightforward delay

(used in both DSM IV and ICD-10 which were current at time of original Elizabeth Newson paper, in 2003)

THE 'FAMILY' OF PERVASIVE DEVELOPMENTAL DISORDERS

(sometimes 'autistic spectrum' is loosely used to describe the **whole** family)



(The diagram shows clusters of symptoms making up specific disorders/syndromes)

Elizabeth Newson
1999

Pervasive Developmental Disorders

- Atypical Autism-ICD 10
- Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS)-DSM IV

National Autism Plan for Children (2003)

Autism Spectrum Disorder is not in itself a category within medical diagnostic systems but it broadly coincides with the category of ‘pervasive developmental disorder’.

NICE Guidelines on Autism diagnosis in children and young people 2011

The over-arching category term used in ICD-10 and DSM-IV is pervasive developmental disorder (PDD), a term now used synonymously with autism spectrum disorder

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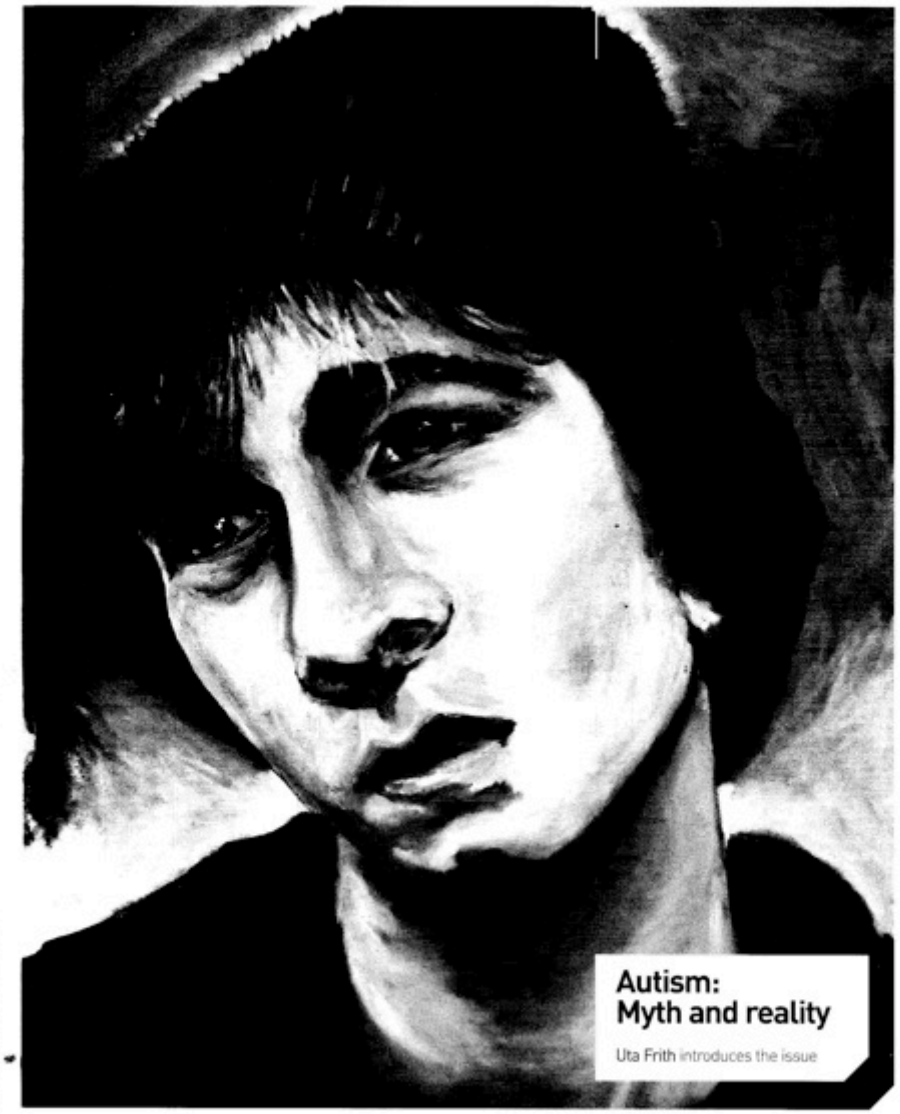

Autism: Myth and reality

Uta Frith introduces the issue

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Refers to Geschwind and Levitt (2007)

…recognising the increasing heterogeneity in the spectrum and sees… ‘the autisms (plural) as a collection of disorders that share some superficial similarities’

Cont…

The central challenge for autism researchers then is to tease apart the various autisms in order to identify the most appropriate interventions and support required by the indvidual.

Goldberg (2013)

… both ICD and DSM focus more on the *reliability* than the *validity* of the disorders they describe…no iteration of either DSM or ICD has acknowledged the fundamental distinction between researchers and practioners…*who* uses diagnostic classifications and for *what* purpose?

Some reasons for diagnosis

- Strategic planning
- Comparison of research findings
- Enabling access to certain resources
- **To better understand the child**

Francesca Happé

Professor of cognitive neuroscience and Director of the Social, Genetic and Developmental Psychiatry Centre

One of the biggest motivations for our research was hearing from parents, teachers and clinicians about young people with PDA who were excluded even from specialist autism schools, and who were the hardest to know how to teach despite apparently good intellectual capacity. If the usual ASC-friendly settings and approaches don’t work, it’s vital to find out what will

Research led by the Institute of Psychiatry, Liz O'Nions Francesca Happé, and Essie Vidings

- Exploring the thought processes and emotional reactions characteristic of young people with PDA
- Comparing profile with typically developing children and those on autism spectrum
- Need to put PDA on the 'radar of health professionals and stimulate awareness in the UK and internationally'

Comparisons between three groups; children with PDA, those with autism and others with conduct problems (CP)

- *When comparing the three clinical groups on items reflecting **difficulties with social interaction**, children with PDA (like those with autism) were in the 1% of the population that has most difficulties with social interaction*

- *When the PDA group was compared to children with conduct problems in relation to **difficult behaviour** (eg impulsivity, temper tantrums and poor planning) both groups scored in the 1% of the population showing the most difficult behaviour.*

Comparisons (cont)

*The PDA group had higher levels of **parent rated anxiety** than both the ASD and CP groups and were in the 2% of the population sample with the highest level of anxiety.*

O'Nions E, Viding E, Greven CU, Ronald A & Happé F (2013) Pathological Demand Avoidance (PDA): exploring the behavioural profile. *Autism: The International Journal of Research and Practice,*

IOP Research References https://sites.google.com/site/lizonions

O'Nions E, Viding E, Greven CU, Ronald A & Happé F (2013) Pathological Demand Avoidance (PDA): exploring the behavioural profile. *Autism: The International Journal of Research and Practice,* 8, 538-544.

O'Nions, E., Christie, P., Gould, J., Viding, E. & Happé, F. (2014) Development of the 'Extreme Demand Avoidance Questionnaire' (EDA-Q): Preliminary observations on a trait measure for Pathological Demand Avoidance. *Journal of Child Psychology and Psychiatry*, 55, 758-768.

O'Nions E, Gould J, Christie P, Gillberg C, Viding E. & Happé F. (2015)Identifying features of 'Pathological Demand Avoidance' using the Diagnostic Interview for Social and Communication Disorders (DISCO). European Child and Adolescent Psychiatry, 25,407-19

O'Nions E, Happé F & Viding E. Extreme/'Pathological' Demand Avoidance (2016). BPS DECP Debate, issue 160

PDA items parent interview/ observational/ multi-informant rating scale

N.B. Ratings: 0= not affected 1=Minor: 2=Marked

(A) Avoids demands using socially manipulative strategies

(B) Obsessively resists and avoids ordinary demands, led by need to control

- Everything must be on his or her own terms, unable to accept reasonable limits. If pressured to comply, may result in an extreme reaction, or a breakdown in the relationship. Parents shocked to discover how much they have adapted to handling the child with velvet gloves when they start school. S/he may also be indifferent to/ reject praise or react badly to it (e.g. tearing up his/her work).
- How did things go when A started nursery/ school?
- Does A strongly resist attempts to make him or her do things, or change his or her behaviour? What sorts of requests does A avoid?
- Does everything have to be on his/ her terms? What happens if you push A to comply or accept limits?
- Does A dislike praise?

Extreme Demand Avoidance Questionnaire (EDA-Q)

Pathological Demand Avoidance Syndrome

Extreme demand avoidance questionnaire

		Not True	Somewhat True	Mostly True	Very True
1	Obsessively resists and avoids ordinary demands and requests.				
2	Complains about illness or physical incapacity when avoiding a request or demand.				
3	Is driven by the need to be in charge.				
4	Finds everyday pressures (e.g. having to go on a school trip/ visit dentist) intolerably stressful.				
5	Tells other children how they should behave, but does not feel these rules apply to him/herself.				
6	Mimics adult mannerisms and styles (e.g. uses phrases adopted from teacher/parent to tell other children off).				
7	Has difficulty complying with demands unless they are carefully presented.				
8	Takes on roles or characters (from TV/real life) and 'acts them out'.				
9	Shows little shame or embarrassment (e.g. might throw a tantrum in public and not be embarrassed).				
10	Invents fantasy worlds or games and acts them out.				
11	Good at getting round others and making them do as s/he wants.				
..	Seems unaware of the differences between him/herself and authority				

DISCO PDA items
Developing examples of behaviour

N.B. Ratings: 0=marked; 1= minor; 2=not affected

5. Rapid, inexplicable changes from loving to aggression (3xiii5)

0 | 1 | 2

Does A at first sight appear to be normally sociable and friendly, but can slip from loving to violent behaviour (or vice versa) for no apparent reason?

May show both together, saying “I hate you” in a sweet voice whilst hugging. May hug others too long and too hard.

Final List from DISCO items

- Lack of co-operation
- Apparently manipulative behaviour
- (Lack of) Awareness of own identity
- Behaviour in public places
- Difficulties with other people
- Repetitive acting out roles
- Fantasising, lying, cheating, stealing
- Inappropriate sociability (rapid, inexplicable changes for loving to aggression)
- Using age peers as mechanical aids, bossy and domineering
- Socially shocking behaviour
- Harassment of others

Christopher Gillberg (Professor of Child and Adolescent Psychiatry, University of Gothenburg) in a 2014 commentary in *European Child & Adolescent Psychiatry*

PDA is already a very real clinical problem, not just in the United Kingdom, but across the planet. Intervention and treatment currently rest almost exclusively on guesswork, clinical experience and trial and error. 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 or ADHD are often ineffective and parents, teachers and clinicians may be driven "half-crazy" by the child's stubborn refusal to cooperate by avoidant, manipulative and exhibitionist-style shocking behaviours

What is the research suggesting?

- The behavioural features of PDA are dimensional across the autism spectrum
- The PDA profile represents a constellation of symptoms that characterises some children on the spectrum
- PDA is comparitively rare
- Females with ASD display more PDA features than males
- There are parallells between features of PDA and descriptions of ODD/CD but important differences
- More research is needed to look at aspects of PDA profile which might be found in other populations

O'Nions, Happé and Viding (2016)

Appropriate description and formulation of the childs' difficulties is the starting point for the identification of potential management strategies and educational support. It is essential that this help is provided to these very vulnerable individuals and their families

DEFINING CRITERIA FOR DIAGNOSIS OF PDA

- Passive early history
- Resists and avoids ordinary demands of life, extensive use of socially ‘manipulative’ strategies
- Surface sociability, lacking real depth
- Lability of mood, impulsive led by need to control
- Comfortable in role play and pretending, sometimes to an extreme extent and often in a controlling fashion
- Language delay, seems result of passivity
- Obsessive behaviour, often focussed on other people
- Neurological involvement

RESISTS AND AVOIDS ORDINARY DEMANDS OF LIFE

- Avoidance may seem the greatest social and cognitive skill
- Strategies of avoidance are essentially socially' manipulative' (or socially strategic)
- Strategies can include:
  - Distracting adult
  - Acknowledging demand but excusing self
  - Procrastination and negotiation
  - Physically incapacitating self
  - Withdrawing into fantasy, doll play, animal play
  - Physical outburst or attacks

Charlie

Charlie's parents described how, at six years old, he wouldn't co-operate with simple day-to-day tasks. He wouldn't eat unless his parent made deals with him. Even then he would often require spoon feeding.

The smallest of demands would initiate 'avoidance mode' and he spent a huge amount of time and energy fighting off the demand, when a fraction of that time and energy would have accomplished the request.

Charlie would offer an ‘escalating amount of resistance. Initially he would giggle, tease and run away. If his parents weren't’t distracted the resistance would become more definite and he might offer excuses such as ‘I’m busy…I’ll do it in a minute…I want to do this first’. His next level would be to say “I feel sick…my tummy hurts’ and so on. He would give reasons such as it’s too hard, too stiff or too heavy. If compliance was still pushed then he became upset and tearful, followed by anger, shouting and throwing, finally throwing himself to the floor if the demand is not withdrawn.

A personal reflection…

I am affected by PDA more at home than at school really. I can't control or predict when it's going to happen but I can tell once it is happening to me. It's like I have two messages at the same time; one says 'Go on, just get in the shower', but the other blocks it. It stops me actually moving my legs to get up to have a shower. It holds me back from co-operating. Sometimes I can overcome it but other times it's too strong. It takes a massive effort to overcome it and it's frustrating that other people don't understand how hard that is.

Daniel (5)

- I can’t do it
- I’ll be there in two minutes
- I want to go back to my castle
- Look…I don’t know
- I want to take my shoes off
- I can’t do it, I told you. I’m grumpy
- I want to be a policeman

Daniel, same assessment!

- You play with those, I'll be in my castle
- A bit later
- I've run out of energy
- My legs don't work
- I don't trust you
- I'm waiting for my family
- I'm not a child

SURFACE SOCIABILITY (BUT APPARENT LACK OF SENSE OF SOCIAL IDENTITY, PRIDE OR SHAME)

- At first sociable and ‘people orientated’
- May have learnt social niceties
- Seem well tuned into what might prove effective with a particular person
- Unsubtle and without depth can be misleading-overpowering, overreacting etc
- Difficulty seeing boundaries and taking responsibility

Mollie

Is naturally a very sociable child who wants to be able to interact, have friends etc…but there is a snag…she doesn't appear to know how to do it intuitively. Certain areas of her social insight are strong, others appear to be very weak…for Mollie, social empathy and understanding is something of a paradox

http://understandingpda.com/my-daughter-is-not-naughty/

Mollie

…mimics and imitates other people or characters…is she trying to mask her difficulties and avoid getting things wrong…? Imagine her confusion when she is taking on a persona without understanding…copying the characteristics of someone who people appear to find acceptable, yet when she behaves in this way she is told off, viewed as rude and deemed odd by her peers

PDA: an examination of the behavioural features using a semi-structured interview-O'Nions et al (2013)

These individuals present a real clinical puzzle. On the one hand the majority appear to use manipulation indicative of good social insight. Yet they also display a striking absence of embarrassment, lack all sense of social compulsion and are unable to judge social hierarchy

Cont.…

This is potentially indicative that some other aspects of social cognition besides theory of mind have gone awry and detailed cognitive experimental investigations are needed to examine the nature of these difficulties

Social Awareness vs Social Identity

Social Awareness
Socially interested
Sufficient to manipulate

Social Identity
Child or adult?
Alternative roles

Need to recognise the difference between understanding at **intellectual** and **emotional** level…

LABILITY OF MOOD, IMPULSIVE, LED BY NEED TO CONTROL

- Switches between moods rapidly, often for no obvious reason
- Switching of mood may also be a response to perceived pressure
- Activity must be on child's terms; can change mind in an instant if suspects someone else is exerting control

Edward

…can lose control of his temper very quickly and then ‘get over it in an instant’. Once he got into a ‘real rage’ at school and in an attempt to distract him, the headteacher asked ‘would you like to come and see the play?’ Edward stopped almost instantly and replied ‘Oh…yes please!’

COMFORTABLE IN ROLE PLAY AND PRETENDING

- Frequently to an extreme extent and in a controlling fashion
- Often mimic and take on the roles of other people, extending and taking on their style (not just repeating)
- Can confuse pretence and reality at times

Georgina (10)

Georgina was engaging and expressive in her play; so much so that at times, it was difficult to distinguish her from the characters she played. She used an American accent and some borrowed phrases (such as *'TTYL'* 'talk to you later') and often gestured elaborately as she spoke. Georgina seemed to have a degree of self awareness about this, as she told Carrie; *'I can start games and think things are real sometimes*

Mollie (at 7)

…the fantasy life and role play reached a whole new level. Blueberry Bear was real and we had to treat her, at all times, like Mollie's baby. Any activity was simply regressed to a role play scenario written, produced and directed by Mollie

Nadine's parents recounted a stage when invented a school called Merrivale. She printed lesson plans, tried to direct mum and dad as her pupils, invited people by letter to attend the school (this was when she was on half days at school), and made visitors to the house become her pupils. She set up desks and gave names and badges to her dolls and teddies and would buy exercise books for them. For a time this took Nadine over and she became obsessed and couldn't break out of it. In the end she sent out her own circular saying that Merrivale school is closed.

LANGUAGE DELAY, SEEMS RESULT OF PASSIVITY

- Initial delay often as result of passivity
- Often sudden and good degree of catch-up
- Pragmatics not deeply disordered-more fluent eye-contact and conversational skills
- Speech content often odd or bizarre

Emerging themes from clinical profiles

- Despite fluent expressive language understanding is often not so robust
- Difficulties with time it takes to process
- Fluency can mislead those communicating with them and contribute to behavioural issues

OBSESSIVE BEHAVIOUR

- Much of the avoidant behaviour described is carried out in a way that feels ‘obsessive’
- Many fascinations link with pretend characters and scenarios
- Other fascinations tend to be social, ie to do with people and their characteristics

Mollie

‘…became obsessed with her friend Gemma…treating her as if she were her child. She tried to control Gemma’s every move and keep her isolated from the group…one particular meltdown at school happened because Gemma refused to use the toilet she had told her to use’

http://understandingpda.com/my-daughter-is-not-naughty/

Terry is very attached to a boy called Adam and takes on his identity. He is only interested in emulating Adam's work and often talks to him and ignores the teacher. He is rather smothering for Adam. He will only eat food if he thinks Adam is eating at the same time (Terry 5:1)

Issues to keep in mind

- As a diagnostic profile PDA is a constellation of symptoms or features
- Variability across time and setting means
  - Access to information over time
  - Information from different settings and sources

The past 20 years or so… what has been achieved?

- Cogent accounts and descriptions from clinicians, teachers and parents
- Emerging insights from those with PDA
- Growing awareness, recognition and interest from practioners and researchers

Cont….

- An emerging research base and tools for future work
- Developing educational guidelines
- Emerging and embryonic clinical tools
- Wide acceptance of the construct of PDA within the UK autism community
- An active, considered and growing parent organisation

We need to…

- refine our understanding of the *essential* criteria and the core difficulty with social identity
- Better understand areas of ‘overlap’ and ‘co-morbidity’ or co-existence
- Reach broader consensus on use criteria and classification in diagnosis
- Develop research tools for use as screening and diagnostic guidelines
- …future versions of diagnostic manuals

We need to…

- Better inform educational practice and provision
- Extend and develop good quality training across the workforce
- Ensure our ‘messages’ are informed and consistent
- Significantly improve awareness and understanding of PDA in adults

The central challenge…

To build on developments, insights and increasing recognition of PDA but maintain the integrity of how the condition is understood and the nature of the support that is needed by individuals

Key References

- Understanding PDA in Children. A guide for parents, teachers and other professionals. Jessica Kingsley Publishers (2011). P Christie, M Duncan, Z Healy, R Fidler
- Pathologcial Demand Avoidance syndrome; my daughter is not naughty. Sherwin, J (2015). Jessica Kingsley Publishers. London and Philadelphia.
- The Distinctive Clinical and Educational Needs of Children with Pathological Demand Avoidance Syndrome: Guidelines for Good Practice. Good Autism Practice Vol 8 (1) (2007). Christie, P. Reproduced 2012 as part of National Autism Standards, Autism Education Trust.
- www.pdasociety.org.uk
- www.autism.org.uk
- Memyselfandpda.com
- https://sites.google.com/site/lizonion
- www.autismassociates.co.uk