Perspectives on Demand Avoidance: Is it PDA, or something else?

A two-day virtual conference hosted by POPARD,
in collaboration with ACT

Session 3:
Understanding and supporting children and young people with a PDA profile

Friday, November 18, 2022

Presented by

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Towards a better understanding of PDA

Phil Christie
Consultant Child Psychologist

November 2022

ACT PDA conference

1

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Outline of Presentation

- Background and Recent Developments
- Diagnostic Understandings and Pathways
- Main features of PDA profile
- Implications for supporting children and young people

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Some Context

- Professional development pathway and association with Elizabeth Newson
- Educational, Clinical and Research perspectives within ASD
- UK setting, policy and practice
- Clinical and research emphasis
- Some key conference themes...varied perspectives, compassion and collaboration

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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

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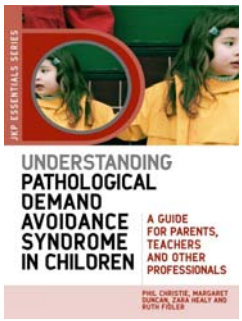
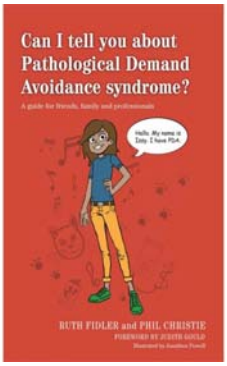
Jessica Kingsley Publishers (uk.jkp.com)





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PDA SOCIETY

Part of the Autism Spectrum

Identifying & Assessing a PDA profile - Practice Guidance

Collating the professional practice and experience of a multidisciplinary group of professionals working in the NHS* and private practice, January 2022

https://www.pdasociety.org.uk

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Key Drivers…

- Increasing contact from parents and professionals 'recognising' child in written accounts
- Appreciation of different emphasis needed in approach

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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!

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Child'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.**

As a clinician... I am convinced that **effective management can only be achieved when you address what is driving these** incredible **behaviours**

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Some Key Milestones

- Original work by Elizabeth Newson (1980's)
- First peer reviewed article (2003)
- Good Autism Practice publication (2007)
- Institute of Psychiatry/University College London research into PDA started (2010)
- National Autistic Society conferences (2011 onwards)
- First Jessica Kingsley publication (2011)

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Some Key Milestones

- National Autism Standards guidance (2012)
- PDA society (2014)
- Development of EDA-Q (2014)
- PDA development group (2014)
- Updating of NAS website(2015)
- Interest from Professional Bodies...UK and overseas 2017 onwards *
- PDA Development group Practice Guidance (2022)

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Diagnostic Understandings and Pathways

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A note on terminology

- PDA
  - Historical context
  - Many people identifying with the profile strongly feel the term is accurate and appropriate ('innate and all consuming')
- Range of terminology used in formulations
  - PDA/PDA profile
  - ASD with PDA profile
  - ASD with demand avoidant profile
  - ASD with extreme/pervasive avoidance

13

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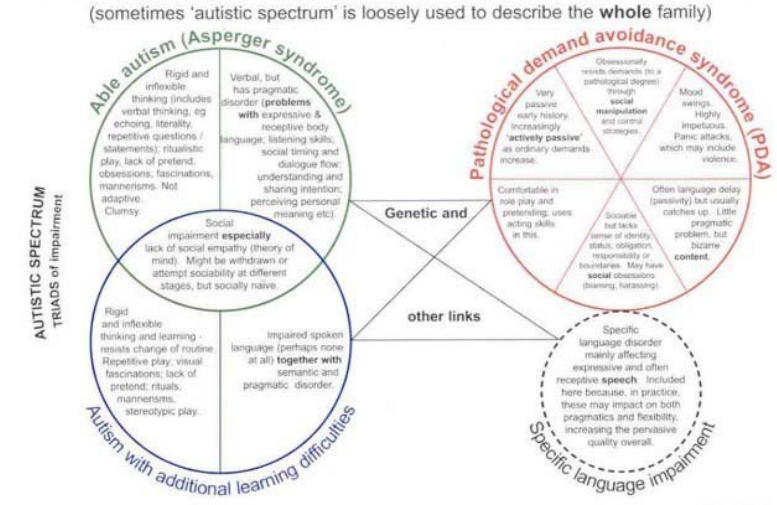
THE 'FAMILY' OF PERVASIVE DEVELOPMENTAL DISORDERS

(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

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THE MAIN FEATURES OF PDA (from Newson 2003)

- Passive early history
- Resists and avoids ordinary demands of everyday life, (extending even to those things they like)
- Surface sociability, lacking real depth
- Lability of mood, impulsivity led by need to control
- Comfortable in role play and pretending, sometimes to an extreme extent and often in a controlling fashion*
- Obsessive behaviour, often focussed on other people
- Language delay, seems result of passivity
- Neurological involvement

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NICE* Guidelines on Autism diagnosis in children and young people UK (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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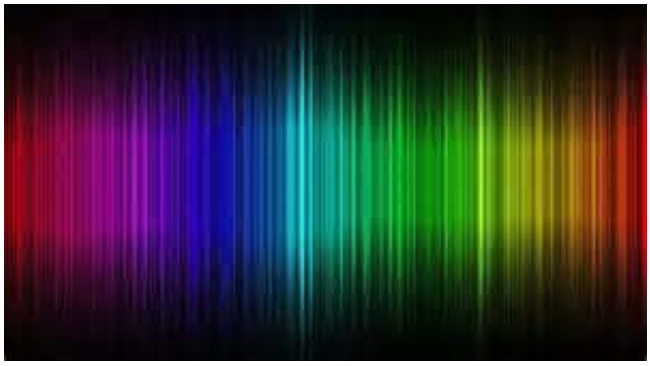
Autism is dimensional and diagnostic formulations continue to evolve and develop



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Some reasons for diagnosis

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

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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

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Thank you to all involved in Fran's assessment…we are already experiencing a better home life with Fran. It seems by simply having a better understanding of her difficulties there is a tangible drop in tension surrounding our interactions

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My daughter is 15. She's struggled her whole life and nothing has made sense as to why. Having a way to describe her set of characteristics and learning styles helps immensely in communicating with her learning team. Already, having a better understanding of PDA has eased her anxiety and healed our relationship.

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What are the diagnostic pathways?

- Often parent led
- Level of prior professional contact variable
- May have had previous diagnosis that 'doesn't fit'
- Often via local ASD pathways
- Role of 'sympathetic', knowledgeable individual professional
- Independent opinion

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What are the characteristics of a good assessment?

- More than one professional involved in the assessment
- Direct observation of the child
- Detailed history from parents or carers
- Information gained from more than one setting
- Extensive clinical experience within the team

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Adaptations to assessment

- Recognising that getting to the assessment can be difficult
- Using indirect approaches and style of language
- Extending assessments
- Being flexible and collaborative
- Accepting it may be difficult/impossible to complete standard assessment tools (* European Child and Adolescent Psychiatry (ESCAP) guidance)

This has implications in relation to resources and protocols

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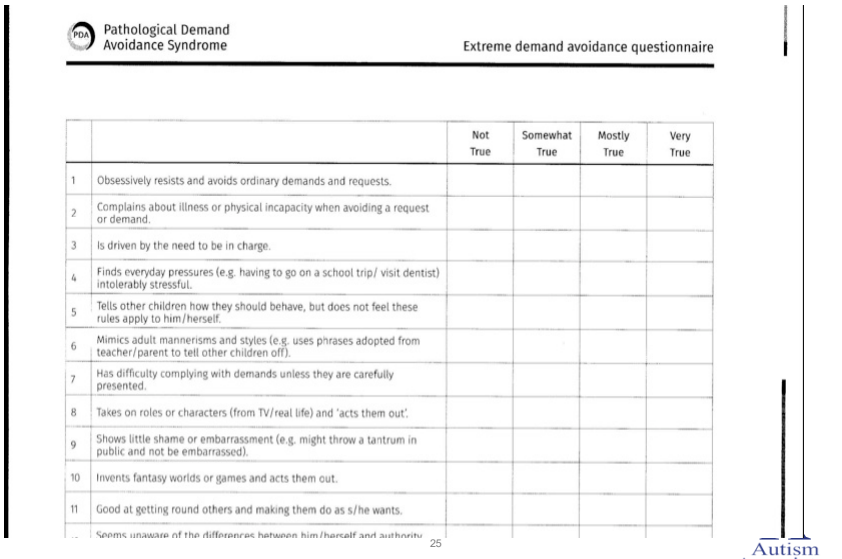
Extreme Demand Avoidance Questionnaire (EDA-Q)



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				

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Phil Christie March 2017

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Final List from Diagnostic Interview for Social and Communication Disorders (DISCO) items (O'Nions, Gould et al (2015)

(differentiated individuals across the ASD group)

- 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

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What is the UCL/IOP research suggesting?

- The behavioural features of PDA are dimensional across the autism spectrum
- The PDA profile represents a constellation of symptoms that characterise some children on the spectrum
- PDA is comparatively rare
- Females with ASD display more PDA features than males
- There are parallels 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

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Green et Al (2018)

- Viewpoint...representing a review of the literature
- Talks about 'PDA symptom constellation'
- Suggests this can be explained by ASD diagnosis and other co-morbid diagnoses eg ODD, OCD, Anxiety Disorder *
- Argues for a 'transactional perspective'
- Makes the case for a common approach for ASD assessment which is detailed and comprehensive and includes 'rigorous trait description'
- Talks about the need for parents to be listened to and believed...'for clinicians and service users to come together'

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O'Nions et al July 2018

- 'We are concerned that conceptualising PDA as a set of comorbidities, including oppositional defiance disorder, could encourage the automatic use of reinforcement based approaches...since these strategies form the core of parenting interventions for disruptive behaviour disorders"
- 'Once high anxiety has been triggered by demands attempting to alter behaviour via contingent reinforcement would be ineffective because it would not address the function of the behaviour: to reduce anxiety'

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Practice Guidance group

- Consensus view of 12 professionals with extensive experience in ASD from Clinical and Educational Psychology, Child Psychiatry, Neurodevelopmental Paediatrics, SLT, OT and Academia
- Endorsed by a further 16, including professionals from Ireland, Australia and South Africa
- Acknowledging paucity of clinically based research
- Intended for practical clinical guidance with the aim of '*improving outcomes via personalised interventions and support*'

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Key findings and issues from Practice Guidance

- All met criteria for ASD
- Confirmed EN's key descriptors but 'comfortable in role play' not universal
- Full profile not just demand avoidance
- Demand Avoidance occurs with other profiles
- 'Transformational' nature of diagnosis
- Dangers of over/under diagnosis

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Identifying a PDA profile

- ...forms part of the 'personalisation and contextualisation of an autism diagnosis and the use of 'specifiers' to identify individual characteristics. This is fundamental to high quality clinical standards in relation to ASD as recommended in ESCAP practice guidance for autism (European Child and Adolescent Psychiatry)

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What are the main features of PDA ?

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PDA is best understood as...

- A profile on the autism spectrum
- An anxiety-driven need to be in control and avoid other people's demands and expectations
- It is the extent and extreme nature of this avoidance that led to it being described as 'pathological'
- But...not just avoidance

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34

THE MAIN FEATURES OF PDA

- Passive early history
- Resists and avoids ordinary demands of everyday life, (extending even to those things they like)
- Surface sociability, lacking real depth
- Lability of mood, impulsivity led by need to control
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RESISTS AND AVOIDS ORDINARY DEMANDS OF LIFE

- Avoidance may seem the greatest social and cognitive skill
- Often includes things they enjoy
- 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

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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.

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Charlie would offer an 'escalating amount of resistance. Initially he would giggle, tease and run away. If his parents weren'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.

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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

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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

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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.

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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

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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

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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

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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...

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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

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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

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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/

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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

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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

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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

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The central challenge is…

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

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What are the implications of this profile for supporting children and young people?

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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.’

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- We thought one of our pupils may be autistic but her needs were very different to other autistic pupils we had supported and none of our usual approaches worked. Seeing her through the lens of PDA enabled us to truly understand her and successfully adapt our practices by building trust and embracing a flexible and collaborative approach (Teacher in school)
- ...following PDA training we were able to devise unique and highly effective approaches...using these is the difference between her being able to live in her own home and being held in a secure hospital (social care manager)

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Autism Education Trust
Good Practice Report 2011

"... I suppose my message to schools is, you're there for the children, they're not there for you. And therefore, actually you do what you can to adapt to the children you've got, and not expect the children to become the children you want them to be."

56

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Attitudes and beliefs... as well as skills and expertise

- Teaching and learning is a transactional process
- Genuine understanding that PDA is an anxiety driven need to be in control and to avoid other people's expectations
- ***'can't help won't'***

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Overall style and approach

- Confrontation should be avoided where possible
- Expectations should be disguised and reduced to a minimum
- Ground rules need to be reduced as far possible... but then maintained

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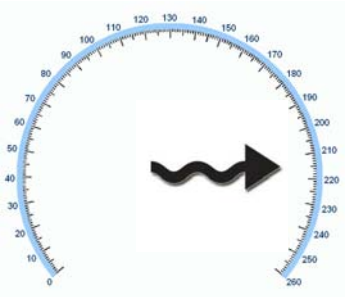
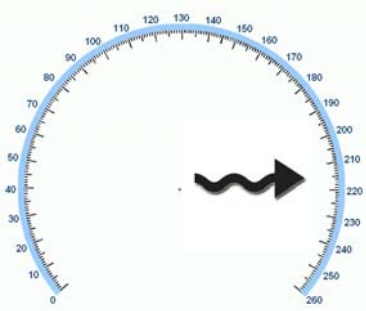
Tolerance and Demand



Tolerance



Demand

59

59

Some key principles

- Observe and listen
- Work together towards negotiated solutions
- Personalise learning experiences
- Modify teaching style...be less directive
- Flexibility and accommodation
- Minimise anxiety to maximise learning opportunities
- Monitor, reflect review
- Be Proactive...Foster emotional resilience and well being
- Recognise the needs of adults

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Collaborative Approaches to Learning – key strategies

- Choosing priorities – picking your 'battles'
- Being indirect – an invitational approach
- Depersonalising requests and behaviour
- Adjusting expectations
- Use novelty and variety
- Use visual clarification to underpin negotiations
- Build positive relationships
- Use drama and role play
- Allow more processing time
- Minimise anxiety
- Promote self awareness and emotional understanding

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"What's PDA? Well the clue is in the name. It means if someone asks me to do something, I'm likely to say no… that's me all over isn't it?! But I'm also like a cat. It all depends on how you ask me. If you ask me in the right way, it's like stroking a cat's fur the way it grows. I may even purr! But if you ask me the wrong way, it's like stroking a cat's fur backwards. I'm likely to hiss!"

62

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November 2022

ACT PDA conference

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