

Pathological Demand Avoidance Syndrome

A Reference Booklet for Health,
Education and Social Care Practitioners



“Awareness Matters”

www.pdasociety.org.uk

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PDA: A brief history



Pathological Demand Avoidance syndrome was first described in the 1980s by Professor Elizabeth Newson at the Child Development Research Unit, Nottingham University, and subsequently at the Early Years Diagnostic Centre in Nottingham (now the Elizabeth Newson Centre).

Children in need of referral to these specialist clinics were, by definition, 'complex', 'puzzling' or atypical in some way. Amongst these were children who reminded their referrers of autism. Yet, although they were clearly not classically autistic, they were also significantly different to others who shared their 'best fit' diagnosis of "Pervasive Developmental Disorder Not Otherwise Specified" (PDD-NOS or 'atypical autism') as classified by DSM-IV.

Newson and her team were aware of the practical consequences and unsatisfactory nature of a PDD-NOS label for these unusual children. Certainly they were 'atypical', but they were often seen as too sociable, too imaginative or too comfortable in role play to be recognised as even 'atypically autistic' outside of specialist clinical settings. Naturally this lack of recognition had negative implications for domestic, professional and educational understanding and support of these children.

After some time the clinic had gathered detailed records and assessments of a number of these 'diagnostically problematic' children and it was noticed that although they were very different to

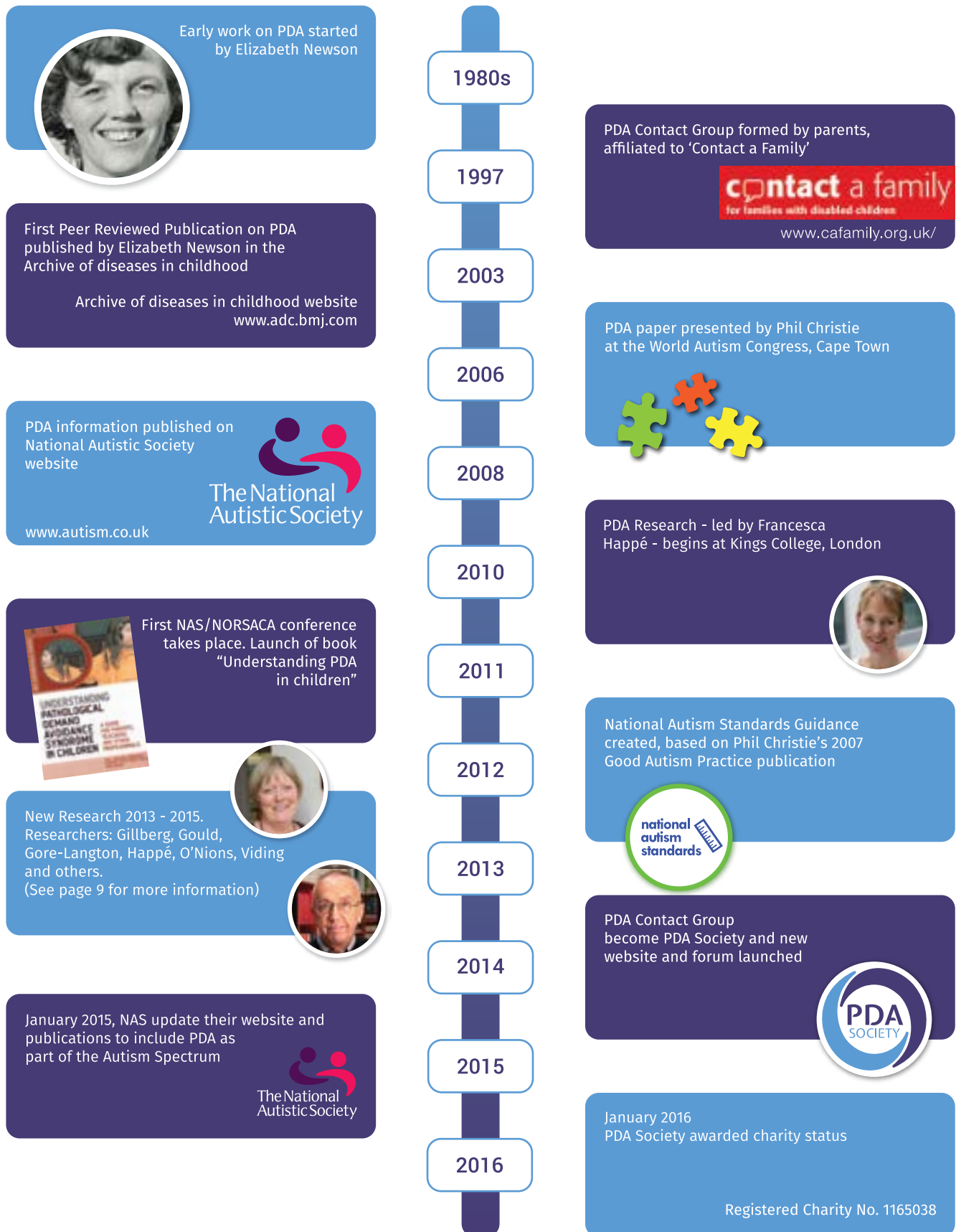
other atypically autistic children, they did have a great deal in common with each other. It was the study of their shared strengths, weaknesses and needs that led to Newson's proposal of Pathological Demand Avoidance syndrome (PDA). PDA identifies the unique characteristics of these individuals, how best to meet their needs and differentiate 'PDA appropriate' support from traditional ASD interventions that are less effective with the syndrome.

PDA remains as relevant today as it did when Newson first proposed the syndrome. The latest revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) has dispensed with the separate categories of PDD-NOS, autism and Asperger Syndrome and merged these under one umbrella classification of Autism Spectrum Disorder (ASD). The sole diagnostic refinement being to assign a level 1, 2 or 3, depending on the severity of the condition.

Some argue that this revision shifts emphasis away from 'labels' and directs focus towards identifying and meeting the needs of the individual. Indeed, establishing needs should be the priority and is precisely why diagnosis and understanding of PDA is so important. Whilst individual characteristics associated with PDA can be found in other presentations of an Autism Spectrum Disorder, it is the uncommon combination of characteristics, strengths and weaknesses that makes the PDA profile so unique to cater for.

A diagnosis of ASD defines the underlying developmental condition, but does little to signpost towards the specific needs and most effective interventions for a person with PDA.

PDA is increasingly being employed as a useful diagnostic term by mental health and education professionals. Those recognising the diagnosis include: National Autistic Society, Department of Education and the Autism Education Trust.



What is PDA?

Originally viewed as a pervasive developmental disorder distinct from autism, Pathological Demand Avoidance syndrome, often shortened to PDA, is now seen as part of the autism spectrum.

Like autism or Asperger Syndrome, PDA is a lifelong disability and individuals may require differing levels of support throughout their lives, depending on how the condition affects them.

The central difficulty for people with PDA is their avoidance of, and resistance to, the demands they are subjected to and encounter. These can range from direct and explicit instructions to the more subtle everyday demands of life.

Individuals with PDA experience high levels of anxiety and there is a strong need for them to feel in control in most situations. Demands and expectations unsettle this sense of control. This in turn heightens anxiety still further and leads to compulsive and obsessive avoidance. It is this 'can't help it' drive to avoid even trivial demands that earns the behaviour its 'pathological' status.

Avoidance can be at all costs and the socially inappropriate behaviour of a panic attack driven tantrum or meltdown is common, especially in children. Some people with PDA have been described as being skilled at using interactive and social communication skills to avoid demands. They are often able to use these skills creatively and may seek to avoid demands through negotiation, manipulation or distraction.

Those with PDA share areas of difficulty with other autism spectrum disorders, but strategies and approaches found to be effective are quite different. Differential diagnosis is therefore important to signpost towards appropriate educational and handling interventions.



What does a child with PDA look like?

Many families who seek the help and advice of the PDA Society have children who superficially appear, at first glance, very much like their peers and may present as very able. However, all children with PDA will have difficulties with a lack of social skills, emotional regulation and communicative reciprocity. They will also show difficulties with peer interaction and relationships, rigid and repetitive interests and behaviours particularly centred on avoiding demands! We must also be aware that children with PDA can be superficially skilled at 'masking', hiding or 'putting on a performance', to hide their difficulties for limited periods of time. However, for those who know the child well and spend longer periods of time with them (such as parents and teachers), the child's difficulties become more apparent through their behaviours.

A typical parental experience



From an early age parents are aware that their child is different and challenging. However, they may well be bright and promising. Children with PDA are determined, stubborn and strong willed, but can also be charming, imaginative and entertaining. Many can show good levels of empathy, social awareness and understanding, BUT this is mostly shown on their terms or when it suits them. In this respect these skills can appear superficial or only skin deep. Bossiness and a need to be in charge cause frequent problems with peers and siblings. In the home children often behave as mini adults and often do not seem to recognise their status as junior members of the household. Relationships can be quite obsessive with an excessive dislike or intense interest in another individual. Generally, adult company is preferred and often actively sought out.

Most parents report having to handle their child with 'velvet gloves' and find themselves constantly treading on eggshells. Mood is unstable with swings that are sudden and dramatic. Changes of emotional state may be sparked by trivial issues, but frequently occur without obvious triggers, apparently coming

out of nowhere. Behaviours can appear to be at the extreme end of 'the terrible twos' and parents may not be unduly concerned until it is apparent that this is not merely a passing phase that they will grow out of. Getting a child to comply with the most basic day to day requirements of life is a challenge and the same battles are fought every day.

For example, there may be issues over getting dressed, washing, cleaning teeth, wearing a seat belt or holding hands when out walking. Typically the child will expend much more time and energy evading and resisting a demand than they would use complying in the first place. Resistance can be extremely active and tantrums or meltdowns are common and can be prolonged. Neither traditional discipline and stern reprimands, nor sanctions or rewards have any lasting impact and are largely ineffective. The child seems incapable of learning, despite diligence and consistency of approach. Parents will often say of their child 'he/she just can't seem to help it' rather than state that it is all due to naughtiness.

Challenging behaviours and general difficulties increase over time, rather than improve after the toddler years. Parents may wonder if there are issues such as ADD, ADHD or autism, but any labels investigated never seem to fully explain their child's behaviour. Parents may find it hard to define their child's strengths and weaknesses or know how to respond meaningfully to questions asked by professionals. Often it is neither a case that a child is 'able' or 'has difficulties' in certain areas, but that they can present with both. For example, a child might be very outgoing and confident in one situation but be painfully shy and diffident in another seemingly similar encounter. This apparent 'all or nothing' variability is common and may be true for a wide range of proficiencies or characteristics including areas such as communication, social skills and flexibility of thought.

Generally children with PDA show good imaginative play and invent characters for their soft toys, dolls or games. At times this imagination can be so strong that the boundaries between reality and fantasy can become blurred. A child might cover a doll's ears so that it cannot overhear what they are saying or become as emotionally involved in a game as if it were real. Many children invent characters for themselves, perhaps modelled on a super hero or cartoon character, or they may behave like a family pet. This too can become more than play-acting and a child may have difficulty breaking out of a role, perhaps only answering to their dog name or wanting to eat from a bowl on the floor. The characterisation can be some complete that the child seems to believe that they really are the character of their imagination. Even for those who do not take role play to such extremes, most do take on roles in a more subtle, but sophisticated, manner. Acting like an infant or behaving like a teacher is common, as is playing the part of 'competent child'. This is much more than slavish 'copy cat' behaviour, but adopting a borrowed style and adapting it to suit their situation.

For many there may be additional areas of difficulty that coexist with the core problems. Specific learning difficulties are not unusual and there could be concerns regarding dyslexia or dyscalculia, for example. Sensory issues are also common, but may be overlooked or underestimated. It can be hard to

distinguish between behaviours that are driven by sensory factors and those that are primarily acts of demand avoidance.

Many children with PDA are unable to cope with the demands of a first nursery or school. This could result in extreme displays of somewhat violent behaviour and multiple exclusions. However, some children cope reasonably well with the first year or two of school. Teachers may not feel that there is cause for concern at this stage, but may note playground problems and a low output of productive work. Even when few behavioural problems are evidenced in the classroom, many parents report a declining situation at home because children appear to 'bottle up' anxiety at school and release this built up tension later.

Some children continue to mask their difficulties in school, and a few (as noted by Elizabeth Newson) may 'take on the role of a compliant pupil'. However, for most, as demands of school increase more difficulties spill out in educational settings. Very often, once this does start, the rate of decline can catch everyone by surprise. Multiple exclusions are common. Frequently, schools are no longer able to cope and managed transfers to alternative provisions are made.

When parents discover PDA it is like a 'light bulb moment', a label that describes their child to a 'T'. It immediately makes sense and adds understanding; it feels like a tailor-made diagnosis.



What is a demand?



The most obvious types of demands are requests, orders and instructions. These are what most people will think of when considering demand avoidance and our first thoughts are of a child who will not do as he is told. Whilst this is an illustration of avoidance in action, it does not provide a helpful picture of what constitutes a demand.

How many of us could state that we live a demanding life or have a demanding job or career? Clearly most of the demands we face are not orders we are given, but are more complex, subtle and indirect than explicit instructions. We deal with a range of pressures, such as social demands: looking good, being polite and sociable or having friends and maintaining relationships. In work we are expected to be punctual, reliable and proficient. Whilst at home, we strive to be good parents, a loving partner and manage many day to day responsibilities.

All of these are demands, some of which we choose ourselves and are self-imposed, whilst others are placed on us by circumstances or by our role. Equally, some we enjoy and desire whilst others are a burden and a chore. Perhaps for most of us, lack of time together with the sheer number of things we feel we ought to do, must do or would like to do, are the biggest demands we encounter.

Demands for the person with PDA cover the same

range of pressures as anyone else. The difference is the ability to cope with, and manage them. A typically developing person learns to cope with pressures as they mature. A demand that might cause stress for a toddler to deal with could become second nature to them by the time they start primary school. Also, demands and pressures that caused anxiety the first time they were experienced, are learned from and the ability to cope with them steadily improves over time. By the time adulthood is reached, a huge variety of demands can be managed with ease. However, for the person with PDA this does not seem to happen, or certainly not at a rate that would be expected.

Seemingly trivial demands can cause acute anxiety for the person with PDA and this is particularly pronounced in children. For them even demands that are regular daily events and should not be a 'big deal', provoke the same levels of anxiety as a truly challenging task or pressure. Common examples would include getting dressed, cleaning teeth or leaving the house for a journey.

It is understandable that any child might display some anxiety over unwanted demands. However, for those with PDA, demands that they should feel indifferent to (or even find desirable) can cause as much anxiety as would be the case for one that could be considered unfavourable. So to a large degree it is the process of being under a demand, as much as the specific nature of the demand, that causes the anxiety.

Demands can have all manner of origins and could encompass physical, sensory, environmental, emotional or mental demands. It would be true to state that many of the demands experienced by the infant/toddler are direct instructions that require compliance. For example to 'sit still', 'hold mummy's hand' or 'not to touch that'. However, as the child grows and awareness increases, demands are more complex and less direct. These will include expectations, perceived or implied demands, aspirations, and peer pressures, to name a few. Frequently it is as these demands increase that a young person with PDA presents with more challenging behaviour.

Current Research on PDA

Early research on PDA was carried out by Elizabeth Newson and colleagues and published through conference proceedings and informal channels.

The research literature remains small at present. However, interest is growing, and PDA is beginning to attract international attention.

Recent work has led to some helpful developments:

Development of ways to quantify PDA features – The ‘Extreme Demand Avoidance Questionnaire’ (EDA-Q, p. 31 of this booklet) was developed to quantify PDA features based on parent report, with the aim of identifying individuals at high risk of exhibiting the PDA profile for research purposes (O’Nions et al., 2014). More recently, work has been undertaken in collaboration with Dr. Judith Gould to revisit existing items within the Diagnostic Interview for Social and Communication Disorders (DISCO). The aim was to identify which items appear most specific to PDA, compared to the rest of the autism spectrum. This analysis identified eleven DISCO items that appear very distinctive to the PDA profile (O’Nions et al., 2015). More information is available in the research paper, which is available open access and can be downloaded from the European Child and Adolescent Psychiatry website.

PDA features are dimensional within the autism spectrum – Two recent studies have compared individuals with PDA to those with more classic presentations of ASD, using informant questionnaires and interviews. Both reported similar levels of autistic traits and core features of ASD in those with and without PDA features (O’Nions et al., 2013; 2015). The findings also suggest that PDA traits are continuously distributed in individuals on the spectrum. Those with substantial PDA features also appear to span a range in terms of the severity of their autistic features. In short, PDA features should be considered dimensional (O’Nions et al., 2015).

Substantial PDA features are associated with difficult behaviours and anxiety – Those with the highest levels of PDA features have significantly higher levels of socially maladaptive and difficult behaviours, plus high levels of anxiety/emotional symptoms, compared to those without (O’Nions et al., 2013, O’Nions et al., 2015).

Better understanding of the clinical presentation of PDA in an adult inpatient setting (Eaton & Banting, 2012), and in children with epilepsy (Reilly et al., 2014) – These case studies provide insight into the usefulness of incorporating description of PDA features in a diagnostic formulation. In particular, Eaton & Banting highlight the challenges of managing an individual with PDA, and identifying triggers of extreme behaviour. They also describe barriers to implementing the recommended strategies.

Insight into the prevalence and stability of PDA – Other work using the DISCO to quantify PDA features has provided insight into the prevalence and stability of this profile in individuals on the autism spectrum (Gillberg et al., 2015). This study reported high rates of remission in individuals exhibiting PDA features. However, the more distinctive set of DISCO items for PDA that have been identified more recently (O’Nions et al., 2015) were not used in this study. A key priority for further research is to ensure that consistent methods are used to identify PDA features.

Insight into the educational experiences of individuals with PDA (Gore-Langton et al., 2015) – This work has shown that children with PDA display a range of hard to manage behaviours at school, and require high levels of additional support. They also experience high rates of exclusion and educational placement breakdown across a range of specialist and mainstream school settings. For more information see <http://pdaeducationalexperiences.wordpress.com>.

Self-report version of the Extreme Demand Avoidance Questionnaire – Dr Vincent Egan, Associate Professor of Forensic Psychology at the University of Nottingham gave a presentation on his research work into adults with

PDA at the NAS PDA Conference in November 2015. The research is looking at whether the EDA-Q can be used to measure PDA features in adults using a self-report method.

More research is needed, particularly in the following areas:

- Studies that systematically examine whether individuals identified as having PDA features meet diagnostic thresholds for ASD.
- Further validation of tools to quantify PDA features.
- Investigation of the cognitive profile in PDA would shed light on how much individuals with PDA have in common with those with more classic presentations of ASD, and whether the presence of behaviours associated with ASD (e.g. socially inappropriate and obsessive behaviour) has a similar or distinct underlying cognitive basis.
- Studies examining which educational and management strategies are most useful for individuals with PDA.

Liz O’Nions,
Post-doctoral Fellow at the Parenting and Special Education Research Unit, KU Leuven,
Belgium

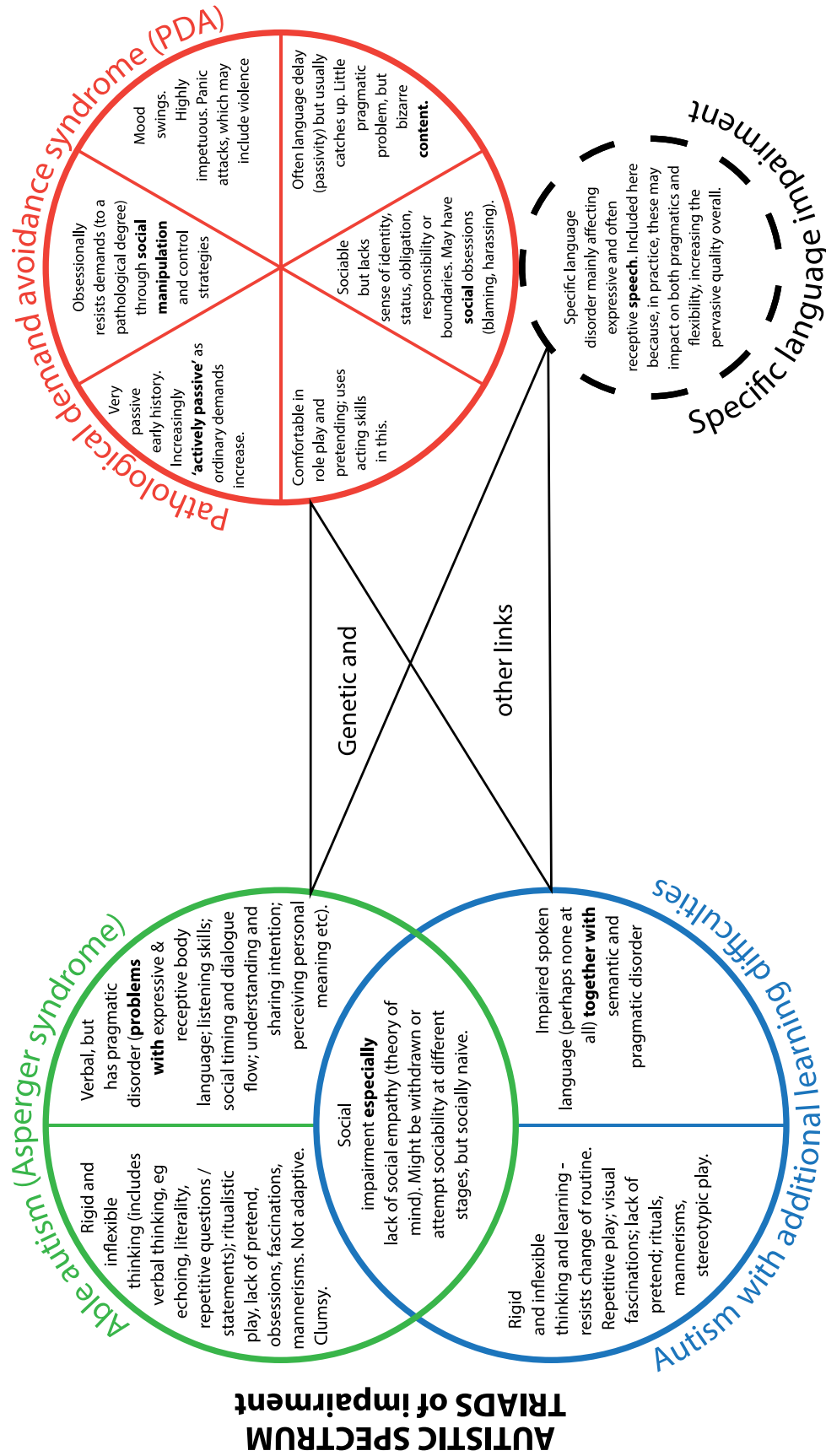
Explanation of The ‘Family’ of Pervasive Development Disorders diagram

- ◇ This diagram on page 11 shows **clusters of symptoms (syndromes)** which make up specific disorders within the family. These will vary in mildness or severity, and intellectual ability will make a significant difference (as in any disability); so will underlying **personality**.
- ◇ Occasionally a child will show a cluster of symptoms that falls between these typical clusters. This is described as non-specific pervasive developmental disorder. However, sometimes this child will more clearly belong to a typical cluster as time goes on and particular symptoms take on greater prominence.
- ◇ In every case, the child or adult has difficulty in coding or **making sense of** a particular area of communicative life where we usually regard making sense as biologically normal. This is not necessarily in terms of spoken language, but may be about the non-verbal ways in which we understand each other, such as **meanings and intentions**, or **identity and obligation**.
- ◇ None of these children chooses to be the way they are. These are **biological**, sometimes **genetic**, disorders. However difficult the behaviour arising from them, the child is not wilfully being naughty, and cannot easily behave differently; though we may be able to help him or her to improve over time. None of these conditions has an emotional **cause**, although any might make a child behave emotionally, especially if misunderstood.
- ◇ **Differential diagnosis has practical implications.** Each of these disorders has its own guidelines for education and management, which have different emphases. Some guidelines suitable for one condition may be very unhelpful for another. This is why accurate diagnosis is important. Specific educational management is essential in all cases, having regard also to individuality.
- ◇ In Asperger syndrome the child usually becomes increasingly aware of his difficulties as he moves into adolescence. This, combined with an increasing wish for friends (often unfulfilled), may lead to anger or clinical depression, and a need for informed and sensitive counselling.

Elizabeth Newson
1999

THE 'FAMILY' OF PERVASIVE DEVELOPMENTAL DISORDERS

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



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

Elizabeth Newson
1999

About the PDA Society

The PDA Society began in the 1990's, as a small group of parents who were supporting each other through Newsletters and were known as the PDA Contact Group.

With the advent of the online Forum and Website in 2004 the PDA Contact Group was the only website and forum dedicated to parents and professionals wanting more information on PDA.

In 2013 the group were awarded a grant from the Big Lottery Awards For All to update its Website, set up an Enquiry Line and produce this Booklet. It changed its name to the PDA Society to reflect the newer nature of the website, and also held the first PDA Awareness Day on 15th May 2013.

In response to the growing needs of parents and the distinct lack of support from services, the PDA Society began running PDA Parent Training Courses at the end of 2014 and now regularly run both long and short courses across the UK; facilitators are experienced parents of children with PDA (as well as professionals in their own fields) and therefore, have a personal understanding and first-hand experience of living with a child who has the condition.

In 2015 the PDA Society held its first national conference which was an overwhelming success, (sold out within 6 weeks) and plans are underway for another in 2017.

We became a registered charity in January 2016 and have a dedicated board of trustees, all of whom are parents of individuals who have PDA. We also have a growing number of parent volunteers who answer telephone and email enquiries; all of whom have undertaken specific training to become 'Enquiry Line Volunteers'.

A PDA Society trustee also attends the 'PDA Development Group' meetings chaired by Phil Christie; which gives us the opportunity to meet with experienced professionals who share an interest in furthering knowledge and understanding of PDA, and also keeps us up to date with the latest developments in the field.

Over the last few years we have seen the PDA Society evolve and this has been a very exciting time, but for us, our first commitment and focus will always remain the same: **raising awareness of PDA, supporting families and providing information to others who have an interest in the condition.**

Assessing a child

A child with suspected PDA is best assessed through a multidisciplinary assessment process at a Child Neuro-developmental Clinic. However, it is apparent that more and more CAMHS services are recognising the condition too. Since the diagnosis is not currently in the diagnostic manuals, a diagnosis may have to come under the term Autism Spectrum Disorder but should be qualified by something along the lines of 'resembles the profile described as Pathological Demand Avoidance' as this is what signposts teachers, parents and other professionals to the understanding and better management of the condition.

The DISCO questionnaire has 17 markers for PDA in it and may be used (Lorna Wing).

The EDA-Q in this booklet on page 30 is also a helpful guide (Liz O'Nions).

Questions regarding diagnosis and training should be directed to the Elizabeth Newson Centre (see inside back cover for contact details).



Comparing PDA with autism and Asperger's Syndrome in children

There are highly significant differences when comparing PDA to autism and Asperger Syndrome. PDA and its diagnostic criteria are regarded as more complex in comparison.

Children with PDA in comparison to those with autism and Asperger Syndrome are LESS likely to:

- » have caused anxiety to parents before 18 months of age
- » show stereotypical motor mannerisms
- » show (or have shown) echolalia or pronoun reversal
- » show speech anomalies in terms of pragmatics
- » show (or have shown) tiptoe walking
- » show compulsive adherence to routines

Children with PDA in comparison to those with autism and Asperger Syndrome are MORE likely to:

- » resist demands obsessively (100%)
- » be socially manipulative (100% by age five)
- » show normal eye contact
- » show excessive lability of mood and impulsivity
- » show social mimicry (includes gestures and personal style)
- » show role play (more extended and complete than mimicry)
- » show other types of symbolic play
- » be female (50%)

Newson et al 2003

PDA is NOT:

- » Another term for ODD (Oppositional Defiant Disorder)
- » AD (Attachment Disorder)
- » ADHD (Attention Deficit Hyperactivity Disorder)

What are the differences between PDA, ODD and Attachment Disorder?

It's inevitably the case that when conditions are defined by what are essentially lists of behavioural features there will be interconnections and overlaps. Aspects of both of these conditions can present in a similar way to those features that make up the profile of PDA. There is also the possibility of the co-existence or 'co-morbidity' of different conditions and where this is the case the presentation is especially complex.

Oppositional Defiant Disorder (ODD) often exists alongside ADHD, and is characterised by persistent 'negative, hostile and defiant behaviour' towards authority. There are obvious similarities here with the demand avoidant behaviour of children with PDA. PDA, though, is made up of more than this, the avoidance and need to control is rooted in anxiety and alongside genuine difficulties in social understanding, which is why it is seen as part of the autism spectrum. This isn't the case with descriptions of ODD. A small project, supervised by Elizabeth Newson, compared a group of children with ODD and those with a diagnosis of PDA and found that the children with PDA used a much wider range of avoidance strategies, including a degree of social manipulation. The children described as having ODD tended to refuse and be oppositional but not use the range of other strategies. Many children with ODD and their families are said to be helped by positive parenting courses, which is less often the case with children with PDA.

Attachment disorder, or Reactive Attachment Disorder as described in the diagnostic manuals, has its own debates about how it is best defined. RAD describes a group of children who show 'inhibited, emotionally withdrawn behaviour' and also 'a persistent social or emotional disturbance'. The criteria, though, also include patterns of 'extremes of insufficient care' and are not judged to meet the criteria for Autism Spectrum Disorder. Some professionals prefer to use the term attachment disorder or attachment problems, recognising that attachment is part of a continuum. There is though little research in this area. When children have

experienced a very difficult early life, or suffered serious abuse or trauma, the presenting problems can appear similar to those of children on the autism spectrum, including those who fit the profile for PDA. One attempt to tease out some of these overlaps and differences was made in producing the Coventry Grid (see bibliography on page 34).

These areas of overlap, and the potential for behavioural profiles being interpreted in different ways, underline the importance of a detailed and comprehensive assessment being carried out by experienced practitioners. Assessments should include the taking of a detailed developmental history as it is vital to know not just how a child presents now but how they developed up until now. This is not always easy with an older child, or a child who grew up in adverse circumstances, as that information might be hard to come by. Assessments should also include detailed observation of the child looking at all areas of development, information about how they behave in a range of different situations, the views of other professionals and consideration of other relevant factors and circumstances, such as their health and family relationships.

Phil Christie, May 2014



What can you do as a Practitioner?

If you are a **practitioner involved in Assessment and Diagnosis of Autism Spectrum Disorders** then these points are particularly relevant:

- There is now an accumulating body of research evidence that suggests that PDA features are distinctive and identifiable and should be considered when making a diagnostic formulation.
- It is confusing for parents and other practitioners if some people are openly accepting and using the term PDA in their diagnostic formulations, whilst others have decided not to recognise PDA.
- Whilst we recognise that this condition is not yet listed in the diagnostic manuals, it is possible to use the term as part of an autism spectrum diagnosis; and give a diagnostic formulation that includes a description of the PDA profile and PDA support strategies.
- You may wish to raise with your organisation or trust the need to develop a firm procedure for assessment and diagnosis of PDA to ensure a standardised response.
- It is also worth considering acquiring training in the use of the new DISCO assessment, or refresher DISCO training which includes discussion/ questions on PDA.

If you are an **Educational Practitioner** then please consider:

- Implementation and use of the management guidelines from the Autism Education Trust, which are included in this booklet (page 16 onwards)

For **ALL PRACTITIONERS** the following actions should be considered:

- Attend training relating to PDA. There are a number of organisations who provide training, and/ or host conferences and seminars relating to PDA. Some of these are listed in this booklet, however please also see the News section of our website for a more comprehensive list.
- There are a number of books and other publications that would give advice and strategies for supporting individuals with PDA. Some are listed on page 29 of this booklet.
- Read research relating to PDA. There is a summary of the current research from page 9 onwards. A full list of peer reviewed articles can be found on page 34 of this booklet.
- Speak to parents, carers and individuals with PDA as only they know what a difference recognising and understanding PDA can make to the quality of their lives.
- Obtain copies of the PDA Society leaflets which can be downloaded from www.pdasociety.org.uk/resources or for hard copies email info@pdasociety.org.uk

The following Leaflets are available:-

- A Parent's guide to understanding Pathological Demand Avoidance Syndrome
- A Teacher's guide to understanding Pathological Demand Avoidance Syndrome
- Recognising Autism Spectrum Disorders in the Early Years (see page 32)

The Distinctive Clinical and Educational Needs of Children with Pathological Demand Avoidance Syndrome: Guidelines for Good Practice.

Phil Christie, UK

Taken from the Good Autism Practice Journal published by BILD, 2007, by kind permission.

Acknowledgements: Special acknowledgement should go to Elizabeth Newson for her pioneering work in this area. Thanks are also due to staff at Sutherland House School and the parents who have contributed to this paper.

Editorial Comment.

Phil Christie is currently the Director of Children's Services within the Nottinghamshire Regional Society for Children and Adults with Autism (NoRSACA) and has been Principal of a specialist school for children with autism for over 25 years. This paper was first presented at the World Autism Congress held in Cape Town, South Africa in 2006. It provides details on a syndrome which was identified over a long period of time by Professor Elizabeth Newson, often in work done jointly with this author, Phil Christie. In the many diagnostic assessments conducted at the Child Development Research Unit based at the University of Nottingham, she found there were children referred with a possible diagnosis of autism who did not seem typical in that they shared some of the features but had other very different behaviours and characteristics. There were also more girls affected than boys. After several years of careful note-taking and interviews with parents, she felt that there was sufficient evidence to create a new syndrome or diagnostic description within the category of Pervasive Developmental Disorders. She named this Pathological Demand Avoidance syndrome and first brought it to public attention in 1980's. Since that time, there has been much debate between professionals as to whether this is indeed a separate condition or whether the behaviours found in PDA can be explained within other disorders such as attachment disorder or personality disorder or a female form of autism. Readers of this paper can send their thoughts and personal experiences to the author or the Editors of GAP to add to the debate.

Introduction

The term Pathological Demand Avoidance syndrome was first used during the 1980s by Professor Elizabeth Newson in a series of lectures, presentations and papers that described an evolving understanding of a group of children who had been referred for diagnostic assessment at the clinic based at the Child Development Research Unit at Nottingham University. This clinic operated as part of a centre for postgraduate training of clinical and educational psychologists and specialised in children who had communication and developmental difficulties. By its nature as a specialist clinic, most of the children referred were complex and anomalous in their developmental profile and many reminded the referring professionals of children with autism or Asperger's syndrome. At the same time, though, they were often seen as atypical in some way. Many of these children came away from the clinic with a diagnostic assessment report which described them, in various ways, as being 'atypically autistic'. Newson and her colleagues began to feel increasingly dissatisfied with this description, especially by the fact that it was not particularly helpful in removing the confusion that was often felt by parents and teachers who were struggling to gain greater insight into the child's behaviour. Over time, Newson began to notice that while these children were atypical of the clinical picture of autism or Asperger's syndrome they were typical of each other in some very important ways. The central feature that was characteristic of all the children was 'an obsessional avoidance of the ordinary demands of everyday life' (Newson, 1990; Newson et al, 2003). This was combined with sufficient social understanding and sociability to enable the child to be 'socially manipulative' in their avoidance. It was this level of social understanding, along with a capacity for imaginative play, which most strongly countered a diagnosis of autism.

Through a series of publications, based on increasing sample sizes (up to 150 cases) and supported by follow up studies (Newson and David, 1999), the clinical description of PDA was refined and the differences between this profile and those found in children with a diagnosis of autism or Asperger's syndrome made clearer (Newson, 1996; Newson and Le Marechal, 1998). The studies also demonstrated the robustness of the clinical descriptions from childhood into adulthood. These publications culminated in a proposal (Newson et al., 2003) to recognise PDA as 'a separate entity within pervasive developmental disorders'. This paper describes the defining criteria for a diagnosis of PDA, together with a comparison of children with autism or Asperger's syndrome through the use of a discriminant functions analysis. In this analysis a sample of 50 children with PDA were compared to two comparison groups: 20 with autism and 20 with Asperger's syndrome. The most strongly discriminant features were the extent of 'social manipulation' and excessive lability of mood in the PDA group. Children with Asperger's syndrome demonstrated more symbolic play than the children in the autism group, but significantly less than the PDA group. Another factor which discriminated the groups was the gender ratio: in the PDA group there was the same number of boys to girls compared to the typical ratios of 4 or 5 boys to 1 girl in autism and 10 boys to each girl in Asperger's syndrome.

Newson proposed that the clinical description of PDA be conceptualised as a separate identity as it gives 'specific status to a large proportion of those children and adults who earlier might have been diagnosed as having pervasive developmental disorder not otherwise specified' (PDD-NOS), a much less helpful diagnosis in terms of guidelines for intervention.

Criteria for Pathological Demand Avoidance Syndrome

A short summary of the diagnostic criteria described by Newson is presented below, together with examples taken from clinical experience of children seen at the Child Development Centre.

1. Passive early history in the first year

Often there are delayed milestones and the child might not reach for their toys or drops them. Child begins to become more actively resistant as more is expected; some are resistant from the start. Parents frequently report adapting so much to their child that they are unprepared for their child's later failure. Early on children may be seen as puzzling in some way but not abnormal.

2. Continues to resist and avoid ordinary demands of life, with strategies of avoidance

being essentially socially manipulative This is the criterion that designates the syndrome. Children seem under an extraordinary degree of pressure from ordinary everyday demands and expectations and attempt to avoid these to an 'obsessive' extent. A key feature is that the child has sufficient social understanding to be socially manipulative in their endeavours and will often adapt strategies to the person making the demand. Strategies may include distraction, giving excuses, delaying, arguing, suggesting alternatives and withdrawing into fantasy. The child may also resist by physically incapacitation (often accompanied with an explanation such as 'my legs don't work') and not engaging in their normal level of conversation. The child may also use simple refusal, or outbursts of challenging behaviour including violence (Newson points out that this is best seen as a panic attack). During a recent assessment, one five-year-old child, who had come for assessment with a diagnosis of ASD and ADHD, gave responses, which included: 'No...I can't...I'll be there in ten minutes... Look, Jenny! I don't know...I think I'm done...I can't do it, I told you, I'm grumpy...I want to be a policeman...I'm going to tell my mum and dad...I hate putting this away...A bit later...You play with those, I'll be in my castle... I'll come back when I'm ready...I've run out of energy...No! That's not my game. I want to go now...I don't trust you...I'm waiting for my family...I'm not a child.'

3. Surface sociability, but apparent lack of social identity

The child may be very misleading in this respect, often coming across as very socially interested and accompanying their conversation with social niceties such as 'please', 'Do you mind?', 'I'm very sorry but..', especially if they have found this to be a successful strategy for avoidance. There is, though, a feeling that this is only skin deep and they can be unsubtle and without depth, as though they know a response is required but are unsure at what level. Greater empathy than in Asperger's syndrome is apparent but sometimes it seems at an intellectual, rather than at an emotional level. Social behaviour can be very ambiguous and a lack of a sense of boundaries can result in very uninhibited behaviour. Does not identify with self as a child and prefers adults, but does not recognise 'status'. One parent described their twelve year-old son by saying, 'to other children he will happily act as if he were their mother 'Have you washed your hands?...Don't put your elbows on the table'...but doesn't have a sense of himself also needing to follow basic table manners.' Another mother described how her son, aged nine, 'didn't know her as a mother' and how she was fearful 'that there's no-one inside...no enduring person that is Chris'.

4. Lability of mood, impulsive, led by need to control

This links with social ambiguity. The child may switch from one state to another very quickly (e.g. from contented to aggressive) in a way that parents describe as 'like switching a light on and off'. This may be in response to pressure and perceived expectations, and emotions may seem 'over the top' or like an act. The child seems driven by the need to be in charge and can change in an instant when this isn't the case.

5. Comfortable in role play and pretend

Interest in this is typically very high and children often mimic and take on roles of others (extending and taking on a style, not simply repeating and re-enacting what they may have heard or seen). This can also often be used as avoidance (eg 'I can't pick it up...I'm a tractor and tractors don't have hands') or to control events and people. A very common example is children who behave as if they were teachers to other children. At the extreme, some children seem to become a collection of roles and lose touch with reality.

6. Language delay.

This seems as a result of passivity. There is often a striking and sudden degree of catch-up. Semantic content is odd and often a prominent feature. Pragmatics are not as disordered as in autism or Asperger's syndrome with more fluent use of eye-contact (other than when avoiding demands) and conversational timing. Some pragmatic difficulties remain such as literality, understanding sarcasm and teasing.

7. Obsessive behaviour.

Demand avoidant behaviour usually has an obsessive feel, other demands tend to be social and can result in blame and harassment, which can cause real problems for peer relationships in school. One teacher, writing about Tom, aged five, described how he, 'is very attached to a boy called Adam. He is only interested in emulating Adam's work and often talks to him and ignores the teacher. He will only eat food if he thinks Adam is eating at the same time.'

8. Neurological involvement

Crawling is late or absent in more than half these children and other milestones can be delayed. Clumsiness and physical awkwardness is often seen, but Newson feels there is insufficient hard evidence as yet.

Diagnosis and classification

The publications on PDA have attracted great interest and some controversy. The overriding reason for the interest has been in the strong sense of recognition expressed by both parents and professionals of the behavioural profile so cogently described and just how different it is from conventional understandings of ASD. The controversy, particularly amongst the medical community, has been about whether PDA does exist as a separate syndrome within the pervasive developmental disorders or whether it is part of the autism spectrum. For example, Wing and Gould (2002) feel that PDA is not a separate syndrome and that the individual behavioural features portrayed in the constellation described as PDA can be found within individuals with an autistic spectrum disorder. They go on, though, to agree that 'recognition of this subgroup with special problems is innovative and clinically valuable'.

The area of classification, categorisation and diagnosis is extremely complex and variable, with a range of views and models put forward by various professional groups and individuals. As stated, Newson proposes PDA as a separate syndrome within the Pervasive Developmental Disorders, which is the recognised category used within the psychiatric classification systems put forward by the World Health Organisation, 1992 (ICD-10) and the American Psychiatric Association, 1994 (DSM-IV). Autism and Asperger's syndrome appear as diagnosable disorders within this category, as do Pervasive Developmental Disorder Not otherwise Specified (DSM-IV) and Atypical Autism (ICD-10). Newson concluded that PDA is a separate entity as the sample demonstrated that the identified children had the pattern of features in common and that these features could be significantly differentiated from those with other syndromes, namely autism and Asperger's syndrome.

Diagnostic systems and categories, though, as well as showing variation across professional groupings and with individual usage, are also evolving concepts. Newson recognised this when devising a diagram (Newson, 1999) to demonstrate how PDA is a specific disorder which, along with other disorders including autism and Asperger's syndrome, makes up the family of disorders known as Pervasive Developmental Disorders. The diagram depicts clusters of symptoms which represent specific disorders within the PDD family. The heading for the diagram of Pervasive Developmental Disorders includes the note: sometimes 'autistic spectrum' is loosely used to describe the whole family.

Autistic (or Autism) Spectrum Disorder (ASDs) has become increasingly used as a term to cover the range of individuals showing the qualitative differences in social interaction, communication and the ability to think flexibly that make up the 'triad of impairments'. As our understanding develops about the spectrum comprising behavioural symptoms that are dimensional rather than categorical, we are increasingly recognising more subtle characteristics as part of the broader phenotype (Bailey et al., 1998).

It is also the case that the spectrum is now usually followed by the term 'disorders' (with deliberate use of the plural) in recognition of the fact that there are almost certainly a number of subtypes within the spectrum. In the UK, a governmental working group across the health and education departments published Autistic Spectrum Disorders: Good Practice Guidance (Department for Education and Skills and Department of Health, 2002) and pointed to

'a number of sub-groups within the autistic spectrum. There are differences between the sub-groups and further work is required on defining the criteria...It may be necessary to adopt specific strategies in relation to particular areas of difficulty in order to assist a child to maximise their potential and preserve their dignity' (p. 6).

David Amaral (2006), co-director of the University of Davis Autism Phenome Project, suggests that,

'the tremendous variation in autism leads us to believe that autism is a group of disorders rather than a single disorder...we are determined to provide the specific biomedical and behavioural criteria that accurately define distinct subtypes.' (p. 43)

It seems that, in practice, the terms ASD and PDD may have become synonymous. Indeed, the UK National Autism Plan for Children (National Initiative for Autism: Screening and Assessment, 2003) seemed to imply just that, by using the term Autism Spectrum Disorders throughout its report as meaning

'the group of pervasive developmental disorders (PDD) characterised by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by a restricted, stereotyped repertoire of interests and activities.' (p.15)

The report goes on to say that Autism Spectrum Disorder is not in itself a category within medical diagnostic systems but that it 'broadly coincides with the category of 'pervasive developmental disorder''(p. 74).

In this context, prolonged debate about whether PDA is a syndrome within the family of pervasive developmental disorders or a subgroup of what has become another 'umbrella term' of Autism Spectrum Disorders becomes rather distracting. Instead we should be constantly focused on the true purpose of diagnosis: to better understand and make sense of individuals and to use that understanding to help us formulate more effective forms of intervention and provision.

Implications for education and management

When providing a service that spans processes of both diagnostic assessment and subsequent education there can be tensions between the medical model of diagnosis and categorisation and an educational model that is based on the identification of individual needs. Critics who use the pejorative term ‘labelling’ to describe diagnosis tend to be relating their own experience of how the diagnostic process was conducted and communicated. Any diagnosis should engage the parents or carers in such a way that leads to a better understanding of their child and is therefore inextricably linked to appropriate educational and other interventions. It should also be concerned with individual strengths as well as areas of need and reflect the child’s individual profile and personality, alongside the way in which they match up to the criteria for a particular diagnosis. Newson describes this procedure as one of ‘mapping’ and details the importance of differential diagnosis, highlighting parental dissatisfaction with the vagueness of general terms such as autistic spectrum disorder when applied to individual children.

Clinical experience of families that have been seen at the centre over many years echoes this feeling. One parent described a common reaction when speaking at a recent conference organised for parents and professionals about PDA.

‘The paediatrician did place Daniel on the autistic spectrum but it didn’t quite fit - if the hole’s big enough, the square peg will fit. We accepted this but then we came across the diagnostic criteria for PDA and this fitted Daniel perfectly. Some people thought it didn’t matter if PDA was on Daniel’s statement (of special educational needs) but it did to us, it did especially for Daniel, so he could receive the correct input’.

As with any child, educational provision for a child with PDA is about attempting to match the curriculum, approach and support that is required to the child’s individual needs. PDA is a dimensional disorder which impacts differentially on individual children and interacts with other developmental factors and personal circumstances. It is almost always the case, though, that the child’s demand avoidance will cause him to function below his potential for much of the time. Children with PDA may be provided for in the full range of educational placements; mainstream, special or specialist schools (such as those designated for children with ASD). Other children will have been excluded from school after a history of educational failure. On the one hand there are some children who seem to have learnt that keeping a low profile can reduce pressure and they are relatively compliant at school (usually, though, at the expense of behaving much worse at home). On the other hand, there are those where school provision has broken down altogether and the child receives varying levels and types of individualised support packages from their families and professional agencies. Sadly, it is not uncommon for children with PDA to be placed in a series of schools, as one placement after another breaks down. Key issues for almost any placement will include how to create an environment whereby the child feels comfortable enough to ‘tolerate’ the educational process, can be kept on task to the greatest extent possible and where any disruption to other children is minimised.

The centre is often contacted for advice about the most appropriate type of placement for children with PDA and this is nearly always impossible to answer briefly. It is usually the character and personality of the prospective school that determines its success, rather than any particular designation. A genuine commitment to inclusion, strong support from the head and a positive, creative, flexible and adaptable outlook are critical. A commitment to work with the child’s family in a supportive and open partnership is also vital.

Alongside the research and practice that has led to a more detailed clinical description of PDA, Newson and colleagues were also developing guidelines that set out some of the implications of this condition for the education and management of these children. This work started alongside the clinical accounts developed at the Child Development Research Unit and continued through work at the Early Years Diagnostic Centre (now the Elizabeth Newson Centre) and its associated specialist school, Sutherland House (Newson, in collaboration

with Christie and staff of Sutherland House School, 1998). The author and colleagues at Sutherland House, as well as those working with children who had been referred for specialist assessment, were describing how many of the generally accepted strategies that are advocated for working for children with autism and Asperger's syndrome were not proving successful for children with PDA; an altogether different emphasis was required.

Typical of the reports that are received by the centre from schools, as part of the process of gathering information to support an assessment, is the following extract from a teacher's description of Jack, a six year old with an earlier diagnosis of autism.

'No strategy works for long and unlike the other autistic children it is better if we keep changing the routine all the time with Jack. We found the more routine there is the worse he is...you need to catch him unawares. We have tried using behavioural approaches with him but these have not worked. He doesn't seem to understand rewards...do this and then you can have that...he will snatch the reward and then not do the task. He has his set agenda and he is always in control of the situation.'

Jack's teacher, working in a special school, points out some of the key differences in emphasis. The use of structure, routine and behavioural principles of reward that are usually effective for children with autism or Asperger's syndrome are rarely so for children with PDA.

Sutherland House School is a specialist school for up to 84 children with autism and related conditions aged between 4 and 19. For many years the school has been recognised for its high level of expertise in providing for children with autism and Asperger's syndrome and its ability to personalise this expertise for the individual child. Like most specialist schools in the UK, the school's pupil profile has become increasingly complex over the past few years. This has included an increase in the number of referrals and admissions of children who fit the PDA profile, all of whom had been in other school placements (both mainstream and special), which had resulted in major breakdown. A number of these children had been out of school for several months; in one case for more than a year. In response to this, a working group of senior managers, teachers, psychologists, therapists and teaching assistants from across the school started to meet regularly to consider the needs of this group of pupils, and to review and update the existing educational and handling guidelines (Christie, 2006) and share experiences and good practice. This work was supplemented by the wider clinical experience of children referred for diagnostic assessment at the centre, which works in very close collaboration with the school.

An initial focus was to consider the features that these children had in common. The diagnostic criteria were a useful starting point and certainly staff were universally faced with the daily challenge of providing for children who were demand avoidant, socially manipulative, impulsive and seemed led by a need to control. The group wanted to look beyond this, though, to the ways in which this impacted on the process of learning and teaching; looking at the child as a learner, the style of teaching approach that worked best and the support needs of the staff and family. In doing this, the group, who had considerable experience in working with children with autism and Asperger's syndrome, were conscious of some of the differences in their methodology, particularly those which were in some way counter-intuitive when working with an accepted autism-specific 'orthodoxy'. This is, though, in no way to suggest that there is one set of guidelines that can be applied to children with autism and Asperger's syndrome and another that works for PDA (if only it were that straightforward). It is more a question of emphasis and prominence; in the end any strategies and approach need to be individualised.

The child as a learner

The overriding state of the child's approach to school and learning is one of anxiety, which for a number of children impacts on their willingness to come to school in the first place (the ultimate avoidance). This requires detailed planning and negotiation with parents, the child and those involved with the transport. Unsurprisingly, this anxiety is largely driven by the child's perception of demands or potential demands, being faced with failure and not being in control. Some of the other key characteristics impacting on the child's learning that were emphasised by staff are described below, most of which relate to their demand avoidance, others to different criteria. Not all of these characteristics are present in every child.

- A very poor sense of self-esteem, which often results in children expressing that they can't do something or won't like it as a 'first response'. Lack of confidence in crossing the threshold necessary to engage in an activity (what has been described as 'can't help won't').
- An expressed desire to be on a par with or better than others, but not seeing it as necessary to put in the effort required.
- An ambivalence about succeeding and enjoying an experience or activity, typified by the child who destroys their work on completion when it is commented on by the teacher.
- A lack of permanence and transfer of learning and experience, which means that there can be very sudden and dramatic set backs for the child after relatively prolonged periods of settled behaviour and progress. This leads to a feeling among staff that changes have often been brought about by managing external features, such as the environment and the way people relate to the child, rather than internal change within the child himself.
- Very poor emotional regulation means the child is prone to mood swings and phases which can be both short-lived or last for longer periods of time. The child's level of tolerance is very much mood-related and there can be what are best seen as 'can't help it days' when it is unproductive to pursue demands. There is often a sense of the child being emotionally exhausted from 'always being on the watch' for the next demand.
- A desire to have friendships and relationships with other children but inadvertently sabotaging this through the need to be in control, manipulating and mediating or refereeing others' interactions. The child may also blame and victimise other children for things that have gone wrong, even though this is often attributable to their own behaviour. This can include the holding of grudges over long periods of time and planned retribution.
- As well as the disruption caused by the explosive behaviour or aggression that may be used in response to pressure (already described as a panic attack) the child may sometimes articulate threats of violence and use obscene and shocking language.
- Extensive involvement in fantasy and role play in a way that cuts off the child and leads to some of them feeling that they have features of those they mimic or identify with. This can be problematic (eg a feeling of being 'omnipotent' when identification is with cartoon characters, superheroes etc).

Teaching style and approach

- The quality of relationship(s) is fundamental. A keyworker system is usually most effective in the early stages. The keyworker can build up an intimate knowledge of the child and know when to pursue an objective and when to reduce pressure, making continual adjustments as needed. The relationship works both ways and the child builds up and accumulates trust in the individual worker, becoming more confident in their ability to adapt accordingly. It is usually best to sit back and observe at first, and to place few demands while the relationship develops. In practice a single relationship of this sort can cause organisational problems for a school, put undue pressure on the adult concerned and lead to over dependency. As time progresses, it is best if this role can be shared amongst a small group.
- The style needs to be highly individualised but less directive and more intuitive than would ordinarily be the case with children with autism. 'I wonder how we might...' or 'I can't quite see how to do...' is likely to be more effective than 'Now let's get on with your work'. Adults need to empower the child by giving more choices and where possible allow a feeling of self-control.
- Adults need to keep calm and level in their own emotions in the face of challenging or disruptive behaviour, or situations that they may find frustrating. The child with PDA is adept at reading these reactions and gains satisfaction from the excitement that their behaviour can bring about.
- It may be best to work alongside or behind the child in one to one sessions, and more group work can be effective, but there is a need to monitor the impact of this on other members of the group.
- Novelty and variety is often effective because the child may exploit routine and predictability. Variety in the pace of presentation and personal style can intrigue the child. Creating a sense of mystery and suspense can be helpful; many teachers describe the value of 'pulling rabbits out of the hat'. Building on a child's strengths and interests (however odd these may seem) provides opportunities for incidental learning.
- Drama and role play make use of the child's interest in imaginative play and can be used to depersonalise requests or teach morality.
- The visual clarification methods (symbol strips, written messages, cartoon drawings etc) that are so successful for children with autism can also be useful for children with PDA, but often for slightly different reasons, in that they can be used in a way that de-personalises demands.
- Expectations should be disguised where possible and reduced to a minimum. Confrontation should be avoided where possible. This should be underpinned by an understanding of the condition; the child with PDA doesn't make a 'deliberate choice' not to comply and can not overcome the situation by 'an act of will'. He may, though, begin to make a series of achievements towards this end as trust and confidence builds.
- Ground rules need to be as few as possible but then maintained using techniques such as passing over responsibility (eg 'I'm sorry but it's a health and safety requirement'), de-personalising (through the use of imaginary characters, visual clarification etc) and giving choices that allow the child a feeling of autonomy.
- For children with explosive behaviour, having a 'den' or 'safe haven' can be very useful. Somewhere the child can have space and time. It can allow the staff to 'regroup' and give the child dignified privacy to compose themselves before they rejoin the group.
- Be flexible and adaptable. Strategies need to be changed much more frequently than for a child with autism. What works one day, may not work the next, but it may be worth coming back to in the future.

- Using quite complex language can often be effective. This may go against the commonly accepted use of concise language styles for children with autism (based on an understanding of some of their processing and receptive language difficulties). Concise language can come across to the child with PDA as confrontational, while more complex language tends to feel more negotiative and may also intrigue the child. Humour can also be helpful and be used to coax and cajole the child.
- Develop strategies that reduce anxiety. Many of the above are aimed at doing just this by reducing the feeling of pressure that the child senses. Other techniques such as teaching relaxation, increasing the amount of physical exercise, giving the child a physical and psychological refuge within the school can all be valuable.
- Try to build personal understanding and self- esteem. The curriculum (in the UK) now gives a much higher priority to the concept of 'emotional literacy', which presents real opportunities for children with complex social and communication differences. Mentoring sessions (at Sutherland House these are described as personal tutorials) can be constructive. Techniques that have been developed for children and young people with autism and Asperger's syndrome can be adapted for use. Sessions draw on principles that include cognitive behaviour therapy (Greig and MacKay, 2005), Social stories (Gray, 1998) and developing self-awareness (Faherty, 2000). One pupil (aged 10), when asked during a session what he thought PDA meant replied 'Well the clues in the words! It means if someone asks me to do something I'm likely to say no...that's me all over isn't it?'. But sometimes children with PDA enjoy this sort of activity enormously, yet have real problems in identifying that it applies to them.

Support needs of staff and the family

Whatever the type of educational placement, mainstream or special, the child with PDA is likely to require an especially high level of individual support. In practice this means that a team of professionals, with varying levels of expertise and understanding will be involved in supporting the child. Access to training is important, but even more critical is the provision of opportunities for communication, planning and mutual support. Children with PDA can be exceptionally demanding in the pressures that they put on individual staff and teams by their avoidant and at times extreme behaviour, their unpredictability and inconsistency and their differential responses to various staff. Working in a creative, flexible and adaptable way is both physically and emotionally draining. Staff need to be able to work together to avoid being played off against each other, know when to take the lead and when to support others and to enjoy the challenge of working creatively with such children. One teacher when asked to describe a child about to leave her class said that he was 'engaging...thought provoking...great company...an original thinker and definitely one of the most rewarding children I have worked with'.

A full discussion of the support needs of the family is sadly beyond the scope of this paper but some of the issues will be self-evident from the above. The initial difficulty for parents is obtaining a diagnosis that enables them to make sense of their child and gives them a starting point in working out ways in which they might more effectively relate to and manage their child. In correspondence, one parent wrote:

'It was a huge consolation to find a set of characteristics and criteria that seemed to have been made for my child...after years of reluctant trawling through ASD diagnostic criteria and really feeling that something didn't sit right, here was a tailor-made paper on my child'. Others have written 'understanding PDA has helped us adapt our own thinking to make small concessions which make all the difference to our son' and 'the diagnosis has helped me understand the reasons behind behaviour and hence I now deal with my son in a different way. I avoid direct demands and give him winding down time during the day to help him relax...'

Beyond this initial period of understanding, parents are likely to face considerable practical challenges when bringing up a child with PDA. These can be compounded in a child who can be so variable and inconsistent in their behaviour in different settings and with different people. It is critical that professionals listen to parents, try to gain as full a picture as they can and work together in a supportive and nonjudgmental way.

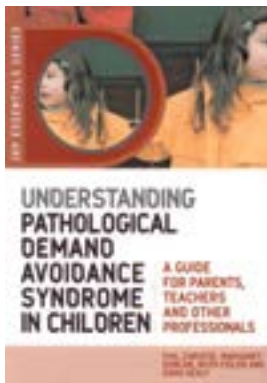
Concluding comments

The descriptions of the distinctive profile of Pathological Demand Avoidance syndrome are resonating with an increasing number of parents and professionals who recognise how it makes sense of children that were previously difficult to understand within conventional diagnostic concepts. This has contributed to emerging insights into the different emphasis that is needed for interventions with such children to be more effective.

It is apparent that other research studies and clinical practitioners are identifying the need to define and describe the various sub-groups that may lie within the broad categories of pervasive developmental disorder, or autism spectrum disorders. The time now seems right to work collaboratively to further our understanding of PDA and the best ways to support these children, their families and those making educational provision.

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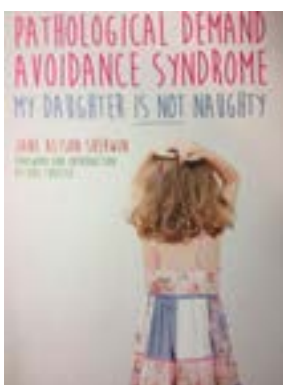


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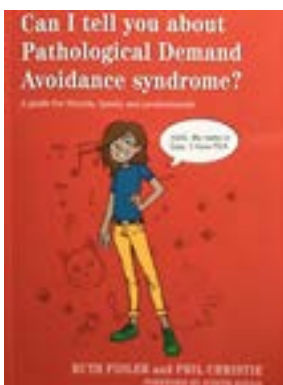


My Daughter Is Not Naughty

Jane Alison Sherwin. Jessica Kingsley Publishers, Jan 2015

ISBN: 978-1-84905-614-4 Paperback - £12.99

Full of advice and support, this book is an honest account of one family's experiences of raising a child with Pathological Demand Avoidance Syndrome (PDA). It includes strategies to help manage PDA behaviours, information on obtaining diagnosis and raising awareness, and explanations to help readers gain a better understanding of the condition.

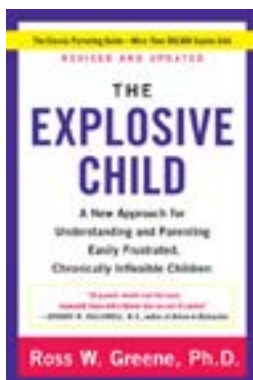


Can I Tell You About PDA?

Ruth Fidler and Phil Christie. Jessica Kingsley Publishers, Jan 2015

ISBN: 978-1-84905-513-0 Paperback - £8.99

In this illustrated guide Issy invites readers to learn about PDA, a part of the autism spectrum, from her perspective, helping them to understand how it causes her to find simple, everyday demands very stressful. Issy tells readers (aged 7 upwards) about all the ways she can be helped and supported by those around her.



The Explosive Child

Ross W. Greene, Harper Paperbacks, 2014

ISBN: 978-0-06227-045-0 Paperback - £10.99

Although not written specifically about PDA, this book offers some really useful management strategies for 'chronically inflexible children'.

Extreme Demand Avoidance Questionnaire (EDA-Q)

This questionnaire was designed by Liz O’Nions to identify individuals with possible PDA for research purposes. It is not a validated tool for diagnostic purposes. It should therefore be used as a guide to identify possible PDA traits and point to the need for further evaluation which should be based on a multidisciplinary assessment.

How to score the EDA-Q

Questions 1 - 26 (apart from questions 14 and 20)

Not true = 0

Somewhat true = 1

Mostly true = 2

Very true = 3

Questions 14 & 20

Not true = 3

Somewhat true = 2

Mostly true = 1

Very true = 0

Results

For children aged 5 to 11 a score of **50** and over...

For children aged 12 to 17 a score of **45** and over...

...identifies individuals with an elevated risk of having a profile consistent with PDA.

The EDA-Q should not be considered a diagnostic test. For diagnosis, a thorough assessment by an experienced professional is required.

The EDA-Q has been developed as a part of ongoing research into PDA and is copyright of Liz O’Nions.

		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.				
12	Seems unaware of the differences between him/herself and authority figures (e.g. parents, teachers, police).				
13	If pressurised to do something, s/he may have a 'meltdown' (e.g. scream, tantrum, hit or kick).				
14	Likes to be told s/he has done a good job.				
15	Mood changes very rapidly (e.g. switches from affectionate to angry in an instant).				
16	Knows what to do or say to upset specific people.				
17	Blames or targets a particular person.				
18	Denies behaviour s/he has committed, even when caught red handed.				
19	Seems as if s/he is distracted 'from within'.				
20	Makes an effort to maintain his/her reputation with peers.				
21	Uses outrageous or shocking behaviour to get out of doing something.				
22	Has bouts of extreme emotional responses to small events (e.g. crying/ giggling, becoming furious).				
23	Social interaction has to be on his or her own terms.				
24	Prefers to interact with others in an adopted role, or communicate through props/toys.				
25	Attempts to negotiate better terms with adults.				
26	S/he was passive and difficult to engage as an infant.				



If an Autism Spectrum Disorder is recognised or suspected a referral should be made to a Child Development Clinic (CDC) where assessments can be made for these disorders. Not all clinics will be familiar with Pathological Demand Avoidance syndrome so onward referral may be required, if the local CDC is unfamiliar with the diagnosis.

Child and Adolescent Mental Health Teams (CAMHS) may need to be involved as the child gets older.

Remember:
Due to their child's complex and challenging behaviour the parent may be exhausted and very concerned. They may have already done a lot of research into what may be contributing to their child's difficulties

LISTEN to their concerns.

LOOK at the evidence before you.

TALK to other agencies involved.

REFER for multidisciplinary assessment.



This is a guide for GP's, nurses, Health Visitors, Social Workers and other primary care workers who are likely to first come into contact with children on the autism spectrum and need to be alert to early signs and parental concerns. ASDs are spectrum conditions so some overlap within these areas and diagnostic terms are inevitable. Many services use the diagnostic term Autism Spectrum Disorder, rather than using the terms Asperger Syndrome or PDA, however it is important to recognise these different presentations of ASD, as this will signpost to the most suitable support strategies. If the right support is given then the child will have the best opportunity to reach their full potential.

Further information about Autism Spectrum Disorders may be obtained at the National Autistic Society website:

www.autism.org.uk

The PDA Society provides advice and information for parents and professionals about Pathological Demand Avoidance syndrome. Visit our website and forum at:

www.pdasociety.org.uk



Recognising Autism Spectrum Disorders in the Early Years



Autism

The three main areas of difficulty which all children with autism share are sometimes known as the 'triad of impairments'. These are difficulties with:

Social Communication
Social Interaction
Social Imagination

Some children with autism may have limited or no speech. They may repeat what the other person has said (echolalia). They may have great difficulty understanding body language and facial expressions. They may be unable to understand what others are feeling or thinking. They may have sensory problems. They may have learning disabilities.

Early signs of autism in young children may include:

- Lack of pointing
- Language delay / lack of speech
- Behavioural problems / frequent and severe meltdowns
- Poor eye contact
- Unusual play (e.g. lining up cars or just spinning the wheels rather than playing with them as a car)
- Insistence on routine / sameness
- Obsessive behaviour
- Seeming distant or poorly interacting
- Repetitive behaviours



Asperger Syndrome

Children with Asperger Syndrome share the same areas of difficulty as children with autism:

Social Communication
Social Interaction
Social Imagination

They may also have sensory problems and find it difficult to stray from routines. While there are similarities with autism, children with Asperger Syndrome have fewer problems with speaking and are often of average, or above average, intelligence. They do not usually have the accompanying learning disabilities associated with autism, but they may have specific learning difficulties, for example dyslexia.

Children with Asperger Syndrome may also:

- have difficulty recognising facial expressions
- be very literal
- find social 'chit chat' very difficult
- struggle making friends
- have an unusual interest in a subject
- may find imaginative games very difficult in the playground



Pathological Demand Avoidance syndrome (PDA)

Children with PDA share the same areas of difficulty as those with other types of autism spectrum disorder (including sensory problems); however the central difficulty is the child's need to avoid everyday demands and expectations. This extreme avoidance stems from an anxiety led need to be in control. Children with PDA appear to have better social understanding and communication than others on the spectrum. Some children use distraction or withdrawal to avoid a demand, however many children can exhibit extreme and sometimes violent meltdowns when asked to do simple things, e.g "put your coat on"

At times the child with PDA can appear to have no difficulties whatsoever. In reality they:

- Experience extreme anxiety in response to the everyday demands of life
- Have extreme and rapid mood swings
- Can be domineering in their play and strive to be in control at all times
- Are comfortable (sometimes over involved) in role play and pretending and may blur fantasy and reality
- May have early speech / language difficulties with a good degree of catch up later on
- Have obsessive behaviours, sometimes involving people, or imaginary characters

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Further information and contacts



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Autism East Midlands

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National Autistic Society

Website - www.autism.org.uk

Multi-Disciplinary Diagnostic Assessments

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The Lorna Wing Centre

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Pathological Demand Avoidance Syndrome

A Reference Booklet for Health, Education and Social Care Practitioners

“Knowledge of PDA is still at an early stage but there are exciting developments happening in diagnostic understanding, greater awareness of successful educational and therapeutic approaches, together with the perspective that is now being gained from research. With all these coming together it provides an opportunity for wider recognition of the condition as well as better understanding and support for individuals with PDA and their families.”

Phil Christie, 2015.

“Awareness Matters”