

The distinctive clinical and educational needs of children with Pathological Demand Avoidance syndrome: guidelines for good practice

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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, *The distinctive clinical and educational needs of children with Pathological Demand Avoidance syndrome: guidelines for good practice*, was first presented at the World Autism Congress held in Cape Town, South Africa in 2006. It describes a syndrome that was identified over a long period of time by Professor Elizabeth Newson, often during 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 displayed 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, Professor Newson 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 1980s. 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.

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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.

The 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 that described them, in various ways, as being 'atypically autistic'.

Newson and her colleagues began to feel increasingly dissatisfied with the description of atypical autism and felt 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.

Distinctive clinical and educational needs

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 that 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 four or five boys to one girl in autism and ten 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.

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.

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 physical 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.'

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. The child 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'.

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 (eg 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.

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.

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.

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.'

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 among 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 agree, however, 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 that, along with other disorders including autism and Asperger's syndrome, makes up the family of disorders known as pervasive developmental disorders (PDD). The diagram depicts clusters of symptoms that represent specific disorders within the PDD family. The heading for the diagram of PDD 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:

'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 ASD 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 ASD 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, together with the way in which they match 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 ASD 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 pediatrician 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 that impacts differentially on individual children and interacts with other developmental factors and personal circumstances. It is almost always the case, however, 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.

As well as 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 four 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, to review and update the existing educational and handling guidelines (Christie, 2006) and to 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 the staff was 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 that were in some way counter-intuitive when working with an accepted autism-specific orthodoxy. This is 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.

Key characteristics

- 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 the necessity of the effort required.
- Ambivalence about succeeding and enjoying an experience or activity, typified by the child who destroys their work on completion when the teacher comments upon it.
- Lack of permanence and transfer of learning and experience, which means that there can be very sudden and dramatic setbacks 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.

- Very poor emotional regulation means the child is prone to mood swings and phases that can be either 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.
- 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 blame and victimise other children for things that have gone wrong, even though this is often attributable to their own behaviour. This can include holding grudges over long periods of time and planned retribution.
- As well as the disruption caused by the explosive behaviour or aggression shown in response to pressure (which can be viewed as a panic attack), the child may 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 them feeling that they have features of those they mimic or identify with. This can be problematic (eg a feeling of omnipotence when identifying with cartoon characters or superheroes).

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 dependency. As time progresses, it is best if this role can be shared among 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 and 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 and 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 depersonalises 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 cannot 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 build.
- Ground rules need to be as few as possible but maintained using techniques such as passing over responsibility (eg 'I'm sorry but it's a health and safety requirement'), depersonalising (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 a pause for breath 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 and giving the child a physical and psychological refuge within the school can all be valuable.
 - Try to build personal understanding and self-esteem. The UK curriculum 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 ten), when asked during a session what he thought PDA meant replied 'Well, the clue's 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'.

Some of the support needs of the family 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.'

Other parents 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 in 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 non-judgmental way.

Effective intervention and support

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.

References

- Amaral, D (2006) Autism phenome project report, *Autism Spectrum Quarterly Summer 2006*, Connecticut: Starfish Specialty Press, LLC.
- American Psychiatric Association (1994) *Diagnostic and statistical manual of mental disorders* (4th edn) (DSM-IV) Washington DC: APA.
- Bailey, A et al (1998) Autism: the phenotype in relatives *Journal of Autism and Developmental Disorders*, 28, 369–392.
- Christie, P (2006) *Teaching and learning strategies for children with Pathological Demand Avoidance syndrome* Information Service, Elizabeth Newson Centre, Ravenshead, Nottingham.
- Department for Education and Skills and Department of Health (2002) *Autistic Spectrum Disorders: Good Practice Guidance*.
- Faherty, C (2000) *Asperger's's syndrome... what does it mean to me?* USA: Future Horizons.
- Greig, A and MacKay, T (2005) Asperger's's syndrome and cognitive behaviour therapy: new applications for educational psychologists *Educational and Child Psychology*, 22, 4 –14.
- Gray, C (1998) Social stories and comic strip conversations with students with Asperger's's syndrome and high-functioning autism in E Schopler, G Mesibov and L Kuncze, (Eds) *Asperger's syndrome or high-functioning autism?* New York: Plenum Press.
- National Initiative for Autism: *Screening and Assessment (2003) National autism plan for children: plan for the identification, assessment, diagnosis and access to early interventions for pre-school children with autism spectrum disorders*, London: National Autistic Society.
- Newson, E (1990) *Pathological Demand Avoidance syndrome: mapping a new entity related to autism?* Inaugural lecture, University of Nottingham.
- Newson, E (1996) *Pathological Demand Avoidance syndrome: a statistical update in therapeutic intervention in autism: perspectives from research and practice*, Sunderland: University of Sunderland.
- Newson, E (1998) in collaboration with Christie, P and staff of Sutherland House School, *Education and handling guidelines for children with Pathological Demand Avoidance syndrome*, Information Service, Elizabeth Newson Centre, Ravenshead, Nottingham.
- Newson, E (1999) *The family of pervasive developmental disorders: diagram*, Information service, Elizabeth Newson Centre, Ravenshead, Nottingham.
- Newson, E and David, C (1999) Pathological Demand Avoidance syndrome: what is the outlook? in P Shattock, and G Linfoot (Eds) *From research into therapy*, Sunderland: University of Sunderland.
- Newson, E, Le Marechal, K and David, C (2003) Pathological Demand Avoidance syndrome: a necessary distinction within the pervasive developmental disorders, *Archives of Disease in Childhood*, 88, 595–600.
- Wing, L and Gould, J (2002) *Pathological Demand Avoidance*, London: National Autistic Society.
- World Health Organisation (1992) *The tenth revision of the international classification of diseases and related health problems* (ICD-10) Geneva: WHO.