

EDUCATIONAL AND HANDLING GUIDELINES FOR CHILDREN WITH PATHOLOGICAL DEMAND AVOIDANCE SYNDROME (PDA)

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(written in consultation with Phil Christie and the staff of Sutherland House School)

Any school will find that they have to make adaptations of one sort or another in order to meet the particular needs of a child with PDA. The first and obvious difficulty is that PDA children are 'active in being passive': they are obsessively concerned to avoid demands, and many parents describe their child as working harder to avoid the demand than she would have done by accepting it. Whatever the child's intellectual level, her PDA will cause her to function rather below that level for much of the time; thus educational support will need to be geared to helping the child to tolerate 'being educated' to the greatest degree possible, in order at least to approach her potential. We do not expect a 'cure', and it is typical that a PDA child's co-operation is maintained by continual effort on the part of staff and parents.

The educational needs of a child with PDA can be summarised under three major headings:

- keeping the child on task for a substantial period of each day;
- ensuring that what she appears to be learning is actually absorbed and retained;
- (not in all cases, but in most) ensuring that a minimal degree of disruption to other children takes place, and trying to create positive peer relationships despite the resentment such disruption can cause in other children. Sometimes this will include the need to keep other children physically safe.

We will expand a little on these needs, before setting out some guidelines derived from the experience of educating PDA children.

Keeping on task

Like autistic and Asperger's children, though for different reasons, most of a PDA child's learning will be done in a one-to-one situation. Children with PDA usually seek the company of adults; however, they have to balance this against their real fear of demands being made on them. Because of the surface sociability of the child, it is often easiest to disguise the pressures of learning through the pleasures of a positive relationship with the adult. This is best done through a keyworker, who will be able to devise many different strategies of 'getting through' to this particular child, learning when to reduce pressure and when (or how) to pursue it. A keyworker can gain an intimate knowledge of the individual child, while the child herself can learn to be sure about this adult's boundaries, and therefore not need to resist them quite so unremittingly.

Ensuring retention

A large part of the time allotted to the child will need to be spent on monitoring and checking what she has actually learned. Often as children seem to be becoming more tolerant, or to be finding ways of fitting-in to the learning environment, it seems that they begin to create a sort of 'act' or 'role' of the compliant child. However, they may actually be 'switching off' from processing and absorbing what they appear to be attending to: one teacher described it as 'she seems to put her mind into neutral as she comes through the door', and another as 'disengaging the brain'. The consequences of this are that the child may seem to have understood what was taught, even when checked at the time, but a fortnight or so later the understanding has gone; thus immediate checking is not enough, and much overlearning has to take place, which of course is time consuming. It also means that PDA children tend to do very poorly in even small remedial groups, where they quickly fall behind others.

The child who learns that fewer demands will be made if she just 'acts' attentive needs to have this strategy recognised and countered before it becomes habitual. For instance, if she is reading for meaning, this still needs to be regularly checked; it is not unknown for a child to have spent two years in senior school before anyone realised that she had stopped reading for meaning; and this can be true for a number of concepts, such as number and time. It has to be emphasised that gains are usually fragile for children with PDA.

Minimising disruption

Not all PDA children are actively disruptive, especially once they learn that keeping a low profile may reduce pressure. However, the possibility is always there because of the high impulsivity and changeable moods. Many PDA children learn compliance and tolerance at school, but then behave much worse at home, as if they cannot keep up the compliance for more than a few hours. It is important to realise that this is not to do with less competent handling at home, and much more to do with the limits of the child's tolerance and the need to 'let their hair down' somewhere; if not understood, this can cause great tension between parents and teachers. This reaction when the child is released from school is so common in PDA that parents need to be reassured that it is not their fault, and that it is most unlikely that children with these problems will ever show equal compliance in all their environments. It can be extremely helpful for children of seven upwards to have fifteen minutes at the beginning and end of each day devoted to counselling support from the teacher or keyworker.

It is very common for a PDA child to resist social demands by lashing out or pushing forcefully, and sometimes by screaming or swearing. It can be quite difficult, when the child is behaving in such an apparently robust way, to understand that this is the result of extreme vulnerability and anxiety. As many people living or working with PDA have discovered, it is not at all helpful to think of this behaviour as 'aggressive'; once they see it as a **panic attack**, which describes it much more accurately, they are enabled to handle the child more appropriately by putting the emphasis on **reassurance** rather than blaming.

Occasionally a child will find that she can produce maximum disruption, *coupled with withdrawal of demands on her*, by pulling her pants down, urinating on the floor, or similar 'sexualised' behaviour. It is important that this strategy should not work as a

distraction from whatever the child is trying to avoid; staff need to remain calm and matter of fact paying the least possible attention to this behaviour, and completing the work in hand without fuss.

Other children in the class are likely to need active help in tolerating disruption; the school will also need to be proactive in preventing teasing and bullying, because PDA children are so naive that they very easily become targets for being 'set up' and otherwise exploited, which is not only destructive for them, but also for the other pupils who are tempted to do this. The 'Circle of Friends' technique has been found particularly helpful in mainstream schools for preventative work, and especially so with PDA children; it also has the advantage that it can be used as part of the personal and social education curriculum for the peer group. This technique aims to inform a group of children about the disabled child's difficulties and so create a protective and understanding 'circle of friends'; and this can be especially productive if the same children will be going forward into secondary school with the disabled child.

Information on the Circle of Friends technique is available from the Early Years Diagnostic Centre Information Service. We also have a booklet on PDA intended for siblings, and this can be adapted as a basis for informing the peer group. A Circle of Friends can be organised by whoever is most interested to do it; in some areas educational psychologists have developed this, but the SENCO, the Head, or in some cases classroom assistants or teachers have successfully led such groups.

SUPPORT NEEDS

It can be seen that the amount of input needed by PDA children is very substantial indeed. An hour each day of one-to-one academic work is needed by the child in order to make progress; taken together with extra support in group situations, this will amount to half-time support from a classroom assistant, as a minimum. Where there is also considerable disruption, and especially if the child hits out in panic when demands are made, many schools find that full-time support is needed. Inadequate support is not tolerable to the school and does not provide education for the child. For instance, in a recent review at a mainstream primary school, where a non-disruptive child was receiving only 2% hours support weekly, and where the school had chosen to devote all of this to counselling plus Circle of Friends, the child showed major gains socially but no progress at all academically; and indeed he had lost academic ground.

Experience suggests that the 'personality' of the school (and of individual key staff) is more important in many ways than its category. However, a mainstream school is appropriate wherever possible, as PDA children are socially imitative and therefore good normative models are important. The qualities one looks for in a 'hospitable' mainstream school for a PDA child are: tolerance, imagination, determination to succeed, adaptability, positive interest in working with an unusual and challenging child, and a commitment to integration. A strongly supportive head is of enormous value, probably a necessity. Inevitably, a mainstream school will need additional external funding. In an 'ordinary' special school, much enhanced staffing would still be needed. A school or approach based on traditional behavioural methods is not recommended for a child with PDA; a more personal and relationship-based approach has repeatedly been found more effective for PDA children: see below.

HANDLING AT SCHOOL AND .AT HOME

The following guidelines have been prepared in consultation with school staff who have experience with PDA children as well as autistic children, and who have needed to re-think their methods and adapt them considerably in response to this condition.

We have already mentioned that it is useful to take a keyworker approach with children who have PDA, and this is because the individual relationship is more significant in making progress than simple consistency. Because the child is socially manipulative, the keyworker needs to know his personality very well, and to establish herself with the child as someone who has definite limits that are going to be respected. Having said that, the keyworker needs to be highly flexible and imaginative, capable of re-negotiating and re-earning the child's interest daily. It is helpful to know that what works today may not work tomorrow (because the child doesn't want to be caught out twice!), but that it may well work again in a week's time. Nothing will invariably work, and that is the price paid for **social awareness** coupled with demand avoidance.

This means that the keyworker needs to have a variety of strategies on hand, and not be too concerned if a particular one is unsuccessful on a particular day. The successful teacher of a PDA child will be someone who has liveliness, ingenuity, humour, wit and patience; this job is not for someone easily depressed, but for a person who enjoys a challenge, who can appreciate the sociable aspects of the child, and who can make use of any of his strengths, such as role-play. A degree of charisma is a bonus, since this will usually intrigue the child!

Teaching style

A highly individualised style is needed, based partly on the understanding of demand avoidance but partly on the individual child's personality and tolerances. Staff need to understand the nature of the condition, and that demand avoidance is not something that the child can overcome by an act of will, although he may manage a series of achievements by making a series of efforts. There is a real coping problem here which has to be recognised; **the problem is an incapacity** rather than naughtiness. The child literally does not know what other children know by nature about how to behave, and is deeply confused; 'being told' cannot solve the problem, and nor can sanctions.

Expect to be **indirect** in all demands made, rather than directive: eg not 'Now get on with this puzzle please' but 'I wonder what's the best way of doing this puzzle- I can't quite see how to do it.....'. Try tape-recording and listening to your requests critically, and practise re-wording them to be more indirect; you will become skilled at this. Don't be afraid to be intuitive, and don't abandon a strategy for good just because it didn't work first time. Use lots of humour: coax, cajole, and even challenge if you do it humorously, eg 'I bet you can't.....'. Use variety in the pace of your presentation; variety in personal style; variety in learning environment. Disguise your expectations to the child. Make sure your colleagues understand why you are behaving in these ways! -you need their support, and also their co-operation in similar handling methods.

Introduce goals gradually, building on positive experiences- don't allow the child to feel he has failed, so make sure he gets some sort of acceptable achievement out of every encounter. You need to limit your expectations, even if you know the child has better ability, remembering that (as one mother put it) 'It's not so much that he can't or he won't, but more that he can't help won't'. Try to empower him by allowing more choice in activities, direction etc. A very useful strategy is to offer a choice of two activities in which the one you really want him to do is the easier. But don't tell him not to do something in order that he'll do it through negativism - this may work a few times, but the message is not a good one.

Relationships

The child's progress at school hinges on his development of a strong, trusting relationship with the keyworker. Keep very calm and level in your emotions, including your facial expression - avoid showing the frustration that you will very likely feel, and never let him see it if you feel wary, scared or embarrassed. Give rather less eye contact than you would expect to. Be cautious about rewarding success: although praise can be motivating, often it makes the child decide not to give in so easily next time, and some children tear up work which has been praised. Ignore negative behaviours so far as you can. It can often be helpful to work beside or even slightly behind the child, rather than face to face.

Avoid actual confrontation so far as you possibly can; you will not win unless you are using unacceptable sanctions. Remember that the child has few boundaries and is driven to avoid demands by obsession. Your aim should be to help the child to discover that co-operation is no big deal after all, and can be very pleasant; confrontation won't teach him that. Take pride in your ability to negotiate and make acceptance more fun for the child, not in proving who's boss.

The teacher or keyworker, one hopes, will have a genuine liking for the child, and the ability to see and draw out his best potential. PDA children can be both frustrating and irritating, because they do their best to prevent teachers teaching. The most successful teachers of PDA children are those who appreciate the child's talents- even the talent for social avoidance - and find much to enjoy in the relationship.

Humour, pretending and role-play

Humour is extremely important, as otherwise the demands as perceived by the child become very oppressive for him. But novelty can be as useful as humour in oiling the wheels of the relationship. Remember that role-play and pretending are strengths, and use these: for instance, get the child to take a turn as teacher, teaching either the adult or perhaps a puppet (or even another child if appropriate). Puppets and toy animals can be useful as 'third person' to de-fuse the feel of confrontation in 1:1 work.

However, in some children role-play is very obsessional, taking up most of their time, and parents and teachers may want to try to reduce this, in an effort to keep the child in touch with reality. For instance, one 8-year-old, Nicola, was very resistant to 'being Nicola' except when being physically cared for. There was little point in trying to prevent this directly, but indirect methods could be tried. For instance, her parents could increase some of their nurturant care of Nicola, emphasising that it was Nicola who was being cared for. They could encourage her into helping with domestic activities that were particularly interesting, such as cooking or spring-cleaning, again making it clear that they were enlisting her help as Nicola to do things for the rest of the family: and the family would show their appreciation, eg clapping the cake or pudding she had made. This helped to show her that Nicola herself was a competent person, and didn't have to become a teacher (her favourite role) to exert this kind of control. One might also try saying to her 'I want Nicola to show me, not the teacher- I like Nicola best, please show me how to do this, Nicola'. Every opportunity was taken to present Nicola as helpful to others; usually by taking her seriously as a helper, rather than just telling her what to do or simply saying that she was not the teacher.

Home-school liaison

Teachers need considerable support from both colleagues and parents, and vice versa. Liaison and trust between home and school are absolutely vital. Schools and parents also need to understand that (as already discussed) the pressure of good behaviour is very difficult

for the PDA child to sustain, and often better behaviour at school may be bought at the expense of worse behaviour at home- sometimes the other way round. This is a special reason for home and school being open, trusting and sympathetic to each other's difficulties. A daily home-school book is very helpful.

Overall, similar handling methods to those already mentioned will be found the most effective at home as well as at school; especially the use of indirect requests rather than direct demands. It can be easy to become extremely authoritarian and even threatening with a PDA child, because this often works briefly; but it does raise the stress for the family as a whole, especially brothers and sisters. Indirect methods, although they take longer, keep relationships happier. It can be helpful to think about priorities, and choose beforehand which issues to press through and which to let go; this makes it easier to be both reasonably consistent and kind. What often happens is that parents try to make a half-hearted stand about everything, and are then defeated: this is demoralising and depressing for parents, and teaches the child to resist still further. It is best to agree in advance those behaviours that the family will accept gracefully! On the whole, more latitude will actually be needed at home; this of course is true for most children, but is much more of a necessity for PDA children, who really cannot cope with being good all the time!

Some children show their reaction to the stresses of school by rocking for an hour or more when they get home. It can be difficult to break into this, but it may be helpful to say 'You can rock for twenty minutes, and then we'll.....', offering some interesting distraction. It seems that some children literally don't know how to stop rocking unless a limit is set for them; but the positive alternative needs to be offered. Again, cooking often distracts effectively.

Most parents find that it is necessary to be very truthful with a PDA child, who may obsessively 'go on' about any deviousness. We believe that truth is also important where a child is uncertain about the difference between truth and falsehood, as is often the case in PDA. Certainly we have found that, although it is sometimes tempting to stretch the truth for the sake of peace, it is seldom worth it; but it is worth a great deal, especially later on, to be able to say to the child with conviction 'Have I ever told you a lie?- no'. Trust is especially valuable with adolescent children with this condition, who do develop a respect for people they can trust, but often have quite suspicious attitudes towards people in general.

We can expect the child's social skills to improve gradually. Lashing out is likely to decrease as she gets more used to the expectations at school being more predictable for her, and as her outbursts are treated as panic attacks and she is offered increased reassurance and calming procedures. Some children are much helped by massage of hands and/or feet, and we have found that this can even be a preventative measure; one child who experienced a build-up of pressure during the morning, and was calmed by foot massage after a predictable outburst at midday, responded very well to having a foot massage **on arrival at school** instead, and often did not need any more during the day. This also gets over any suggestion that the child might feel rewarded for her outburst, though this in practice is not very relevant. The few minutes of 'counselling', recommended earlier, can also act as a calming procedure at the beginning and end of the day; and a similar quiet time on arrival home sometimes helps to reduce stress levels for the rest of the evening.

FINALLY

Perhaps it's worth reminding school staff of two things:

- However great the stresses of finding ways to teach a child with PDA effectively, they are nowhere near the stresses that families have to cope with; and one of the biggest stresses on families is the fear that the school will give up on their child. You can make an enormous difference, not just in helping the child to tolerate demands and to learn, but in enabling parents to meet the child's continuing needs at the same time as creating a happy family life for brothers and sisters.
- Whatever the difficulties, this is probably the most interesting and potentially rewarding child you will ever meet, who will challenge your ingenuity and flexibility every working day. This can be a growth experience for you and for your professional skills. One head teacher said 'We never realised how interesting she was until after she'd left us, and we missed her', reflecting perhaps the difficulties of having had to work without the support of guidelines.

We hope that this booklet will give staff a head start in understanding *and enjoying working with* a child who has PDA.