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PATHOLOGICAL DEMAND AVOIDANCE SYNDROME

diagnostic criteria and relationship to autism and other developmental coding disorders

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In 1980 I presented a paper to the East Midlands branch of the British Paediatric Association in which I discussed a group of twelve children who in a space of five years had been referred to my clinic. Thesechildren seemed to share a pattern of features so consistently with each other that it seemed appropriate to describe them as suffering from a developmental disorder which added up to a recognisable syndrome. However, I could not find such a syndrome described with any precision in the literature : the nearest references have been Lorna Wing's description of a 'few' children in her epidemiological survey with what she called 'repetitive speech syndrome' (Wing, 1976) and John Richer's much more recent description of 'timid' children in an Asperger-like group (Richer 1989). Neither of these descriptions includes the detailed pattern of features in common that I was finding in my group. The central salient characteristic in all the children was an obsessional avoidance of the ordinary demands of everyday life, and I therefore used the term 'Pathological Demand Avoidance Syndrome' : for which I have been apologising ever since, but which is at least descriptive of the major problem that parents and professionals face with these children. (PDA is a more manageable term, and seems to have gained currency.)

During the eighties, further children have been referred to me who show the same pattern, and the present discussion is based on 36 children who show the syndrome in terms of what seem to be its essential features, together with a further 5 whose cases are not so clear cut. The original description has turned out to be surprisingly durable; it has been enlarged on in terms of detail, but not changed in its essentials. What has been added is a conceptualization of how PDA fits into a 'family' or constellation of developmental disorders; in a sense this has been a conclusion gradually arrived at, but it will perhaps be helpful to outline this argument first, then to describe the syndrome in some detail, and finally to return to the overview of PDA in its suggested context.

I am sure that the referral pattern of my clinic has been significant in bringing enough of these children to my attention to recognise their shared features. This clinic specialises in children with anomalous psychological development, and particularly in children with complex problems of communication. This means that we often see dysphasic and autistic children (autism also being a major research area for us); but we also see children who are puzzling because they have one or two apparently autistic features alongside many characteristics which are clearly against the diagnosis of autism. PDA children tend in fact to remind people of autism while in many ways showing a quite different picture, and indeed they are not usually thought of as non-communicating children. Nonetheless, it is the reminder of autism which brings them to my clinic. They do present as having extraordinary difficulties, and often create extreme stress and even panic in their carers, especially once they get to school. One could say that PDA children do not make sense to the people around them because the demands of the ordinary world don't make sense to them.

However, these are not the only children whose development is characterised by a failure to make sense of some important aspect of their world. Table 1 shows four syndromes which can be described as developmental coding disorders, and which perhaps can be seen as a constellation of related disorders. It also tries to make the point that these disorders may be found at variable levels of severity and associated with any level of intelligence.

The majority view of autism nowadays is as a global communication disorder in which the primary disability is a difficulty in coding (or making sense of) language in any mode. That is, the autistic child has problems with the languages of speech, gesture, facial expression and other body language, and also has difficulty with the social pragmatics of language — the social timing that allows dialogue flow and interchange. The global nature of this failure to make sense of all communicative modes imposes a major handicap, even greater than the more specific disabilities of dysphasia (the failure to code or make sense of spoken but not gestural or facial language) and dyslexia (the failure to code written language). I have come to see PDA as a failure to code social and personal identity. I shall come back to this in due course; for now we need only note that the sense of being firmly rooted in one's own self, and therefore being responsible for oneself, is central to psychological development, and that the loss of that sense must be seen as deeply destructive.

Defining features

Having been involved in the history of how best to define autism, I have been very aware of the leap forward in our understanding once we began to separate the essential or defining characteristics of autism from the secondary symptoms. I therefore took the same approach in trying to clarify what features essentially made up the syndrome of PDA. We have to remember, of course, that children may show the defining characteristics of a condition in different ways according to their individual personalities. A dramatic example of this is that some PDA children may avoid demands by becoming almost mute, while one or two avoid by talking so fast and so constantly that no-one can get a word in: neither muteness nor verbal diarrhoea is itself a defining feature of PDA, but the motivation to avoid demands is, and the child adopts a strategy to this end according to his temperament.

Table 2 shows what I took to be the defining features for my first 21 children: that is, the features which seemed to be held in common and to be salient to the group. The first page of the table shows the original twelve children the following nine having been added a few years later. By that time I had begun to think of 'mimicry' (fifth column) as evidence of uncertain identity, but it is interesting that this was the only change I felt the need to make in the second half of the table. Table 3 shows secondary features of these 21 children, for background interest at this stage. Of course, the very act of analysing data in this way helps one to become aware of what is salient; and in fact the final column, the question of soft neurological signs, was originally planned for the 'secondary' list. Evidence of neurological involvement recurred to a greater extent than I had realised, and had to be included as a 'defining feature'.

By 1988 I was frequently being asked for a list of diagnostic criteria, and was also beginning to hear of children being diagnosed as having PDA on somewhat surprising grounds; I decided that fifteen years was long enough for even the most cautious person to be amassing data, and set out a definitive list of criteria, including descriptive examples based on thirty-two children, and adding for completeness a comparison with autism in order to point up the contrasts. This list appears as Table 4. It can be

seen that the headings differ from those in Table 2 only in the way the data is arranged and conceptualised; in fact the consistency of this pattern as it has emerged has been unexpected, but also reassures one that the reification of the data into an identifiable syndrome is indeed justified.

We can now enlarge on each defining feature in turn, drawing now on thirty-six children in illustration.

Passive early history

While autistic children's parents usually realise that something is wrong by the time the child is two, and often before this, in PDA children the honeymoon period tends to be much longer. The baby is usually felt to be very passive, but this may at first be construed as 'being good'. Some are particularly clinging and demanding of attention; typically, however, they are content to sit back and watch, accepting affection but not actively seeking it. Many carry their passivity to an extreme degree: Dan's parents say that 'you could have left him on a sofa indefinitely' right up to 3 years old: Ellen, Cathy, Polly and Laurie would all drop rattles from a limp hand, even at 18 months, and refused to reach for toys; Billy as a baby wouldn't look at toys if he could help it, and 'didn't seem to think anything was worth the bother'. - this was still true at 6 years. Dan, Janette and Anne not only refused to play but seemed afraid to walk; once Dan had been actively taught to walk he would fall without trying to save himself. Gavin needed to be entertained as a baby, and this was still true at two years, when his father realised that he was doing the playing while Gavin sat watching.

During these early years, it is typical for the parents to feel that they have a rather difficult and eccentric child who needs to be, as many put it, 'handled with kid gloves'. However, the children do not usually come to serious medical attention early on because families manage to make them seem relatively normal by making heroic adaptations to their behaviour. Often parents do not even realise to what extent they have conformed to the child's idiosyncrasies and provided a protective and undemanding environment for her.

As the date for entry into nursery class or infants school approaches, parents may feel a little apprehensive about whether their child will fit in well or whether the teacher will find her difficult; but they are seldom prepared for the extreme failure which ensues as soon as ordinary group demands are made on the child. Similarly, teachers may be warned by parents that the child can be awkward, and typically they will offer confident reassurances that they are 'used to awkward children' and that 'she'll soon settle down'; equally typical is the horror and panic which sets in within a few weeks, and the school psychological service tends to be approached within the first term. It appears that the ordinary group-oriented demands of school literally disable the PDA child.

Avoidance of demands

Resistance to demands is the most obviously salient feature of the group, and in fact is the major reason for their dramatic failure at school, which is true for all the children unless equally dramatic educational intervention takes place. The child seems to be overwhelmed by a sense of being presssurised. However, where an autistic child reacts to social demands in an asocial way, by withdrawing, ignoring, or using stereotyped behaviour to cut out the demand, PDA children are at their most socially skilled in the efforts they make to avoid pressure. They are not only supremely motivated to avoid demands; they are well able to do so because they have enough social empathy to be manipulative. I very rarely describe any child as manipulative, because of its pejorative connotations; but it is difficult to avoid this word in describing the single-minded talent which PDA children bring to circumventing anybody who tries to get them to do anything. Parents and teachers alike agree that this is the child's major skill: commenting on the child's lack of achievement, both will often suggest that 'she must be more intelligent than she seems, because she is so very devious'. variety and determination of the strategies that the child uses in escaping demands is likely to defeat all but the most persistent adult. It is worth quoting comments from psychologists in my clinic following a two-hour play-based assessment of such a child:

Susannah, aged_7

I found Susannah extremely sociable and outgoing. As the session progressed, I felt that she was trying to keep situations

under control by asking questions - many of which seemed intended to be diversive from the task in hand. I am not sure whether the answers given by me to her questions were fully listened to, or, in fact, important at all. I found her a very pleasant girl throughout the afternoon, and her ability to decline my requests was superb. She was successful in diverting my attention. In fact there were several times when I was conscious that she was leading the session and not me. And yet she was doing it in such a nice and non-directive manner, it was difficult not to respond to her many questions, despite being conscious of being diverted from my purpose.

Dan, aged $6\frac{1}{2}$

I enjoyed my afternoon playing with Dan, but found it very tiring since, however hard I tried to engage him in tasks, he somehow slipped away to find something else that he wanted to do. I found that he was successfully sliding away from the demands I was trying to make of him, and felt that I must be doing something wrong which was preventing him from showing me more of what he could do. I felt as if he was in charge at times. He played in the Wendy house for quite sustained periods of time, and at first I felt fully involved in his Wendy house play. But as I continued to make demands of him in the Wendy house he made it clear that 'enough was enough', said 'I'll bash you' and took the broom saying 'I'll brush you up'. In general he demonstrated good social skills, and said 'please' and 'thankyou'. He was very busy throughout the afternoon, but when I asked myself what activities I had succeeded in getting Dan to carry out, I realised that these were few and far between. His best achievements were in doing things he chose to do himself.

Ellen, aged 7

Ellen was very good at getting me to do things the way she wanted them done, and seemed to find great pleasure in testing me to my limits. Consequently, trying to engage her in things

I wanted her to do took a lot of time and energy.

Several times Ellen used ways of avoiding my requests, either by forcing me to find some alternative that she would accept, or occasionally through direct confrontation, saying 'No' quite definitely. During the 'pretend play' session she used quite elaborate excuses such as 'No, I'm still cooking the dinner' or 'I'm sorry, I've got to do the washing up'; 'Would you like some grapes?' when I'd asked for coffee several times, and 'I've got to go home now' to avoid more work. The one or two occasions when I was very firm and direct with her, she did respond, but made me feel quite the villain of the piece. If there were to be a winner in this game, it had to be Ellen.

Laurie, aged 8

I realised from the start of the session that it was not going to be easy to maintain Laurie's interest in any particular task for any length of time. Laurie constantly expressed his desire to 'move on': 'I don't want to do this any more'; 'I don't like games, you see'; 'This is the last one, right?' 'Let's don't do these now, let's climb the climbing frame'. I had to coax him constantly, and I felt I had to be always one step ahead. Laurie did not ignore any requests I made, he simply argued with me and insisted on doing something else.

Although occasional children may spend much time weeping or hiding, it is much more typical for them to adapt situations to their own ends, taking control in a charming and sociable manner, and using a whole series of tactics so that the adult can fail to realise how little has been achieved. Distraction of the adult is a favourite social ploy, and this is so often used that parents may develop their own name for what they face daily in their dealings with the child: for instance they talk about Jack's 'side tracking' or James's 'diversionary tactics'. 6-year-old Kelly is described as 'better than she should be' at distracting people from what they are trying to get her to do, and has many techniques: she will offer excuses, such as having a tummy-ache or needing the toilet; or change the subject; or point out something irrelevant, 'Oh look, Mum, there's a tree!'; or say 'I'm not Kelly'; or will throw objects, wether knickers, swear very loudly if she's in a public

place, hide, or say something bizarre. Many children will give answers at random, showing that they recognise the need for an answer, but fobbing the adult off with the first thing that comes into their heads. Gavin's mother thinks he deliberately gives a wrong answer to discourage her, and some children's teachers share this view.

Again, it is worth giving examples from play-based assessment sessions, which the children usually enjoy very much, but which bring out the richness of their avoidance repertoires.

Anne, aged 11, used the following strategies to resist demands during the 2-hour session with Susan, the psychologist:

- 1 Ignoring, used many times. A variation was singing to herself as if Susan was not talking at all.
- Diverting Susan's attention. She commented on how pretty Susan's jumper was, talked about other activities she would prefer or things she wanted (like a sweetie). The complexity of this was shown when she steered Susan away from one task by persistently asking for skipping; then, when Susan gave in to skipping, Anne changed her mind and asked to play ball instead. Other successful distractors were offering to tie Susan's shoelace and talking jargon.
- Delaying tactics: 'No, not yet'. (Notice that 'yet' is a social acknowledgement of the need to comply, though if the request is not repeated, compliance is unlikely to take place.)
- Excuses, e.g. 'I'm poorly'.
- Saying she was already occupied: e.g. she could not join Susan at the table because she was already playing ball. (Often children add force to this excuse by saying 'I can't because I've got

to play ball, wash the dolly, push the pram' etc. etc.)

- Flicking her eyes from one side to the other as a means of avoiding attention (Anne uses this so often that her parents have a name for it 'Action Man eyes', and she did originally copy it from an 'action man' doll).
- 7 Giggling bouts resorted to several times.

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- Pretending she couldn't do something. Sometimes she did silly things with apparatus when it was certain she knew what was required, e.g. stacking shapes when asked to fit them in a formboard; giving the wrong answer when she had already demonstrated she knew the answer; saying things were 'too hard'.
- 9 Flatly refusing: 'I don't want to do it';
 'let me go'; 'I don't want you'; and also
 pushing Susan away physically.
- Disruptive behaviour: e.g. deliberately knocking the toys off the shelf, tipping over the abacus and allowing the beads in her hand to drop to the floor.

(We did not actually see the whole of Anne's avoidance repertoire: her parents also reported that she would ask for food or drink, control her bladder to serve diversionary ends, hit her chest rapidly, bite her mother, shout, and use echoing as a smoke-screen; at school, she 'seems dull from the moment she walks in each day' and 'seems to put her mind into neutral').

Dan, a bright $6\frac{1}{2}$ year old, had even more strategies for avoiding Beverly's demands; he showed most of Anne's tactics, but also the following:

Frantic pace: for most of the session he switched activities constantly; we might have assumed that this was not under his control, except that in his preferred activities, in the Wendy house, he showed no distractability.

- Role reversal: he skilfully took control by giving Beverly directions and things to do.
- Aggression: especially at the beginning of the session, he halted her requests by threatening to 'bash' her, 'get' her and 'brush her up'.
- 4 Monologue: he was able to shut her out by incessant talking.
- Parrying: he skilfully countered her intentions, several times; for example, Beverly suggested, 'Come and stand by the mirror' and Dan countered 'I've got my own mirror', looking at his reflection in the Wendy house waste bin; later, Beverly said 'Simon says put your hands on your head', and Dan, sitting on the trike, parried 'Simon says put your hands on your bike' and continued to ride.
- Disengagement: he often pulled away from Beverly and slipped into the Wendy house, where he would shut Beverly out by slamming the door and pulling the curtains across.
- Procrastination: Dan often used delaying tactics by saying 'hang on a minute', 'wait a minute' or 'how about this?'
- Diversionary 'act': Dan would announce 'I've got an idea!', distracting Beverly from her purpose. In this 'act', his whole demeanour would change; he adopted a stooping walk, a change of facial and vocal expression and the 'thinker's' pose of chin cupped in left hand and right index finger poised in the air, very difficult for Beverly to ignore.
- Rational explanation: he would offer sensible reasons why he should not do as Beverly wanted:

 'We've got that at home' dismissed one game, 'That's too old to play with' rejected a slightly worn pack of cards, 'Not playing this game, it's silly' was another scornful comment.

- Humour: squirting Beverly with water in the toy lemon to deflect her approach.
- Boredom: this was expressively conveyed in answer to Beverly's suggestions, by lengthening the vowel in 'Ye.e.es' and by responding in monosyllables while looking at something else.

These examples convey the single-mindedness of the child's resistance, but perhaps not the degree to which pressure is genuinely experienced by the child. The apparent robustness of the use of strategies can mask the fragility and vulnerability behind the need to use them. Most of the children become extremely agitated and panicky if their bluff is called, and it is probably in deference to this that parents adapt so completely. at five cannot accept the offer of help, and finds this intolerably pressurising, although she might ask for help voluntarily. Billy at six cannot bear any kind of confrontation : this extends to the tiniest confrontations, and his father gives as illustration the fact that he cannot even offer Billy a cup of tea in the morning, but has to put it on the kitchen table so that Billy can get it when he has turned away. Cliff's parents describe themselves as living their whole lives around the need to take the pressure off Cliff at 8 years. He sees demands in the slightest expectations of him; for instance, he will not accept a suggestion to take his jumper off on a scorching hot day - one has to leave him to come to this in his own good time. Nonetheless, all the children enjoy the company of others if they are enabled to feel free of demands, and are particularly happy in free play around the Wendy house or dressing up, provided they are in control of the action.

Surface sociability

It is clear from the examples already given that PDA children are very much oriented towards other people, if only because their antennae are constantly alert to what others might ask of them. Often their manner is replete with social graces: they use 'please', 'thank you', 'do you mind?', 'excuse me', 'I'm very sorry, but ...', to great effect. Many are exceptional charmers, and at least three of the girls have been compared to Shirley Temple! In manipulating adults, they can be aware of what tactics are especially suitable for particular people; Anne plays sweetly helpless with a particular male teacher, avoiding all demands; Amanda at 10 terrified a male teacher by removing her knickers whenever she felt under pressure; many of the girls deliberately try to show their

mothers up in public by the things they say. Marilyn at 6 has an effective method of getting out of her school's social skills expeditions into town: in a busy shop, she will choose a nice old lady to approach, saying sweetly 'Hallo - what are you doing?', and once she is getting a kind response will shout 'Bollocks!' - which tends to achieve her removal from the demanding situation. Significantly, Marilyn never uses words like this unless she thinks someone is listening; she has said to her mother, who tries to ignore her, 'I said bollocks!'

There is no lack of eye contact, and indeed PDA children need to use eye contact if they are to monitor their manipulation of people effectively; in fact they are much more likely to withdraw visual attention from a task than from the person presenting the task. However, their sociability is only skin-deep, and when it is not serving demand-avoidance it becomes unsubtle and ill-judged. Often it seems that the child is aware that some social response is called for in a situation, but has no idea what is appropriate. Sometimes this is in terms of level of response: one can be overpowered by a beaming smile and a pumping handshake from a child one has never met before, or literally bowled over by a hug from a twenty-year-old; it is common to find that the child is unpopular at school because she hugs other children in a way that frightens them. Similarly, the child may explode into passionate crying or angry shouting in response to a relatively trivial refusal. Lorna at 9 lay on the floor in a bookshop and screamed when her father refused to buy a baby's book she fancied. Sometimes the nature of the response is inappropriate: Gavin, at 11, within five minutes of his first arrival in our Unit, was organising drinks for everybody present; Dawn, excited at playtime in her first week at school, poured her milk over another child's Kathy cannot accept praise, and insists that it is not meant. Interestingly, it is quite common for these children to regret any achievement and to spoil their own work, and this may be one aspect of their insistence on avoiding demands - in retrospect; as it were.

All the group find it extremely difficult to negotiate with other children, and their peers tend to back away from them, partly because they shock other children by the degree to which they will go 'over the top', and partly because they confuse others by their own confused behaviour.

Billy, at six, has never known how to relate to children; he will hug them too hard, mis-judging intensity and duration - then, when they are scared, he will bite them and pull their hair, not knowing how else to react. He has never been possessive or aggressive, but could seem aggressive because of his agitation: he might go into what his mother calls 'his cross act' if confused by a child, quite inappropriately. Children now pick on him, and he doesn't retaliate or tell an adult, nor fight back verbally. He allowed a child to pull his pants down and hit him with nettles and just stood there, not knowing how to react; he might mention it weeks later. He will reassure himself by repeating catch-phrases borrowed from his parents and used back to them: 'Best ignore Mandy, isn't it Dad?' many times over.

They are usually prepared to negotiate with grown-ups, who perhaps are better able to organise a negotiation. For instance, Kathy like the idea of being bribed, and would agree to it after lots of preparation; but she would then not keep the bargain, and this is true for most of the children. As one might expect, there is a constant attempt to wriggle out of it or improve the terms, and no sense at all of honour.

A common feature of the children's ill-judged sociability is both lability and ambiguity of mood. Just as hugging may become strangling, so kisses may turn to bites. Kathy until she was nine seemed to get mixed up between hugging, pinching and squeezing, and this happens at some time with most of the children. Cassy was observed smiling happily as she danced in a ring at school, while her nails were digging deep into her teacher's Sandra and Helga both demand their mother as if pining for her and then attack her physically; Marilyn embraces her mother, saying 'I ha-ate you!' in a pleasant voice. Lorna was observed walking with her arm round her mother saying in a sweet voice 'Hello my darling, horrible, hateful mother!' Simon at 8, cannot find a happy medium between a cowed, withdrawn manner and a rude over-bearing one: merely asked to clean his teeth, he might first look ridicoulously meek and frightened and the retort to his father 'Oh don't be stupid, Jim!' - his parents see both these manners as 'acts' rather than 'the real' Simon, and he shifts from one to the other within a few seconds, as do many of the group. Harry will be looking forward to his father coming home and

then slam the door in his face shouting 'Don't want to talk to you!'

John switches from being calm and happy into silly behaviour which he seems unable to control, and which his parents describe as 'as if his intelligence had slipped'. Kelly, at six, may glare angrily, then show tense excitement, then become pleasant and relaxed, in quick succession; her manner changes too quickly to anticipate, and one can be taken aback by the force of the way she expresses dislike and hatred.

Lack of sense of identity or sense of pride

Parents of PDA children are in fact continually taken aback by the lengths to which their children will go in pursuing their own ends. Earlier I described their sociable avoidance of demands as their best talent; however, in some ways it is misleading to think of it as a talent because, as we have seen, their social skills are basically rather poor and have little depth. The reason they succeed so well in their rather unsubtle manipulation is that they also have no sense of the boundaries of what is acceptable behaviour; they will therefore continue to push the adult in a single-minded way, and are successful because they will go further in this than the adult expects. It is typical that they seem to have no sense of pride, or of what is fitting to their age, and will persevere in their unbridled behaviour where an ordinary child would recognise that this was going too far. Other children are often amazed and disapproving at the degree to which PDA children flout the unwritten rules. For instance, where most children know that they have to behave in a more inhibited way with people they don't know well, PDA children will behave as disruptively with a stranger as they will with their parents. In fact, one recognises how precisely regulated are ordinary children's social boundaries when one sees the extreme stretching of these boundaries by PDA children.

In practical terms, this means that parents are not able to appeal to the child's pride or to her 'better nature' because she seems to have no concept of being true to an idealised self. If Lorna is screaming on the bookshop floor, she will not be moved by the fact that people are looking at her in astonishment because she is a big girl of nine, not a toddler. When Lorna was $6\frac{1}{2}$ she would lift her mother's skirt in public, and poke at her father's trousers saying 'What's in there?'

We noted then: 'She has enormous trouble living in a social world because her immediate needs, as perceived by her, always come before any sense of social dignity. Her parents always feel a great sense of satisfaction and pleasure after an outing where things have gone well - they can never take such things for granted or be casual about doing things that most families do'.

All the parents of this group would empathise with that statement. Cliff's parents find that on outings they have to constantly buy a little more time with 'Yes, we'll go home in a little bit!; although he is 8, he might refuse to leave the car park, or scream throughout a school pantomime, and often outings are completely spoiled, which is hard on his sister. Arlene has ruined outings because she will scream if she has to walk on sand or rough ground. Ellen will handle ornaments in other people's houses, and ignores disapproval. Pauline at twelve tore off her clothes because she was annoyed and ran up and down the beach naked, shouting obscenities at cowering family groups. Amanda at 10 hurled racial insults at a black psychologist working with her, despite her avid enjoyment of the sessions.

A further aspect of the lack of sense of personal identity is that the child fails to identify with other children as a group, and gravitates more naturally to adults - perhaps partly because adults adapt better than other children to his needs. If we ask parents 'Does he know he's a child?' (which always seems an extraordinary question to be asking), they tend to react with recognition that this is indeed a major problem for him; they will say something like 'I hadn't thought of it like that, but it's true, he probably doesn't'. PDA children usually fail to understand the social divide between adulthood and childhood of which even the most democratically brought up normal children seem to take heed. They may become aggressive or bossy with an unfamiliar adult in a way that is clearly not ordinary 'cheek'. Gavin will monopolise his headmaster and talk at length to him, but will ignore the greetings of other children; in fact most PDA children ignore their peers' overtures, and are much more likely to approach other children in the role of a teacher, as we shall see shortly.

Besides having difficulty in constructing their own identity, most of the group seem to have problems in understanding the personhood of other people. Parents have little confidence in their own personal importance for the child. Several comment that the child has a closer relationship with her dolls than with them. There is often an uncertainty as to whether the child actually recognises a difference between 'real' people and dolls or toy animals, and we sometimes see this confusion in the clinic playroom where the big toy dog can begin to seem an equal participant with the psychologist. The lack of salience of personal identity is beautifully illustrated by Gavin's attitude to his twin brothers, either of whom he will refer to as 'the twin' without seeing any reason to specify which he means.

Janette is puzzled by shadows, and will look from them to her parents and back; she will also hit and spit at her own reflection in a mirror. Pauline has had a relationship for some years with her reflection, to which she gives the name Pauletta; she talks to it and of it, and treats it as a slightly sinister alter ego.

Clearly, if the child's conception of personal identity, including her own, is as fragile and vague as this, the result will be a lack of responsibility on her part: a difficulty in accepting social obligations, in understanding the rules of 'what is expected', and in experiencing a sense of pride or of shame. These children are indeed irresponsible, and at first sight could often be described as 'naughty'. it is interesting, however, that their parents, who suffer most from their behaviour and who are often ashamed and embarrassed on their account, do not see them as deliberately naughty; they recognise a deficit in the child's understanding, and describe her as confused and lost rather than deliberately badly behaved. For instance, the parents of Lenny, aged $6\frac{1}{2}$, feel that he doesn't know how to conform, and doesn't realise that other children do expect to conform. Peter's parents are sure that he 'can't help his naughtiness'. Children also recognise the deficit. The four year old friend of Ellen's little sister, Beth has commented that 'Beth is the big girl really'.

Role play and pretending

Unlike autistic children, whose symbolic play is very poor indeed unless their intelligence is very high, PDA children are in their element in this kind of play. This is immediately seen in a play-based assessment, when there is likely to be a repeated escape to the Wendy house, not as a refuge but as a base for protracted role-play. What is notable is how seriously the child takes the role of shopkeeper, doctor or whatever; there is little acknowledgement that this is just a game, but almost the feeling that the child has actually become the person he is acting. With the more intelligent children, such roles can be happily sustained for an hour or more.

Let me quote from the psychologist's report on Gavin, aged $11\frac{1}{2}$.

A large proportion of the 2-hour session was taken up in role-play where the theme of a zoo dominated. Gavin had adopted the role of zoo-keeper/veterinary surgeon, but his role-play felt almost obsessional in quality. When I disagreed with his sedating animals, he became frenetic, and shouted down the phone that it was all right and completely safe. He showed considerable imagination and ingenuity. At the same time, Gavin's play did not have a 'pretend' feel about it; it felt as if I was playing with a Gavin who was also a zoo-keeper and a vet. As zoo-keeper or vet, he still wanted to control the situation and people around him as Gavin wanted to do too. He didn't acknowledge the 'pretend' nature of the situation in the way that other children do.

Gavin is said by his parents to 'live through his roles'. This is the child who organised drinks for everyone within five minutes of arriving; we discovered that the role of barman was in fact one of his current personae - he had demanded and got a cocktail shaker for Christmas, and pursued this among other roles in a very single-minded way, without regard for time and place. He also slips into TV roles without warning or self-consciousness; if a telephone is available, Gavin is likely to wrap his handkerchief around the mouthpiece and mutter darkly into the phone, peering furtively over his shoulder as he does so. His parents have been very tolerant of Gavin being constantly in role, but they realise that they certainly would not expect his ten-year-old brother to behave like this.

Other children may become equally lost in role, though they may not sustain them with quite Gavin's verbal talent. Simon, at 8, escapes pressure through a charade of adult roles; his parents feel that he is now almost living at second-hand, and has lost his own identity; that he now doesn't know who he is, and that because he cannot cope, he lives through other people's characters. At school he mimics the teacher's role as a 'way of being and doing', so that he doesn't have to work out his own social role towards other children; at home he has two characters, both of which his parents see as 'acts' - one withdrawn and almost cowed, the other over-confident, bossy and cheeky. His parents comment: 'It's got to the stage where we don't know what he's really like - what he'd be like if he wasn't acting any more'.

Acting the teacher's role in school is very common indeed, and naturally does not go down well with other children. The child may tell other children to line up quietly, or put on a directive or patronising voice and use the word 'dear'. Kelly often instructs children in her teacher's voice before the

teacher has had time to do so. Susannah and Marilyn do the same, using their teacher's gestures as well; Susannah also has a repertoire of phrases picked up from teachers and parents, 90% of which are negative and therefore useful for avoiding demands: 'You're not old enough, darling', 'You're not big enough for that, Sanna'. Susannah and Dan, at 7 and 6 respectively, both attempt to take over the teaching at their Sunday school, adopting the teacher's manner in a way that takes the teacher aback. Lenny borrows the teacher style in a large proportion of his spontaneous speech: the most obvious way he does this is repeatedly to make comments in which the last word is omitted and left to be filled in : 'Here's a pretend ...'; 'What's wrong with the ...?'; 'Cat's chasing the ...'; 'He's closed his ...'; 'Here's the salt and ...' when it is clear that he is quite capable of retrieving these omitted words. Marilyn may mimic either teachers or children, and includes both words and gestures. Disabled people are another group who are much imitated. Kelly mimics disabled movements, and says she wants to have crutches and glasses like a child at her school. Billy has been fascinated by disability for years; at six he would make a walking frame from the vegetable rack and limp around the house; at 12 he would be thrilled to be taken into a disabled persons'toilet, and would proceed to become disabled before one's very eyes, collapsing in a heap on the floor and demanding an ambulance to take him home. His favourite acquisition was a black eyeshade with which to become 'blind'. His parents have always felt it was difficult to get through to the 'real Billy'; that his acting covers up his real self, and saves him from having to involve or commit himself.

A further way of distancing oneself from the real world is to move into a world peopled by dolls and toy animals; dolls also have the advantage that they are easier to negotiate with than real people, and will allow themselves to be manipulated without answering back. Indeed, they can be used as allies in manipulating others. Many children are said to 'live through their dolls'. Yvonne is very passive in her speech, but with her dolls she becomes lively and talkative, and will do the speaking for two dolls at once as well as herself. Marilyn has several soft toys whom she treats as people, using voices for them; she would not look after them in a motherly way. For Kelly, dolls are as real as people'; and Susannah is obsessionally interested in dolls, whom she refers to as 'my girls'. Arlene is preoccupied with little dolls and finger-puppets which she holds between the fingers of her left hand (which usually prevents her doing very much); she also has an alter ego, a doll called Alice, who backs her up in her demand avoidance: 'Alice doesn't like this game';'Alice

is getting a bit tired of this'. Anne seems very confused about the personhood of dolls in relation to herself, and is especially afraid of big dolls; she is anxious if she sees dolls with a broken hand or finger, and will flap her own fingers in response, apparently testing whether they too are broken. Micky imitates a doll's facial expression, then throws it, shouting 'Don't look at me like that!'

The precariousness of the distinction between 'real' and 'pretend' can also be seen in the child's reaction to particular events in symbolic play. We have seen how some children are puzzled by shadows and reflections. Kelly was mystified and uneasy about the joke fried egg in the Wendy house, and ran away from it several times, showing the fragility of her notion of 'pretend', despite the fact that pretending is her favourite activity. PDA children often show fear at glove puppets, despite being attracted by them: Billy showed both emotions within a few minutes. Billy also reacted to the 'washbasin' inset board interestingly: without prompting, he cleaned his teeth with the wooden 'toothbrush' piece, washed his hands with the 'soap' piece and offered the psychologist a 'drink of water' from the wooden 'tap' piece (all of which would be unlikely for an autistic 6-year-old); he then went back to cleaning his teeth, and actually spat in the piece depicting the basin. Typically, he couldn't fit the pieces when asked because he wouldn't look at the task any more.

Both doll play and role play can be seen as highly functional for children who are very uncertain as to what is required of them and how they should behave. Lacking confidence in their own ability to manage things socially, they may fall back on other people's styles as a way of carrying them through a situation. As we have seen, these children usually have a history of watching other people passively, and have had plenty of opportunity to find out how people behave; but without any sense of being securely rooted in their own selfhood, they fail to discern which bits are appropriate to themselves, and grab at whatever role comes to hand, pulling on secondhand roles like ill-fitting secondhand garments. This at least gives them a 'way of being' in which they can feel comfortable. Unfortunately their comfort may itself be highly inappropriate. Carol, sent by a despairing educational psychologist to a school for aggressive maladjusted children, learned ways of behaving which felt good to her but did nothing for her family's comfort, especially when she threatened to 'rearrange her mother's face with the breadknife'. Amanda came to us at nine for a period of play therapy, part of which used drama and role play; like no other child before or since, she was quite unable to leave behind in the playroom the aggressive roles she

chose. Where normal though disturbed children treat the playroom as a protected environment that is kept separate from the real world, Amanda used it as a seedbed for new and frightening roles which she proceeded to act out in school and home. We learn from our mistakes, and this is the first and last time we have used drama therapy with a PDA child, however bright.

The uncertainty surrounding the self can be seen in other ways than role play. Many of the children will take an outsider's view of themselves, addressing themselves or commenting on themselves. (Autistic children can seem to do something similar using echolalia, but this is different as we shall see shortly). For instance, Susannah uses both gesture and speech to control herself from the outside. If her mother smacks her bottom, Susannah will smack herself, and it almost seems she is more responsive to her own smacks than to her mother's. If she gets up a mealtimes, she will push herself back into her chair saying 'Sit still, Sanna!' She will take herself by the hand and pull herself back to her seat; or she will physically pull her own head round towards or away from something. Helga used a mixture of persons in which to comment on herself during the clinic session : 'Helga cries in the bath - no I don't!!; 'Are we going home yet ?' - I don't want to go home yet. Do you get fed up with me saying go home ?'; 'Who bought that ? I always say that. She told you who bought it'. Kelly, like Pauline, talks to an alter ego - in Kelly's case, obviously, i.e. over her shoulder or over someone else's shoulder, and in these situations there is lots of 'telling off'; but she may equally pinch her own arm, saying 'No, naughty Kelly!' In the clinic session, she suddenly said 'Shut up', to which the psychologist responded 'You weren't saying that to me ?' - Kelly replied, 'No, shut up Kelly'.

It is easy to mistake some of this talk for echolalia, and in fact a few of the children have shown true echolalia at an earlier stage. We found we had to ask ourselves why we were calling the repetitive speech of autistic children 'echolalia' and the rather similar-sounding repetition of PDA children 'mimicry'. The difference seems to lie partly in its quality and partly in the child's conscious intention. Autistic children seem to offer echolalia because it is all they have, or because at a moment of stress they cannot provide spontaneous speech. PDA children mimic not only speech,

but a whole style; they add well-observed gestures, and some of their mimicry is of the style alone, the words being spontaneous. For instance, Anne's mother tells of her witnessing on a bus another mother being brightly informative to her children: Anne turned to her mother, and in precisely the same bright manner took up the spirit of the occasion with 'Oh look, Mummy - my feet are falling off!' When mimicking, they know who they are being; when Marilyn mimics another child, one can ask who she is, receive the reply 'Nicky', and bring her back temporarily by saying, 'Well, I'd rather speak to Marilyn please'. Echoing is often used by PDA children deliberately to tease, mock or manipulate: two of the children regularly meet their mothers after school with 'and what did you do at school today?' in their mothers' tones, adding 'I'm not going to tell you !' Amanda looked in a cage at the zoo with 'Oh! Look at this, darling', then walked away as her parents came up to find an empty cage; on a similar outing, Polly used as a lure my own enthusiastic tones, 'Look at this lovely animal!', and I responded, only to have her duck under my arm and open the cage of baby rabbits that I had been guarding from her. Echoing is also used by some to blot out demands, in the same way as others use incessant informative speech.

Obsessional behaviour

The obsessional aspect of these children is mainly shown in terms of the degree of sustained motivation with which the behaviour I have already described is carried out. In particular, the children are successful in escaping demands because they recognise no boundaries as to how far they might go in achieving this: the child's aims are pursued without social inhibition - which is perhaps a reasonable functional definition of an obsession.

As with verbal autistic children, obsessional questions are common, but they again tend to serve the purpose of demand avoidance. On the whole, the questions of PDA children feel much more sociable than those of autistic children, and at a later age they can be focused on the adolescent's concerns about herself and her difficulties. For instance, throughout adolescence Pauline has liked nothing better than long heart-to-hearts about disabled people generally, and in particular about why she is so obsessional and so impulsive; she is adept at trapping the listener into yet another half-hour of such conversations, and also highly skilled in making one agree with the most

logical maze. Some young adults become obsessed with public figures rather than themselves.

A few children weep in an obsessional way, but this again tends to be a tearless 'act' intended to distract people from the demands they are trying to make. There are a few obsessional objects, but not nearly so many as among autistic children, and again they tend to be diversionary in nature: Arlene cannot bear to get dirty in the slightest way, and keeps her hands occupied by little dolls; Kathy loves sellotape and uses her demands for this to rule her mother; Kelly is obsessed with dungarees, Peter with doing a Billy Connolly act, and Carol with repeating the word 'Stella' incessantly to annoy her mother - in which she is extremely successful.

In keeping with the <u>social</u> direction of their obsessionality, PDA children often blame other people for what they see as difficulties in their lives. Helga frequently goes on at her mother for sending her to 'the daft school'; Carol is angry with hers because she won't go out and get her a friend (she wants to be friends with two disruptive girls who are disliked by her younger brother); most blame <u>someone</u> for making them do things!

As a result of their obsessional demand avoidance, the children show a very low achievement level indeed at school; for the less able children it is common for them gradually to drop through school placements to the 'severe learning difficulties' level, simply because they have achieved nothing. However, their teachers are seldom satisfied that this reflects their actual potential; it is usual for referral letters on these children to be full of puzzlement and guilt. It is undoubtedly the mis-match between the child's manipulative skills and her academic failure which so confuses those around her : one continually receives comments such as 'We suspect a much deeper level of thought than is shown in her school work'; 'We feel we have failed this child'; 'I am certain he has a much better potential than we have been able to tap'; the children are described as 'extremely odd', 'exceptionally complicated' and, in Yvonne's case, 'delightfully enigmatic'. The more able children are in some ways still more puzzling: they may teach themselves to read but then refuse to be taught anything after that. It is, of course, almost impossible to give an intelligence test that means anything; for instance, children now known to be in the normal range of intelligence have previously tested at 30 or 40 IQ. In a play-based assessment it is invariable that the child's most capable cognitive and linguistic performance will be drawn out during role-play of some sort.

Neurological involvement

Very few of the children have had a full neurological investigation, and this would seem to be the next research step. The defining feature of neurological involvement is at present based mainly on soft neurological signs. All the children except one currently have some degree of poor coordination: the one exception was very slow to walk as a baby, and is believed never to have crawled; she also does have what might possibly be described as momentary absences. Failure to crawl is common: of those whose crawling history is confidently remembered by their parents, less than half crawled on hands and knees, a quarter bottom-shuffled only, and a quarter neither crawled nor bottom-shuffled; while two or three crawled very briefly after much training. Most of the children have shown a curious mixture of floppiness and over-determined forceful movement: some used to be floppy and are now forceful, others may show either extreme according to mood.

Frank fits have occurred in only a very small minority (about 10 per cent); however, one child has suffered from hypsarrhythmia in infancy. The 'absences' that are reported in a number of the children can be difficult to distinguish behaviourally from the emphatic withdrawal of attention as a strategy which so often occurs as one aspect of demand avoidance; for this reason, until we have harder evidence it does not seem useful to quantify the prevalence of absences.

Coding disorders as a constellation of clusters

Let us now return to the notion of Pathological Demand Avoidance as a developmental coding disorder which is related to other such disorders, and which can indeed be seen as one cluster among a constellation of related but distinguishable clusters (diagram, Table 1).

Perhaps the most useful test of whether a syndrome is distinguishable from other syndromes is whether children described in these terms make better sense to both parents and teachers as a result. Twelve years ago, I and others were forced to describe PDA children as suffering from 'atypical autism', this being the nearest description we had. The problem was that PDA children really did not make sense in these terms, however broadly one

explained the autistic syndrome, and both the child's carers and myself were left dissatisfied with an explanation which had so many contradictions in it. Sometimes, too, autism was so clearly misleading a term that it seemed to be unhelpful to use it at all, and I would confine myself to a careful description of the child's apparent problems; this, too, was unsatisfactory in setting out guidelines.

As I began to realise that I was seeing a group of so-called atypical children who in fact had many features in common with each other, I also began to be re-consulted by parents and teachers of children whom I had seen much earlier. Parents would repeatedly tell me, 'She's still just the same as when you saw her six or seven years ago, and just as much of a puzzle'. As I re-read their files, and the careful but non-diagnostic notes I had made, I began to realise that I now knew where these children fitted in, and to share these thoughts with parents. What was striking about their reaction was the sense of their coming home to a description that finally hung together, after years of bewilderment; it was typical that they would say'Now she's making sense for the first time'. Those whose children had been described previously as atypically autistic said that they had never felt that their child had been like other autistic children whom they had met. The sense of the meaningfulness of the PDA description is equally clear for parents who come for diagnosis for the first time; the usual reaction is relief that someone has seen children like theirs before, and can relate them to a systematic symptomatology. It is especially notable that parents find that the notion of a failure to code social identity and consequent lack of social need to comply, makes sense in explaining their child's major presenting problem.

What does it mean to say that the developmental coding disorders are related? We already know that this is true in terms of the possibility of overlap between them: we are very familiar with the notion that a majority of autistic children are dysphasic with the additional problems that are specific to autism. It is believed that some dysphasic and autistic children have problems of coding the written word; though their educational problems generally may reduce the salience of dyslexia as a specific problem. At least one PDA child (Gavin) appears as time goes on to have greater problems with reading and writing than are explained by his demand avoidance; but clearly a total lack of motivation may also have disguised such problems in

other PDA children. Some PDA children show a real overlap with autism, especially over time: that is, they may start with one typical picture and gradually move to conform more closely with the other; and one or two are both atypically autistic and atypically PDA, showing a pattern of symptoms midway between the two. One has an overlap with dysphasia.

Another way of showing relationship is in terms of genetic links. These have been found in communication disorders as a group, in that children with one of the disorders have a higher chance of genetic links with either the same or a different communication disorder. Two of these 36 PDA children have autistic siblings; the father of another shows symptoms of able autism (Asperger's syndrome). Fragile X chromosome has been found in two, including one with an autistic sibling, but not in the child with a putatively autistic father; not many of the children have yet been tested in this way, unfortunately.

One further point that should be noted here is that the sex ratio which is so notable in other developmental coding disorders is not seen in PDA. The ratio of boys to girls in autism is usually taken to be 4:1 (and 10:1 in autistic children of normal intelligence). In both developmental dysphasia and dyslexia it is held to be 3:1 (Cantwell and Baker, 1987); (Thomson, 1984). In the 36 cases of PDA on which this paper is based, the ratio of boys to girls is 13.23. This does not show a significant difference between boys and girls in terms of risk though p is less than 1 in 10; but it does show a significant difference from the ratio sine any other coding disorders (p<.001).

Educational implications and general prognosis

I have mentioned that PDA children inspire guilt and dismay among their teachers because their verbal, manipulative and dramatic skills are at such variance with what they achieve in school. Among the first ten of the group, it was fairly typical for children to have started in mainstream infants school or nursery, and to be moved successively into schools for moderate and then severe learning difficulties; they did not improve in these environments however. With the brighter children, the early years in school were characterised by crisis interventions

to prevent exclusion, despite the fact that some were clearly intellectually capable, having taught themselves to read (though they would not allow others to teach them). Apart from these self-taught children, school achievement was evirtually nilgin every child. As one would expect, they are perfectly happy to escape notice during work periods, and use an impressive repertoire of avoidance tactics when their teacher attempts individual teaching. they do not in fact escape notice because of the disruptive nature of their general social behaviour. It is instructive to watch videotapes of the children in classroom settings when demands to work are not being made: for instance, James puts up a smokescreen of incessant talk for over an hour which reduces a usually assertive educational psychologist to near-silence and total impotence; Lorna wrecks a half-hour story session with her objections to the seating arrangements, and just when the teacher and other children have done their utmost to meet her wishes, and are finally settling down to hear the story, she wails loudly 'Don't point your foot at me!' - which effectively brings the session to an end, time having run out.

Over the past ten years, East Midlands education authorities have provided for PDA children the kind of special input that they would offer for autistic This has been done using the rough criterion that each child will receive at least an hour per day of individual attention for work sessions, with additional help in group sessions: this means an attachment of at least a halftime welfare assistant for any one child. Some have had an attached teacher, which tends to be more effective, and some have been given anything between halftime and fulltime attachment. This kind of input has been successful in ensuring that the child will make educational progress. staffing ratio seems to be the most important need, given the difficulty in gaining the child's cooperation. Some children have been helped by autistic units where this high staffing ratio is the norm; but it seems unsatisfactory to place a single PDA child in an autistic unit, where the children are so much less sociable than PDA children, and where autistic manneristic behaviour invites mimicry by children whose roleplay is alerted by disability. However, two or three PDA children placed together can very much benefit from the individual programmes available in autistic units; the staff comment that they are more difficult than autistic children to start with,

but eventually become easier as they become more tolerant of demands. Wherever the child is placed, the category of school is not of the greatest consequence: what matters is the school's personality, in that it needs to be interested in a challenge, imaginative, innovative, patient, possessed of a sense of humour and, in a mainstream school, committed to integration. It is essential that both the head and the class teacher are positively willing, otherwise the difficulties are such that the placement will inevitably fail: one head, who had excluded such a child, said some years later, 'I didn't realise how interesting she was until she'd gone' - and it is true that the daily frustrations can outweigh the sense of interest at the time!

It seems essential that the high input should be resorted to early in the child's school career (or even at nursery level) so that the child learns acceptable working habits as early as possible; this can pay off later on, and one child of normal intelligence is coping quite well in comprehensive school without help, having had halftime assistance from nursery age until halfway through junior school. Another equally bright child who did not have any help in his primary years now needs almost fulltime teaching attachment in comprehensive school. One child was able to take a CSE at the end of a career in autistic units from eight years onward. having been considered unmanageable in ordinary special schools from five to eight. Less able children may be better placed in special schools, but the very high staffing needs will still apply, and may be more difficult to obtain out of mainstream in some counties.

Given substantial one-to-one teaching, the question of how to teach arises. One could almost say that 'Who' is more important than 'How': the teachers who have been most successful have been firm and methodical, but they have also been flexible and have had an element of charisma. The child needs to be intrigued by his teacher's personality; since the teacher has to be capable of out-manoeuvring the child, it is important that this should be done with humour and empathy, otherwise the child may feel merely oppressed.

Short-term techniques which are most successful tend to use an indirect approach to the task rather than compulsion. If the child is fond of dolls, the doll's wishes may carry some force. We have often persuaded children to complete a puzzle by saying that a glove puppet needs to learn how to do it, or that the big toy dog wants a turn. Coaxing or diversion are usually more

effective than confrontation, which only achieves agitation; however, the child needs to sense the strength of the adult behind the persuasive front. Often the child itself uses direct pressure in reply to the adult's: asked to do a matching task, Laurie said 'Can I get Ben to help me?' (Ben being the toy dog), and when told to do it himself this time, replied 'Ben will be upset he wants me to watch him do it'. David was persuaded to take turns with a baby doll to draw shapes, and finally objected because the doll was 'so tired'. Adults tend to feel mean and unkind on these occasions! It can occasionally be effective to withdraw a demand ostentatiously, because the child is in fact sociable enough to want attention. Vicky, the psychologist, used this with Cliff successfully when he was trying to withdraw into the Wendy house: the dialogue went as follows:

Cliff goes to the Wendy house. 'Bye-bye' he says firmly.

'Bye-bye' says Vicky.

'See you in the morning... you can't come in yet', says Cliff.

'I don't want to', retorts Vicky, 'I want to look at my pictures', and she turns her back and leafs through the cards.

Cliff relents: 'If you want to come in, knock at the door'

'I'd rather look at my pictures, thank you' says Vicky.

'If you want to come in, tell me' says Cliff.

During early work with PDA children, strategies have to be continually changed in order to remain one step ahead of the child. Often a school will find itself making extraordinary provision in response to the vulnerability and fragility that the child expresses. One school, which had provided fulltime staffing for a child, also set aside a study area within the classroom where other children were not allowed to impinge on him; this was perhaps going too far in condoning the child's helplessness, and it was not particularly successful. However, the rewarding aspect of PDA children is that they can eventually give in relatively gracefully and work comparatively willingly if they are able to establish what they can see as a give-and-take relationship with someone they like and respect. Nonetheless, both liking and respect have to be continually re-earned by the teacher, and the child never seems to give up for good his attempts to manipulate. It appears that the best schools can hope for is that the child will save most of his more difficult behaviour for home; and parents, too, will usually settle for that balance. The majority of parents find themselves being much more directive and authoritarian with their PDA children than they would normally wish their parenting style to be, and this itself can put heavy stress on parents.

Prognosis

As in all developmental coding disorders, level of intelligence plays an important part in deciding how well the child is able to progress in its education. It is clear that a child who is, in particular, more verbal will be better able to use ideas and constructs, and this will include ideas which may be helpful remedially. However, just as autistic children who are verbal tend to develop a much greater repertoire of obsessional behaviours, so intelligent PDA children may also develop both more fully worked out obsessions and more subtle manipulative strategies.

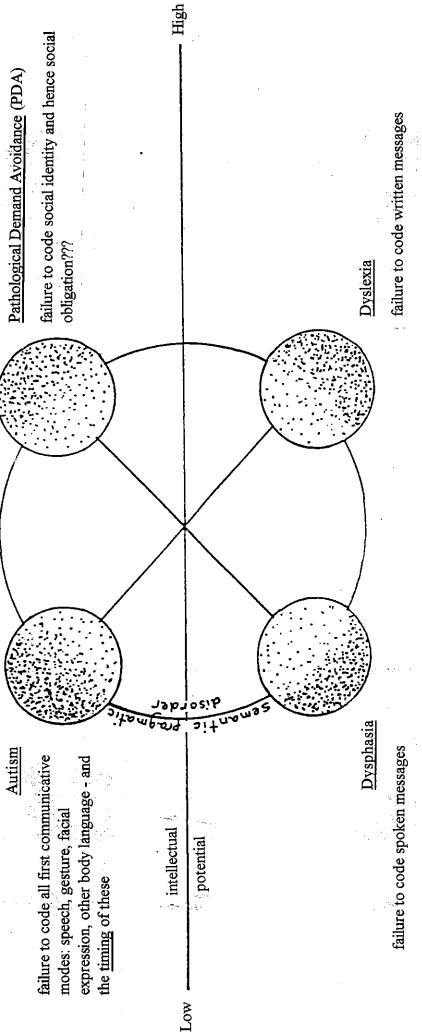
So far we do not have enough systematic observation and knowledge of these children as adolescents and young adults. There are certainly some young adults who retrospectively seem to have had a PDA history, and who are proving quite difficult: especially, perhaps, the young women. Tentatively it appears that boys may be easier, tending to passivity; so far, a number of the girls have developed adolescent fantasies concerning violence, but we have not yet enough numbers to know whether this apparent sex difference will hold up statistically. Management can be particularly problematic because behaviour modification is seldom very successful in the face of the manipulative skills; it is still worth using negotiative and contractual techniques, but these have to be carried out on a much more personal basis (which some of us much prefer in any case). Some degree of psychotherapeutic management in terms of counselling may be helpful at certain times; however, counselling has not yet proved very durable over time, and a very great deal of backup to families seems to be necessary in the long term.

The charm and fascination of PDA children, and the love and loyalty that they receive from their parents—should not blind us to the intense stress that they induce in their families and in any carers and teachers. Their best hope so far lies in high input education from an early age, and this has proved at least helpful. It is essential that the extraordinary special needs of this small group of children should be generally recognised and generously met.

Table 1

Schema for the

PERVASIVE DEVELOPMENTAL CODING DISORDERS



Note: interconnections imply the possibility of overlap

of two or more disorders in particular children, as well as

disorders. Speckles indicate possibility of greater or the possibility of a focus somewhere between two

lesser severity.

Nottingham University Elizabeth Newson

March 1986

Over page: following 9 children) (1980, 1986)) (This page: first 12 children. Table 2

Elizabeth Newson, Nottingham University

Features	
defining	
syndrome:	•
avoldance	
1 demand	
Pathologica	

		Pathological demand avoidan	idance syndrome: defining features	atures		
Child (age	Coping history	Resists demands	Manipulative	Difficulty in judging social	Mimicry and N	Meurological Involvement?
(pseudonyms) Marilyn 4:1	ng acerbated actn at	ve wans	traction ategies;swears effect:usescharm/ e for shock effect	in.	sant, Mimics ows who;	Clumsy - lurches, trips. Poor obj.management, Slight leg drag. Too much force in manipulation.
Jenny 4:8	ኢ ኢ	ay t weepy, ivate		Likes childn can't cope.Stares,touches, feels, throws things.	Repet.doll play. 'h' Copies c'hn if not h	'Clumping'gait; bit hamfisted'. Too much effort, hands shake. Dribbles somewhat.
Ruth 5:5	Seemed idiosyncrat, no more, parents amazed at total schl, failure 4:8	Yes ++ Totally overpowered by sch: go quict, answer randomly	Reverses questions to avoid. Distracts.Comp- lete family adaptation.	Totally thrown by grp.sit, nil adapt-	kg', not	Seems to trip a lot. Can't pedal trike ofter 2 yr. Otherwise quite competent.
n111y 6:2	; 0)	1 .		· -	ms to	Redundant + jerky movts from infancy; clumsy; drilbies a little.
Sandra 7:4	5. o.from 5 allure++	Yes ++ home and school. No sch. skills still at 9:0	Disruptive speech, distract— Ing, counter-demends, agression, checks.	Demands then attacks control of the	Obsessional Os as diversion	Convulsions 6-9months. controlled since by medication; sl.spastic left leg: bal.imperf.
Yvonne B:11	<pre>3 yr 'went quiet' Mute at' playsch 4.'Lost', total fail.inf.sch (for 2}yr)</pre>	Yes ++ Only skills shown if ignored. Still no progress sp.sch.	, Charm,	Strokes other chidn though they dislike. Qs pobsni but not anxious.	'Lives through ther dolls' obsessional Qs	Oldn't trawl or b.shuffle Hyreractive IT-36mo. Competent now (peels, spreads,not.draw,
Sean 9:10	Speech problems, but normal primary till juniors, unmotivated	Yes ++ Cries frequently and long periods.	also	Varied eye-contact, (Poor/over-does), 'odd' with chidn, used by them.	Repetitive crying! Mimics sounds more than voices: cor spch	Flat footed, stooped gait, scussive vigour in movt., better on manipulation.
Janette 10:0	<pre>3 'naughty' pl.sch; 5 inE. sch., 'babyish'; 6 ESN(H) tantrums; 7 (S) but no prog</pre>	и ю т.	emed fragile' tracts/diverte. Charms itely. Says'I'm agitated'	V. amenable on surface (1.e. passive, hence string masked.	Obsessional questns; some immed.	Odd gait, stiff. Clumsy descending stairs (but balance OK). Vis. avoidance hinders.
Helga 12:5		Yes + Easily feels threatened, refuses, avoids.		Overpowering social numnmer, loving/violent talletrately.	Takes several roles, talks to self, reportit. Obs. questns.	Poor gross and fine coordination, awkward effect, flappy hands.
Carol 5:4 (normal 10 range)	. e (j	eks	, De			Clumsy, bottom shuffler; poor timing plods,not pedal.
orna IQ 1				No pride/soc.dignity. Cant negotiate W.peers FSilly, giggly,rude	Doil play ++, mimic for them Uncase with speech	Indistinct specdi Cross-lateral Otherwise OK
Stmon 7:11	Concern re fail to thrive Not cope in inf., nor ESNn nor ESNs. Home tutor, no progress.	Yes ++ 'Drops the curtain', seems devious, shrinks/over acts	Yes ++ 'Drops the Puts on act ++ (very like curtain', seems devious,Billy), acts adults, throws shrinks/over acts out placating words:'Eh? Eh?	Switches angry/mock (both inappropriate) Embarrassedipoor eye c.	Namics Adults ++, lost identity. Chs Qs Likes domestic play	Cant pedal trike, use strawywas hyperactive Autistic elder brother
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Pseudonym (age at diagnouis)	Coping history	Hesists demande?	Manipulative ?	Difficulty in judging social response lovel	Mimicry; uncertain identity; repotitive speech	Neurological involvement?
Aranda (normal IQ renge) 3:3 ??able aut; 9:3 FDA 'flrut twe she's made sense'	Unresponsive, nuapect deaf but c.300 words at 16 mo. 'Passive' in nursery! excluded private sch.6½ yr; junior sch. confident but needed žime attach staff	Yes++: at 3 by tantrums/ ignoring/demanding help; at 9, arguing/deflecting. Won't admit own skills 3-9 yr. Imperious and deflant/abject self-pity	Theres, deliberately emborrasses, exploits vulnerability of others, distracts, 3 thru 9 yr. Terrorises male tencher by displaying knickers;	Cant interact with chn, wont compromise, 3 thru 9; highly dramatic stance; 9, cant find widdle ground between over-polite/caring and violent talk/action	Echoed from 12. Fron.rev 2-3 Delib, mlwery 3 thru 9 yr. No identifon with children. Seems a curicature of adults Role-play in play therap. tock over reality - disastronely	Never file, but L.anterior temporal sharp wave focus at 4 yr. Absences? 9 yr. Inconsistently clumsy, L.H., poor figure-ground, awkward with tools,pencil.
Polly 5:7	Nursery: normal if left to self; withdr/tantrums if any demands. Infants: gleacher attachd from 6; sch. for outistic chn from 8	Yes +++ Mainly diverto; angry/hostile if presed. Tears up drawing, other products, if praised. Likes people, not their approach.	Given fob-off answers; distracts with consummate skill, then doubles back to alternative; charms strangers to give things; wanders off smilingly.	Apparently friendly, hugs children, overpowering; pushes/throws chn without provocation. Children very wary of her; might kick; squeeze animal.	Numics reading aloud. Lots of bizarre speech (some under breath) incl. others' voices. Imitative dramatio gesture/intonation.	No positive evidence. Agile, does pedal trike, manipulates small objects if interested.
Susannah 7r B	Parents very adaptive, enabled normal function pre-5; infants: !unttentive 7:welfare helper; sp.resid proposed at 8 - p.rejected.	Yes ++ Diversionary tactics her major skill. 'Impossible to pin down' Many excuses - not old enough, not big enough, too late now (after evasn)	Politely changes topic, asks why indefinitely (doecn't listen to ansur) Talks fast as evasion; sch/home find her 'deviution' v.disruptive	Often embarrassing persni comments. No pride, ignores chn's complaints e.g. if swelly (urinated anywhere till 7). Wants to organise, falls. Her comments 90/ánes;	Takes on others' roles ++ incl. speech, gesture. Pulls own hand to places, pushes self into chair.No identity with chn as opp.to adults/ bables. Nepet,questlons.	Paediatric opinion'clumsy' at 3:3. Absences thru infancy: EEG at 5 'normal limits'. Cdri pedal trike, cant tie laces, otherwise fairly good motor skills.
Dawn 513	'Always needed kid gloves' Jealousy, bad behav,from 16mo. Infant ach. comfdent could cope at 5 - needed fulltime asst for her by	Yes ++ by giggling, getting annoyed, excusos, chengo topic/activity. Evades fulltime teacher! Showdown at least demand	Takes advantage of vuln. moud or state. Frovokess drink baby oil, pour talc/cream over upholstry to distract.	Alternates over-flat or aggressive, Gets high and giggly, switches mood, flude. nemes: 'Smelly bottom!' Shouts, Krovis, Grits teeth Embraces chn, overpowers.	Calls peers 'my children'. Takes on mother's, teacher's roles, Dolls all have names of real people, Repet.ritusl patterns with dolls.	(Talipes) but generally clumay, No idea of catch, throw, pedal, scoot. Sudden unprovoked throwing, attacking, home and school.
Arlene 7:0	Parents protective of timidity, Mursery:help for delayed speech. Infants till 7, then mod. L.Diff. Akaiable, timid.	Yes ++ , by appearing frightened (inc.of treats) keeping hands full, panicking, Her sweetness prevents others'	Dolls may they don't want motivity, or hog the conversation! Stereotyped Qs and other conversationl red herrings. Propitiates.	May approach adult, then dry up or ignore; or penic, scream. Most comfortable with dolls.	Repetitive questions, Conversations with dolls interrupt real conversation; also talks as dolls,	Occan.absences (eyelid flicker). Foor coordin., poor spatial sense.Cant catch, pedal, walk down stairs,reach accurately.
Matthew 6:8 (prob.normal IQ)	lethargic lying-about pre- and at hursery; concern re aimleus/grizzly there and infants, no progress. Juniors: gime aide,	Yes ++ Resentful, oppositional, or limp, lethergic. Parents!Dare I sak him if he wants this drink? Inaccessible episodes (pencil banging)	blverts with 'silly' talk, retreats into TW acting, goes limp,grizzles. Frantic act (can control). Maken family act TW with him; fobs oif Q with'Q.	Yes ++ Mood switches. Cant negotists w.children, cant organise conventionl greeting patterns.Over- reacts aggressive/timorous	Sometimes asocial repetitive frantic alured speech, with pencil-tapping. Acts TV; acting and real life get mixed; 'real life behaviour often seems an act'.	4 febr.convuls in 3rd yr. Lethargy alt.whyperactive, limpness w.tenseness. Awkward, tentative movt, some jerky some int.tremor Poor spat. REG norm.5&6yr.
Anne 11:2	'Fimid and stubborn' till playschool at 2½, when collapsed. Repetitious, switched off. 'Evesive' ½. Infants 'aumihilated'. 5½ ach Milly now propsd.513	Yes +++ Gives wrong answer delib.if questiond - OK if no qurtn. Darts eyes, giggles, egitated under pressurewhich sees in everything.	Major skill diversionary strategies. Acts sweetly helpless, emp. with men. 'Shows up! anxious sdults, plays on people's weaknesses.	Over-reacts both affection and hostility, wants to interact w. chn, but pushes. Hits mother when angry w. brother.	Catch phrases as conversn opener.Copies manner of strangers (not cenoing). Instructs self/others.Minics granny's limp. Confused by dolls in relation to self.	L.H., was fully ambi-dex. Foor gross coordin, improves on self-instructn. Cant use scissors, blow bubbles or harmonica, examine hidden object, aim ball.
Jack 515 (10м аv.1Q ??)	Undereccupied always, passive. Nursery concern re poor play, inconsequential behav.	Yes +++ Resists being show, but learns by watching if ignored. Play performance way above test perf.	Many strategies for sidetracking, e.g. distract, pain/sick, toilet, diversionary Qs. blaming, verbal parrying etc.	Over-reacts verbally (threats, swearing); gets silly, giggly, aggressive. Can't negotiate with children.	Mimics grandfather; takes adult roles inappropriately; silly 'as if inteligence has slipped'. Repetitivo questions.	Floppy baby; poor balance then and now. Absences. Involuntary actions (tips, throws) puzzle him. Fine motor O.K gross poor, falls.
Dan 615 (1Q normal range??)	Underoccupied always, hyperactive 18-30 mo. but thought wd cope infants. 'Distractible, inappropriate behav', sp.ed.needs prom. started after 2 yr. IQ not thought low by sch.	Yes +++ - resists very competently. Parents feel choosing in shop too stressful for him.	Yes +++ At least 14 avoidance strategies identified, incl. some aggressive.	Misjudges w.chm, barges in, they make allowances, Inapproprly indecisive/ rude/over-forceful.	Uncertain re identification with chn or with teacher. 'Special' voice and manner. Many roles taken. Rapid and repet.speech under pressure.	Poor gross coording esp. clumsy in 'acting' mode. Fine manipn, better than gross motor.

Table_:	3 -	. 14.010g	tcar ue	MATIC AVOI	dance syn	Growe:	packgrou	nd reatur	es .	(1	980, 19	86)
,	Marilyn 4:1	Јеппу 4:8	Ruth 5:5	3illy 6:2	Sandra 7:4	Yvonne 8:11	Sean 9:10	Janette 10:8	Helga 12:5	Carol 5:4	Lorna 3:5	Simon 7:11
Preg/birch	12 days post. Debendox	Inducd 42 wks	norma	l forceps	Pr.HBP foetal maln? 3.11 3w.prem	normal	s.f.d. 4.9 cord r neck	unknown adopted		?	?	?
Birth order	3rd/3	1st/3	3rd/4	1st/2	only	3rd/4	1st/2	2nd adoptive	2nd/3	1st/2	2nd/2	2nd/2
Feeding	'lazy'	reflux	no proble		no problem	refused solids	poor	good	good	?	OK but first frustr wearing	irrit., failed to thrv.
Milestones	slow, normal limits	sac 10m cr.11m w.19m Cried wh.trie	w.18m	cr.12m ran 18m	normal	no.cr. orh.sh w.11m then ra		slow, normal lim. Wg taught 20m	Strong; b.sh; st.12m w.18m	b.sh; w 22mo (spoke first)	c.11mo w.18mo	Bit late
Baby type	very placid	passive neither happy/ sad		F-	? seemed hormal'	? 'Never still' 11-36m	placid: hyperac 1;-5;yr	t. content	irrithl			+
Ciddly baby?	cnly in right mood	no, too passive	yes	yes	yes till 5y	yes till 3y	yes	yes but very passive	yes till 17mo	yes	yes but anxious	not very
Sociable now? (i.e. age given)		yes but better by 6y.	yes esp.w. ext.far	3rd party	yes but violent; ambiv.to mother	•	contact	Yes:tell parents when agitated	Same as Sandra	Less so; variable Poor ey	clingy, very wary; varies.	Variable, easily feels pressure
Speech delay?	Rather slow/ gradual	30 words 18m; disappro 19m	slow;	Very;no word comic till 4yr	no	no	yes, deaf; op.4yr	6 words at 2!, comb.	slow	sent- ences by 20 mo. (spont)	yes and poor artic	a bit; best skill if relaxed
Speech anomaly?	occ.into gabble	Return lost/ret 29,3:0, 4:1	no.	Erratic jargon	no; better than most skills	to	Only short sent.9	Ednolal. Social but poor lang.use	echol. + to self	No flow echoes. Q&A No clap	single words;	echoes if tense Being listed to makes ths!
Uses gesture?	yes	?	?	pointing 18m	?	1 -	yes, v.good	?	?	?poor	point	yes, complats
Cbsessional?	1	repetitr	tates to TRISIC	re vibration and recetit. speech	checks on M's behaviour	toilets repetit	Cries compul- sively	, - I	speech, questns & as Sandra	obs Qs and re mimic re plans	yes re toilet, hair; icreaso	mainly re mimicry
Flitting?	yes	yes	eacaping when nc,exc.	Yes, even prefrrd activity frantic	yes	dreamy/ flitting except chmesti	yes g except 1:1 c struct	ves	obs. questns distract her	Yes	yes	Espec. under pressure (often!)
Symbolic play?	softoys'	dolls'	pobrah	roleplay +++; object symbols	some doll play	voices: 2 dolls at once	shop; fingers 'people dolls	some with ; dolls	some with dolls	house, puppets	flitty (dolls	best skills in play house
Musical?	Dances to tune; sing 18m	loves singing (alone)		tune,w. actions	turn to music but continue beyond	sings words & music; rocks	?	yes	sings, tries quitar		sings in tune 3:5	7
Special skills	mimicry	any domesti		mimicry	- '	cooks on	memory, jigsaws swims	, -	cook, knit, (not well); Knows 100 records	taught	verbal	mimiczy++
(at age given)	n/a	nil	nil	nil	nil	nil	write name	group	name colours	exceò≄	self (taught	very poor

Pseudonyme:	(IQ normal)	1	İ.	(IQ normal)	, - ,	7	j ,	l Tank	IQ prob.nm) <u>st</u>
15 girls, 6 boys. (age diagnosed	Amenda 3:3 ??aut. 9:3 PDA	Polly 5:7	Susannah 7:8	Dawn 5:3	Arlene 7:0	Matthew 6:8	Anne 11:2	Jack 5:5	Dan 6:5	6:10 non
Pregnancy/ birth	?	toxacmia at 7 mo; induction full term; normal	normal pregn., 10 days post; forceps	normal pregn.and birth; talipes	normal pregn.and birth	normal pregn.and birth	nauseous pregn with Debendox. Rapid delivery	nams.preg Debendox?? breech Peth++/fcps, distress, jaun/asphx	normal pregn/ birth	451
Birth order	1st/2	2mi/2	1st/2	1st/2	2nd/2	1st/2	2nd/2	1st/1	2nd/3	10/1 7/21
Feeding problems?	?	non-projetl vomiting first 12 m.	Br.fsd to 10 mo. Proj.vom. 6-8 mo.	Projectile vom.0-3 m., then colic	non-proj	no problems	no problems	?	Hard to establish Proj.vom. sevrl.mos.	You 3 pa
Milestones	?	Sat 15 mo Walked 19m	Smiled 5m Sat 9 mo Hardly crawled Valked 13m	Sat 4-5mo Walked (talipes) 14 mo	Génerally late. Walked 18m	Sat 9 mo Walked 15m (both after urging)	Sat 6 mo B-shuffled Stood 10 m Walked 15m	Sat 12 m no crawl or b-shffl Walked 2+ after urging	Sat 7-8 m no crawl Ram 18 m (wd fall, not save self	11 18s
Baby type (first year)	Un- responsive 'too good' passive	Unrespny, passive	Unrespov, passive	Very irritable, alert, inquistv.	Very irritable but responsive	V.passive, unrespons. V.grizzly from 1 yr	Placid, sleepy b.d. Scream night Alert 2nd.y	Wakeful	Placid, passive, immobile, inactive	13 p /pa
Cuddly baby?	No:distant jyr: body contact, no eye-c.	No, too passive	No - socially indifferent	Yes - but rejected affection from 2yr	Fairly	No, too passive	Yes - sociable, responsive	Fairly	No, too passive, unrespons,	fir fir yes
Sociable now? i.e. at age of diagnosis given above	j-9 years: Yes, but inconsist. eye-cont. Clingy jy+ (mother Only)	Likes soc. presence, tags onto strangers, 'adopts' groups	Yes, very sociable, outgoing. Panics if M.prolongs cuddle	Yes; but can reject rudely. Excited++ by chldn.	Charming if 1:1 adult. Ultra shy in group, horror of toddlers	Dislikes children. V.sociable re 1:1 adult playmate	Yes - a social charmer (low eye-c only when demands made)	Yes, very, but gets inappropr- iately aggressive, bossy	angry	18 79 3 v
Speech delay?	No: precocious, 300 words at 16 mo. Verbal humour 3:3	Yes: single inappr.wds at 3 yr; 2-wd sent. at 4 yr.		Sociable, unintelgbl. at 2y. 2-wd sents at 3. Still delayed 5y	Delayed till 3yr	Not delayed	ist words 10 months. Immature 4 yr and still	Some delay, Pivot-open by 3 yr. Structure now normal limits	Yes till 3 yr, incl. comprehn.	so de
Speech anomaly? (history or now)	Some echo (immed/del) 18-36 mo w.pron.reve Ability way beyond actual use.	rev),4-6 yr No Qs. Garbled, jargon, if	Echo w.pro rev.4-63 Spontan. speech 6 onwerd	No echo. Spontan., a little chaotic at 5 yr	Some echo at 3 yr. Some label confusion at 7	Only slurring if in frantic mood	Mute at school only 3-10yr Echces now as strategy to put off	whispered words till 2:10 Jumbles sometimes only (mood)	Sometimes jumbled under pressure; or gabbles to put off	
Uses gesture?	At 3 ?? At 9, yes, dramatic effect	No pointing by 5:7, (dramatic at 8 yr)	Takes over gestures of others. Depl. facial expression	L VAG	Some (obs. objects held betw fingers!)	Yes, but difficulty organising conventnly.	?	?	Yes, for extreme dramatic effect	13 def. gest
Obsessional?	Ritual phrases 3 thru 9yr	Re dolls 5 thru 8 Prefers to parents. (8 - re hi-heel sh.)	Re dolls; obs. Qs esp.on ieath & meat	also many ritual sequences	Re dolls; obs.objects from 2 yr; obs.feers of dirt, grass, sand etc.	Agitated ritualistic episodes daily re TV. Qs re numbers	Demand avoidance obsessvly worked on!	Re peoples positions etc Questions Finger- flicking	Upset at change of routine	All lead some
Poor concentration?	Dreams, switches off. ??absences. Good in role play.	Wanders, dreams. Excellent, prolonged if pursuing obsession!	distracted,	Poor with anything demanding; fine with dolls	Poor become preoccupied - better if obsumbroken (difficult)	Good with TV, or if 'gentled' 1:1 Otherwise poor	'Puts mind into neutral' esp. at school	Poor - voluntary span 10 mins	(Hyperactv. 18-30 mo) Good now if self- chosen activity	Most (con with moti
Symbolic play?	Some empathic dollplay at 3 yr Role play over-real at 9	Dolls her favourite play. Draws yrams, babies, mummies.	Much doll play and imaginaty drawing. Confust re what 'real'	Much doll play, gets ritualised - not very imaginaty.	Much doll play.Dolls interrupt demands. Phone play as escape.	Little at 3 yr. Lots at 6 yr.	Afraid of dolls/toy animals. Acts people.	None till 3 yr. Good now.	Yes, lots since	have some some a lo
Musical	3: moved to tears by m.	?	Sings w. sister only	?	?	?	Very. Good pitch	Yes, all, incl.class.	Yes	11 ; 8 w
Special skills	Verbl puzzla + some self taught reading yr	maniph of doll equipmt.	Vis.memory Imaginaty drawing, color sense:		Selfprotest by charm, propitiatn.	arith- metic	Diversionry strategies	At best in imaginativ play	Cooking since 4yr, dislikes supervisa	va se: ta:
Academic achievat at diagnosis	As above; serious under-ach., unoccupied at 9yr	(also nil	Reads flash cards, not word build	NII without 1:1 teach	Writes name only; primitive drawing	school	Nil: 'becomes dull as enters sch'	None yet	Very little indeed: 'disengaged'	low unle