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Therapeutic Intervention in Autism:
Perspectives from Research and Practice

PATHOLOGICAL DEMAND AVOIDANCE SYNDROME : a statistical update

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Introduction

At the 1995 Durham Conference, I gave a descriptive account of what appears to be a 'new' diagnostic entity, in so far as there do not seem to be any detailed symptomatologies available that correspond with this developmental condition. My own work in identifying its parameters has been spread over more than twenty years, and was made possible by the fact that, throughout that period of time, I have had children referred to me who have 'reminded' people of autism (particularly the Asperger's group), but who have been puzzling or atypical in terms of that diagnosis. Indeed, the only diagnosis available to me and to others, at the beginning of this period, was 'non-typical autism'; however, this has not been a helpful diagnosis for the families of these children, for two reasons. Firstly, parents did not find it explained their child in any way: the more they learned about autism, either through reading or by meeting other families, the less credible they found the diagnosis in relation to their particular child, and, as they later admitted, they were inclined to dismiss the term as irrelevant. Secondly, whatever guidelines might be invoked as helpful in the education and handling of autistic children proved to be at best off-beam and at worst deleterious: this especially applies to traditional behavioural methods.

Pathological demand avoidance syndrome (PDA) is seen as related to autism in terms of being an identifiable pervasive developmental disorder. I find it particularly helpful to see both autism and PDA as members of a family of developmental coding disorders, which allows us to include dyslexia. For this purpose, the family of disorders is better seen in these terms than in terms of 'autistic spectrum', which is too narrow. Within the family, the different conditions can then be seen as clusters of symptoms. This conceptual model has the advantage of being wholly understandable to the lay person, including parents; it is also understandable that there will be a few children who fall between the main clusters in their patterns of symptoms. This is true of children with semantic pragmatic disorder, who fall between developmental dysphasia and autism; and it is also true of some non-typical children who have autism with some PDA traits or PDA with some autistic traits. However, the PDA children who show the whole pattern in its typical form are very different from autistic children in their strengths, their difficulties and their needs.

Table 1 illustrates the conceptual model I have described, which also includes the reminder that intellectual level has a crucial significance for function and for how the symptomatology is expressed (for instance, the difference between autism and Asperger's syndrome). Table 2 gives a descriptive summary of PDA and the main ways in which it differs from autism/Asperger's. This table is barely changed from its first edition in 1988, and shows how robust the concept has proved. We are now able to base our information on over 120 typical cases. My first paper on the topic was given to the British Paediatric Association in 1980 and was based on my first twelve cases, later enlarged to 36; this statistical update is based on my most recent 50 cases, and shows no essential differences in the symptomatology. There has been added some information on language development, which I earlier ignored for lack of data; and the one earlier belief that has proved untrue has been the impression of a greater prevalence in girls than boys. Over the large sample of 120, boys and girls are equally prevalent: this, of course, has its own interest when comparing the fourfold greater prevalence of boys in autism, the tenfold rate in Asperger's, and the threefold rate in both developmental dysphasia and dyslexia. About six families are known to have one child with PDA and one with autism, which seems to show a not dissimilar genetic link to that found in autism, and certainly a genetic connection.

The tables that follow the first two are given as histograms showing percentages, N=50. Where the table is not self-evident, I have added notes, and these follow below:

Table 3: Background data

PDA children are less likely than autistic children to cause serious anxiety in the first three years, largely because their parents make such heroic adaptations to their idiosyncrasies. Birth details are included but mean little without trustworthy normative data.

Table 4: Resistance of demands; aggression

As the name suggests, pathological resistance to ordinary demands is invariably seen (see Table 5 also). Aggression was present in 68% of children at age of diagnosis (see Table 3). Almost always, however, this behaviour is best seen as a panic attack, brought on by the difficulty of escaping a perceived demand. Adults respond more appropriately (ie with reassurance) if they can reframe 'aggression' as panic.

Table 5: Manipulative strategies

This is a major diagnostic differential between autism/Asperger's and PDA: 'manipulative' is a word invariably used spontaneously by parents during history-taking or positively agreed with. Autistic children's parents, in context, feel themselves to be manipulated by 'fate', but not personally by the child. To manipulate involves a degree of social empathy (theory of mind) which autistic children do not have; PDA children do.

Table 6: Already passive in first year

Note that passivity is distinguished from placidity. Later on, most children will become actively passive, ie they will actively reject demands. In the first year they tend to sit or lie unoccupied, though they may be watchful. Nearly half drop the toys put in their hands; parents try to play with them, but find they are simply 'entertaining' an uninvolved child.

Table 7: Physical milestones

Late milestones may be one aspect of passivity, often combined with stories of being able to leave the child 'on the settee' etc, knowing she wouldn't move. One child crawled 'privately', ie only when nobody was looking! Some children have been thought to be neurologically 'floppy', not borne out by later history.

Table 8: Speech delay - and do they catch up?

Speech delay is almost always a feature, usually attracting speech therapy. However, the catch-up rate (to normality of speech forms) is much higher than in autism, which suggests that the delay is another aspect of passivity. This is confirmed by speech therapists' impressions: they commonly find the child exceptionally resistant, but then find a sudden rapid improvement. There is even an impression that the child finally catches up as a result of realising that speech could serve their demand avoidance; certainly much of the speech is used for distraction and making excuses!

Table 9: Speech content and speech pragmatics

The most notable abnormality of speech is its content (and see next table). However, the speech pragmatics, so abnormal in autism and Asperger's, are rather rarely significantly affected. The missing data denotes that no definite statement on this item was made in the case-notes; however, if abnormal eye-contact, social timing or

facial expression had been observed, they would have been noted, therefore the percentages referring to normality are a conservative estimate. Facial expression, if abnormal, is more likely to be over-emphatic than depleted, unlike that seen in autism.

Table 10: Speech anomalies

These anomalies refer to content. Jargon is an early phenomenon in some children but does not last. Non-social echolalia, of the kind common in autistic children, may occur, but in fact there is often a social agenda to it, eg it may be used at an early stage to deflect or shut out demands. Acting out videos is semi-social rather than conventionally echolalic, in that the whole style is mimicked, not just the soundtrack, and additions may be made. Social mimicry may be very skilled role-play, again using the whole style with a creative element, and there is usually an agenda of control. Some children will achieve a great deal in the assessment if allowed to take the role of the psychologist!

Table 11: Symbolic play and role play

This is another major differential from autism/Asperger's: symbolic play is a strength, and may also be a retreat. In play-based assessment, the PDA child makes strenuous efforts to get into pretend play rather than other activities. However, a third seem very confused about the boundary between real and pretend. The role play referred to here excludes non-social echolalia; some of it is extraordinarily skilled in acting terms, involving different voices and creative scenarios, and can be sustained for over an hour in older children. Some fantasies can be violent, especially in older girls. Choosing role play as a preferred 'way of being' is confusing to parents; many report that the child has 'better conversations with her dolls than with us'. Some children talk to their reflections or shadows, and a few to inanimate objects which they apparently perceive as animate (eg 'the cups on the dresser').

Table 12: Social response

Most PDA children by age five are showing very inappropriate behaviour, at best embarrassing, at worst very disruptive. Demand avoidance in itself is not here counted as 'inappropriate', but often the behaviour serves the need to avoid - for instance, distracting the adult from the demand being made by throwing things, urinating, sexual posturing, swearing etc. Lability of mood describes a switch of mood not justified by circumstance.

Table 13: Confusion of identity

It is suggested that the 'coding problem' in PDA is a central difficulty in coding identity, and that this brings about a failure to understand the concept of responsibility, which results in obsessional demand avoidance. Whereas autistic people lack social empathy (theory of mind), PDA people have a degree of social empathy but have no sense of the ramifications of the self as 'the central core of being' (Allport). The data given here refers to evidence other than the lack of responsibility implied by demand avoidance, since demand avoidance occurs in 100%. It can be seen that in most cases there is evidence that confusion of identity applied in terms of both self and others; this is particularly striking when compared with the child's excellent ability to manipulate socially.

Table 14: Flitting

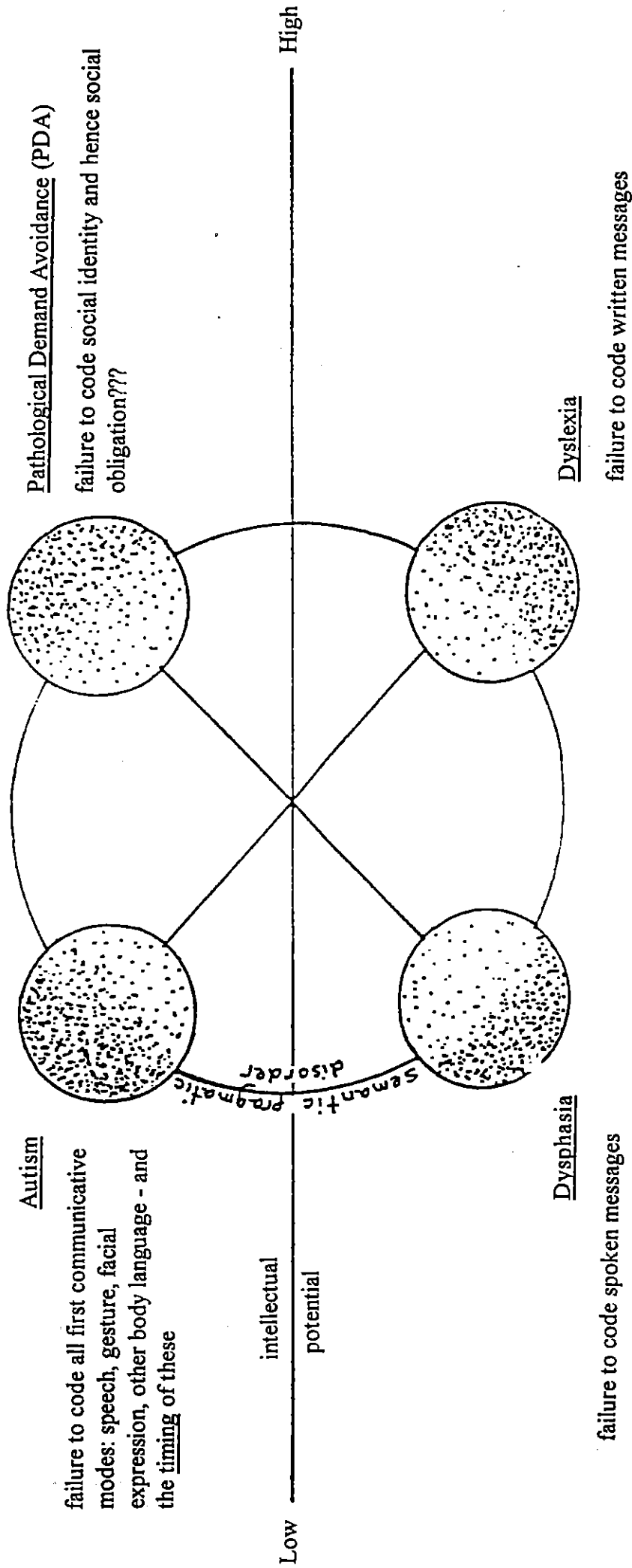
Because the children refuse their attention to what they perceive as demands, sometimes they have been described as having attention deficit disorder. However, only 4% of this sample have shown 'flitting' behaviour in any general way. About half have no flitting behaviour at all, but avoid demands while giving good attention (notably to controlling the situation). Of those whose attention is flitting only when demands are being made, half are very well able to give impressively sustained attention when they choose to. Clearly this has implications for management, and the circumstances under which attention is given should be carefully ascertained before taking any decision to medicate.

Note: I would like to thank my assistant, Kathryn Dent, for her many hours of meticulous work in extracting data from case files.

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

Table 2

DEFINING CRITERIA FOR DIAGNOSIS OF PATHOLOGICAL
DEMAND AVOIDANCE SYNDROME

(with descriptive notes and comparison with autism)

PDA CHILDREN

1. Passive early history which usually masks the degree of abnormality: parents tend to have adapted so completely to child's passivity that they are ill-prepared for the extent of failure once child is subjected to ordinary group demands of school or nursery: they realise child needs 'velvet gloves' but don't perceive as abnormal. Professionals too regard child as puzzling but normal at first. Both see her as 'so devious that she must be more intelligent than her school achievement suggests'. Early concern may centre on language delay, but language is not disordered though content may be odd.

2. Resists and avoids ordinary demands of life Seems aware of feeling under enormous pressure from the normal requirements of young children, can't tolerate, devotes self to actively avoiding these. Avoidance of demands may appear the greatest social and cognitive skill, and most obsessional preoccupation. Strategies of avoidance are essentially socially manipulative, and include: (a) Distracting adult: 'Look out of the window!', 'I love your jumper!', 'I want to wee', 'I'm going to be sick', 'Bollocks! - I said bollocks!' (b) Acknowledging demand but excusing self: 'I'm sorry, but I can't', 'I'm afraid I have to do this first', 'I'd rather do this', 'I don't have to, do I', 'you do it, and I'll'. (c) Physically incapacitates self: hides under table, curls up in corner, goes limp, dissolves in tears, drops everything, seems unable to look in direction of task (though retains eye contact), removes clothes, removes glasses, 'I'm poorly', 'I'm hot', 'I'm tired', 'Too late now', 'getting dark', 'I think we're lost', 'I'm handicapped', 'I'm going blind/deaf/spastic'. (d) Withdraws into fantasy or doll play, including appealing to doll etc, 'Philomena won't let me do that', 'Dolly doesn't like this game'. (e) Bombards adult with verbiage which drowns out demands. (f) (if necessary) Screams, tantrums, hits, kicks; best construed as panic attack.

3. Surface sociability, at first sight normal; sufficient for child to manipulate adults in the way shown in (2), but otherwise ill-judged, labile, ambiguous, without depth. Child may greet overpoweringly, hug other children too long and too hard, react to social situations with confused anger, panic or tears of an extreme order, slip from loving to violent behaviour, or vice versa, for no apparent reason, or show both simultaneously: 'I hate you' in a sweet voice while hugging. No negotiation with other children. When asked to do some small thing, may go 'over the top' in anger or cringing, often in quick succession.

AUTISTIC/ASPERGER'S CHILDREN

Seems much more abnormal much earlier; lack of social response alerts, if nothing else. Any language is disordered, with significant problems in pragmatics of both verbal and non-verbal communication.

Ignores or shuts out pressures in a-social manner, without acknowledging others' needs. Has very few conscious strategies for avoidance. Doesn't adapt particular strategy for particular person.

Because of lack of social empathy, autistic children don't purposefully manipulate, though people around them may feel manipulated by the situation. They give no impression of sociability except with obsessional questions from verbal children.

Table 2 (continued)

4. Apparent lack of social identity or sense of pride

Although conscious of others' reactions, this doesn't constrain behaviour, which can be grossly disruptive (eg pouring milk on another child's head without provocation). Wants other children to admire, but usually shocks them by complete lack of boundaries. No sense of responsibility. Uncertain of, or uninterested in, others' identities (one child refers to each of his twin brothers as 'the twin'). Doesn't identify with children as a category; the question 'Does he know he's a child?' makes sense to parents, who recognise that this is a major problem. Behavioural approach ineffective.

Doesn't consider other people's reaction, and often seems incapable of doing this. Can be helped by clear rules (which may themselves become obsessional), and by the structure of (negotiative) behavioural approach.

5. Particularly comfortable in role play and pretending,

to the extent that child appears to have lost touch with reality. Appears to take over second-hand roles as a convenient 'way of being', ie a coping strategy. Rather than work out own role, may behave to children as teacher might, therefore seems very bossy; or mimics others and plays out their roles so fully that parents are confused as to 'who he really is' - much more complete and conscious roletaking than echolalia. Takes charge of assessment, very interested in mimicking odd or violent behaviour, and may seem unable to keep in control of this pretence. Role play of 'good person' can help.

Lack of symbolic play and lack of social empathy make it very difficult for autistic children to pretend or to take roles more fully than by simple (often meaningless) echoing - though Asperger's children may learn this with difficulty and without fluency.

6. Obsessional behaviour Much or most of the behaviour described is carried out in an obsessional way; as a result, child achieves in school at very low level indeed because motivation to avoid demands is so sustained and because she knows no boundaries to how far she will go in avoidance. Can be more difficult to teach than autistic children for this reason. Obsessional questions very common, often used as a distraction device, but may signal panic. Obsessions of PDA children are usually social, ie to do with people and their behaviour and characteristics; in particular, they may obsessively blame other people when things go wrong, or obsessively harass people to whom they have taken a dislike. Major one-to-one intervention productive, and often also needed to control disruption.

Autistic children share the obsessional characteristics, but are less obsessed with social topics, and do not use their obsessions so consciously for manipulative purposes.

7. Neurological involvement Soft neurological signs are seen in the form of clumsiness and physical awkwardness with all the children, no crawling in more than half. A very few have actual fits or apparent absences. Not enough hard evidence as yet.

Similar evidence of involvement, but the problems are more specific in autism.

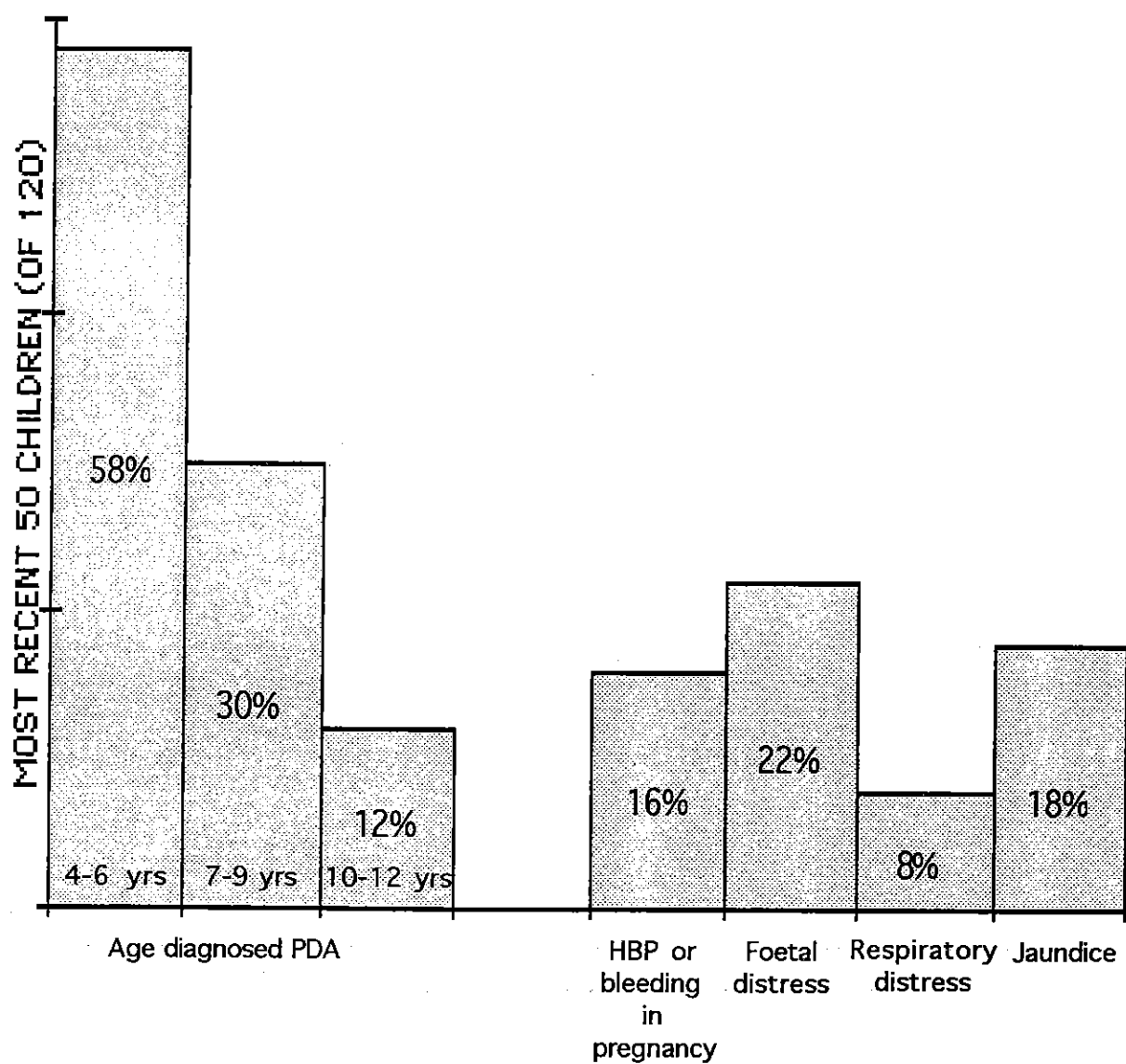
Some genetic links with autism.

Elizabeth Newson 1988

Revised 1995

Table 3

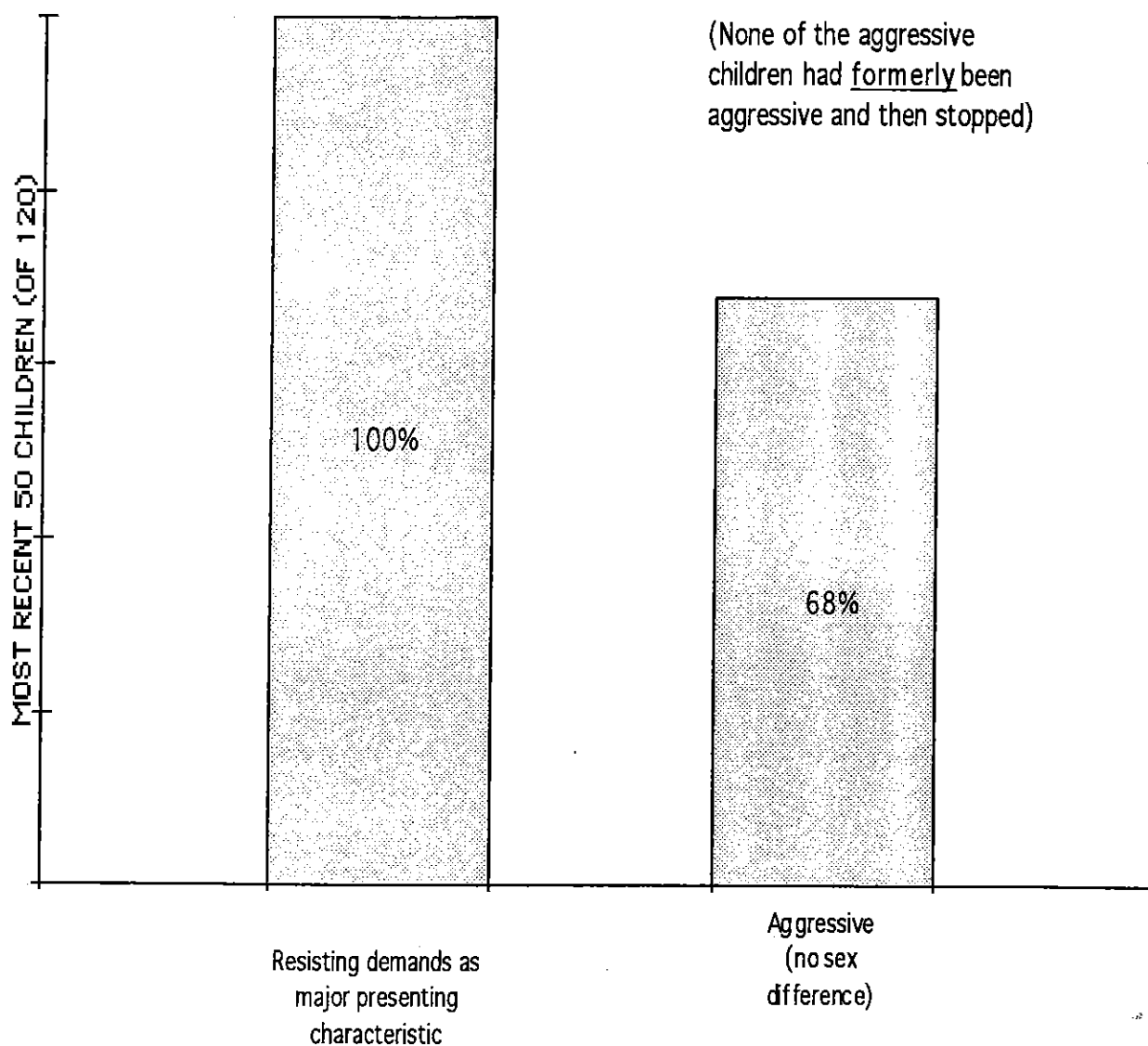
Pathological Demand Avoidance Syndrome :
Background Data



(Newson 1996)

Table 4

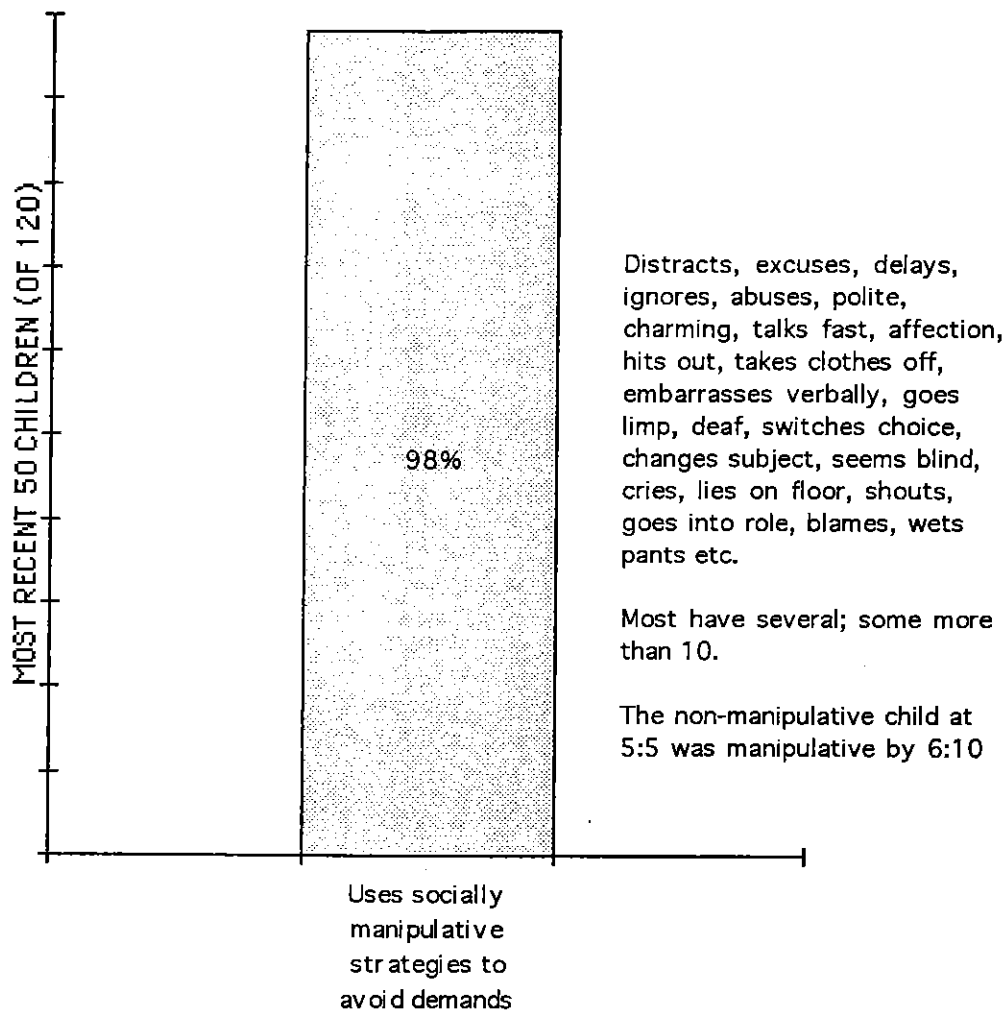
Pathological Demand Avoidance Syndrome :
Resistance and aggression



(Newson 1996)

Table 5

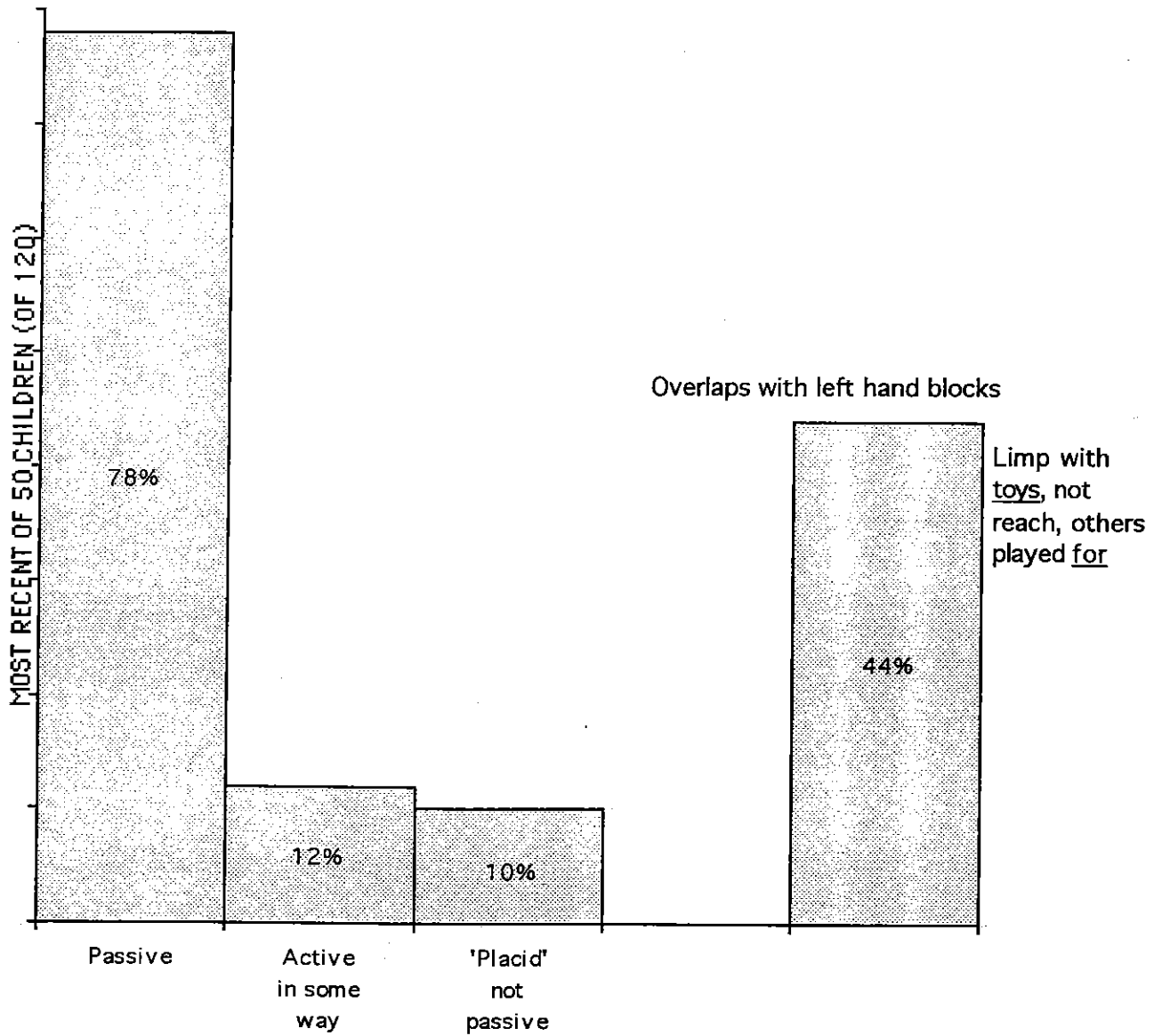
Pathological demand avoidance syndrome :
Manipulative strategies



(Newson 1996)

Table 6

Pathological Demand Avoidance Syndrome :
Already passive in first year



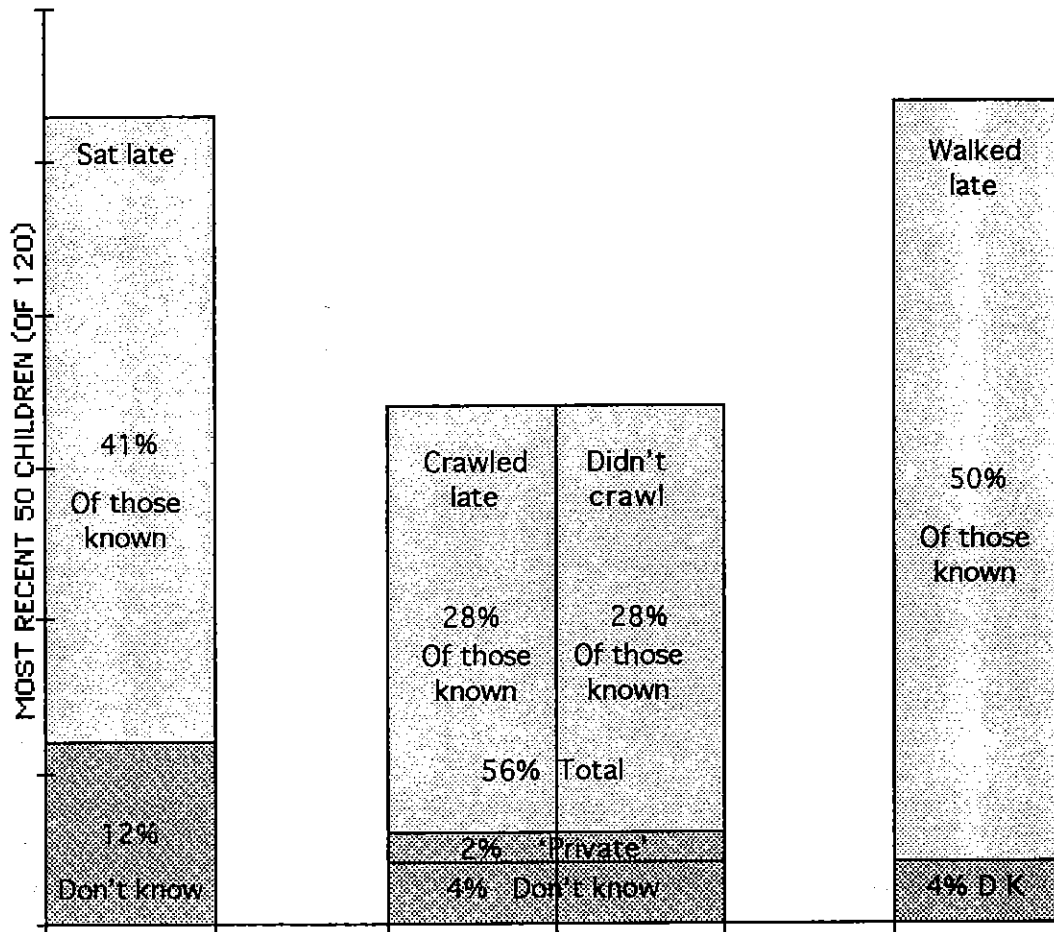
(Newson 1996)

Table 7

Pathological Demand Avoidance Syndrome :

Physical milestones

'Late' defined as :
 sitting - 8 months plus
 crawling - 11 months plus
 walking - 15 months plus
 (Ref. David Hull
Child Health 1985)

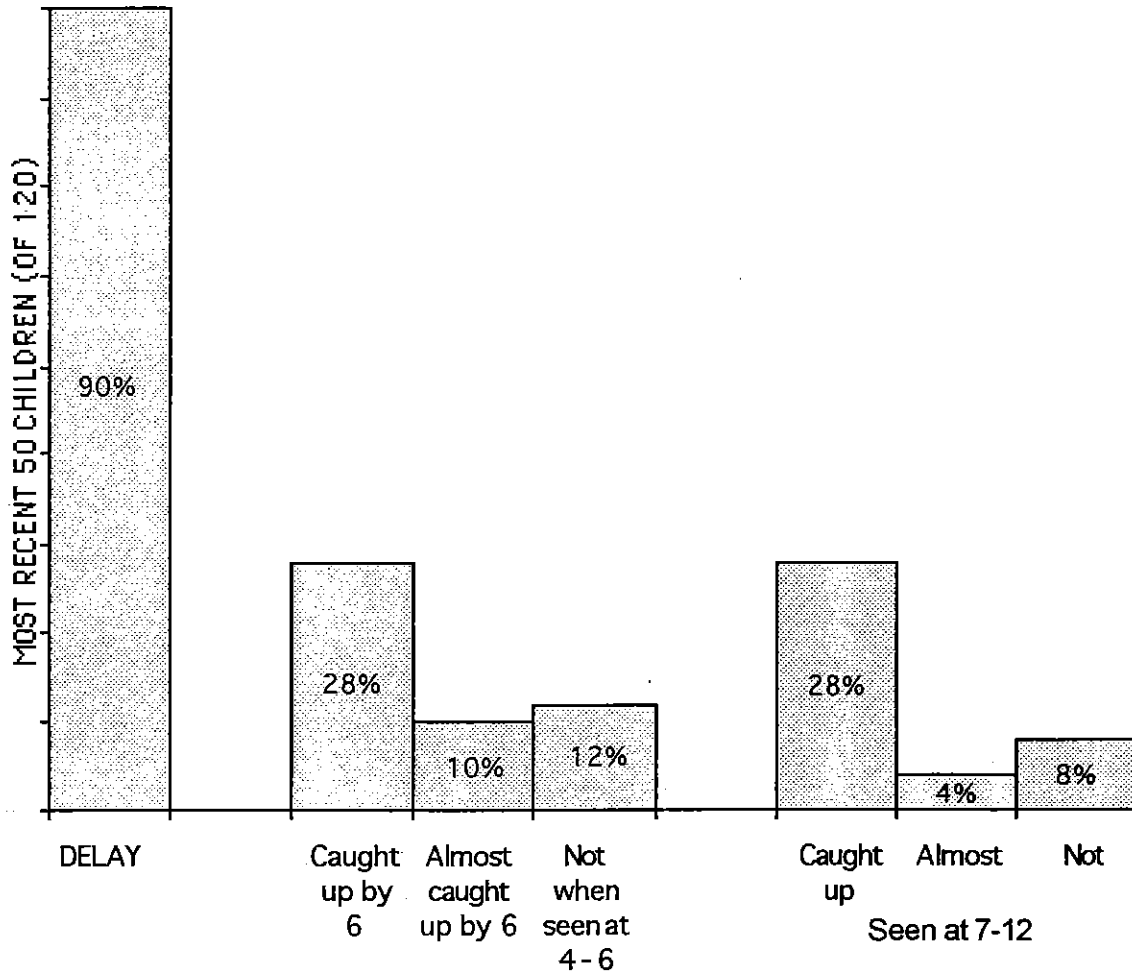


(Newson 1996)

Table 8

Pathological Demand Avoidance Syndrome :

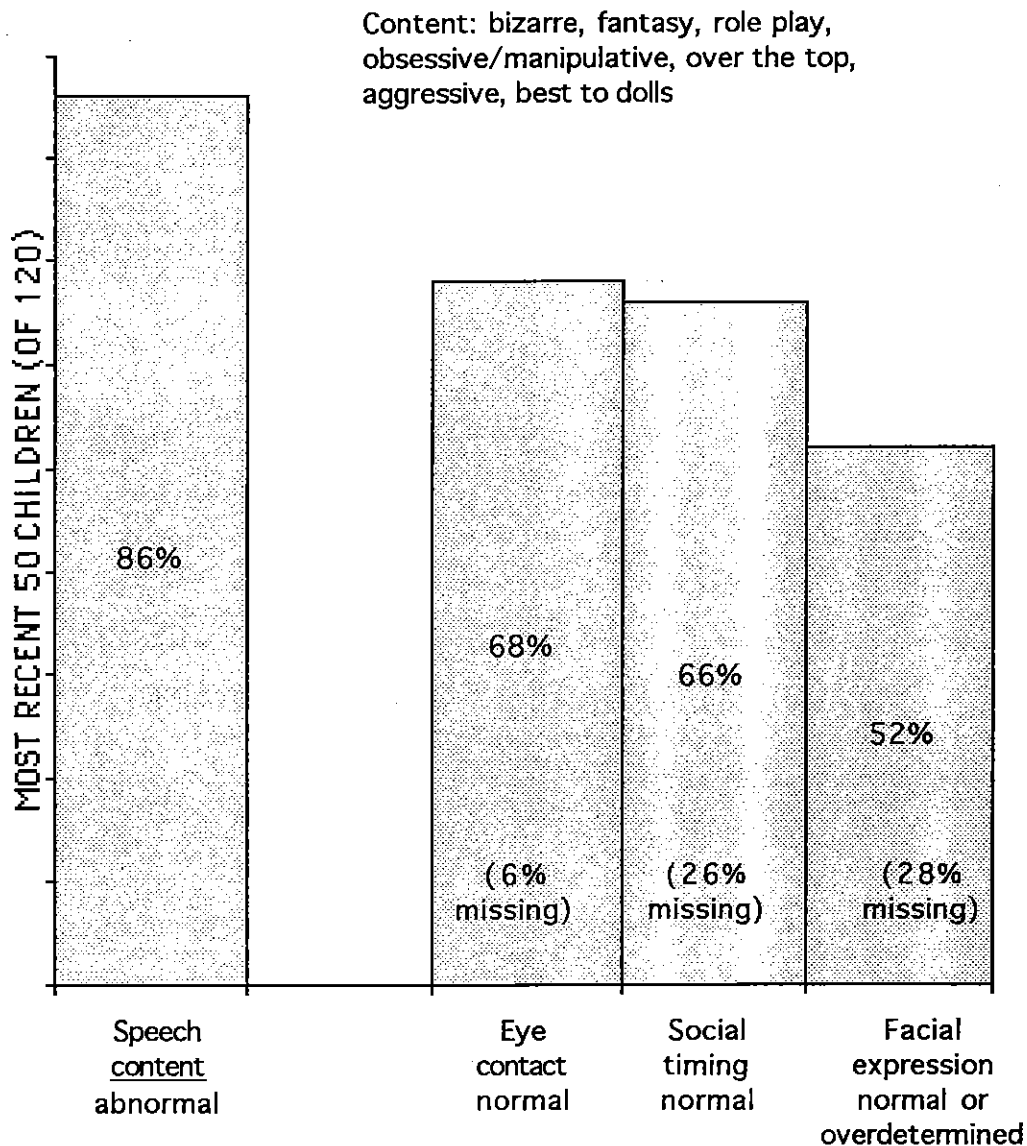
Speech delay - and do they catch up?



(Newson 1996)

Table 9

Pathological Demand Avoidance Syndrome :
Speech content and speech pragmatics



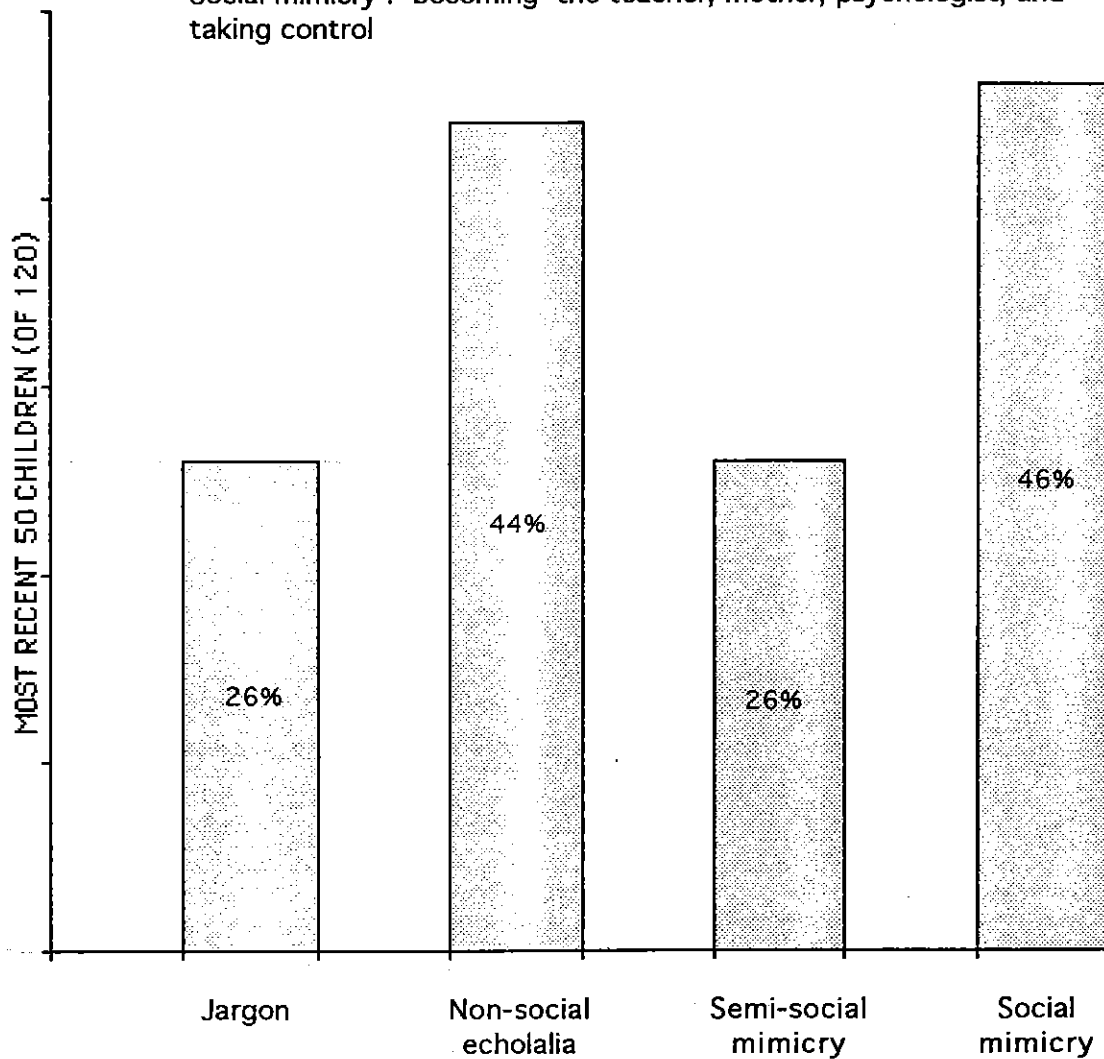
(Newson 1996)

Table 10

Pathological Demand Avoidance Syndrome :
SPEECH ANOMALIES

Semi-social mimicry : mainly acting out videos or story characters.

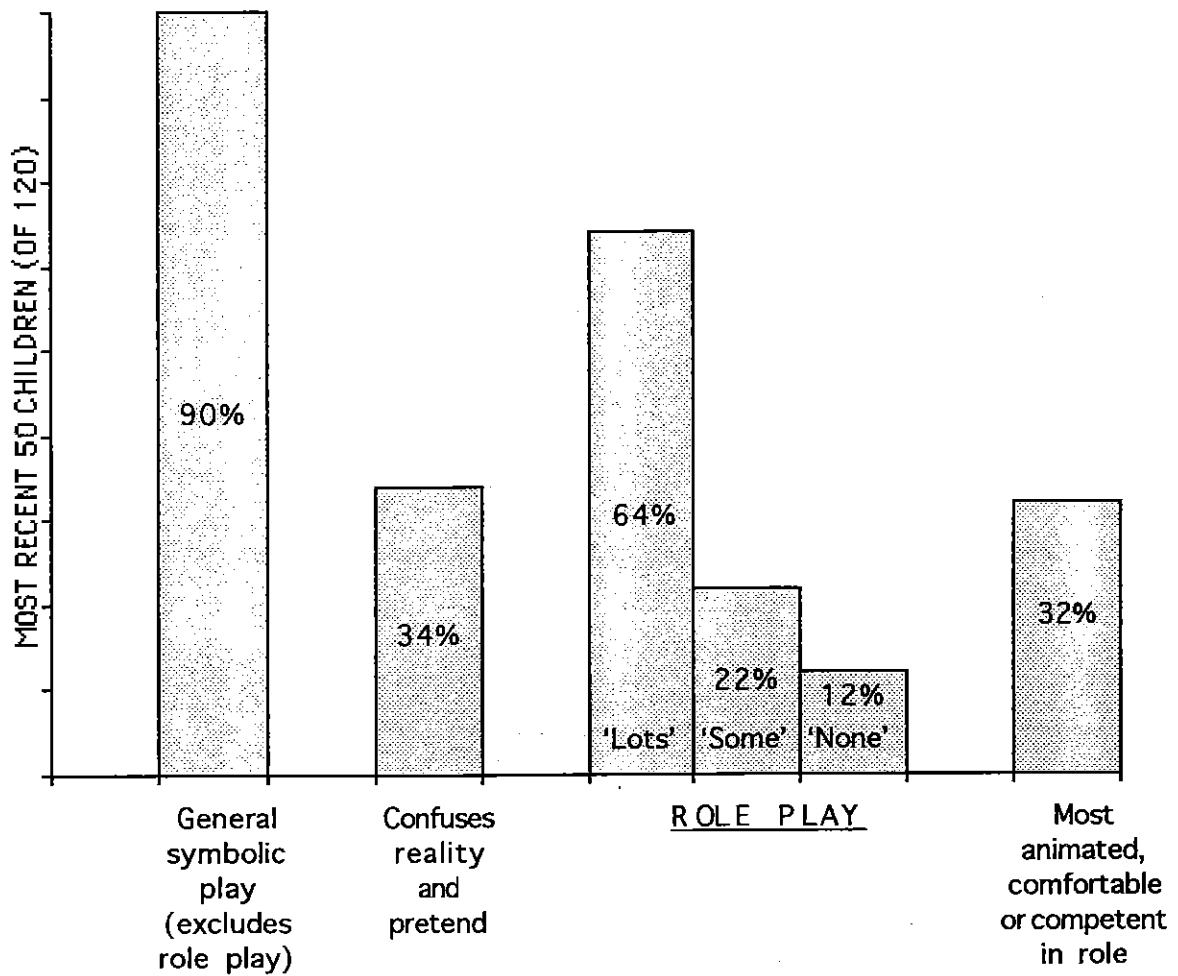
Social mimicry : 'becoming' the teacher, mother, psychologist, and taking control



(Newson 1996)

Table 11

Pathological Demand Avoidance Syndrome :
Symbolic Play and Role Play



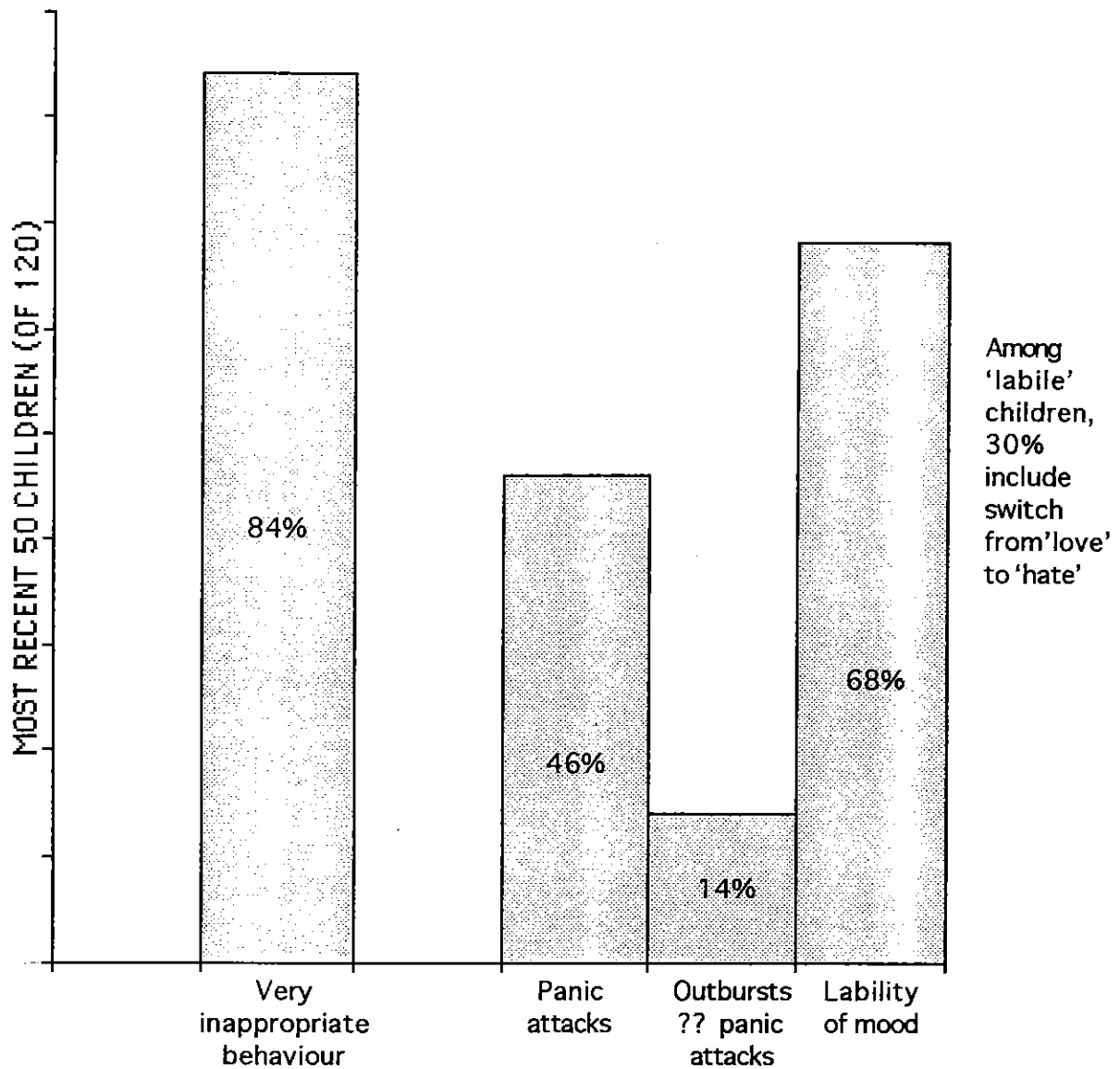
(Newson 1996)

Table 12

Pathological Demand Avoidance Syndrome :

Social response

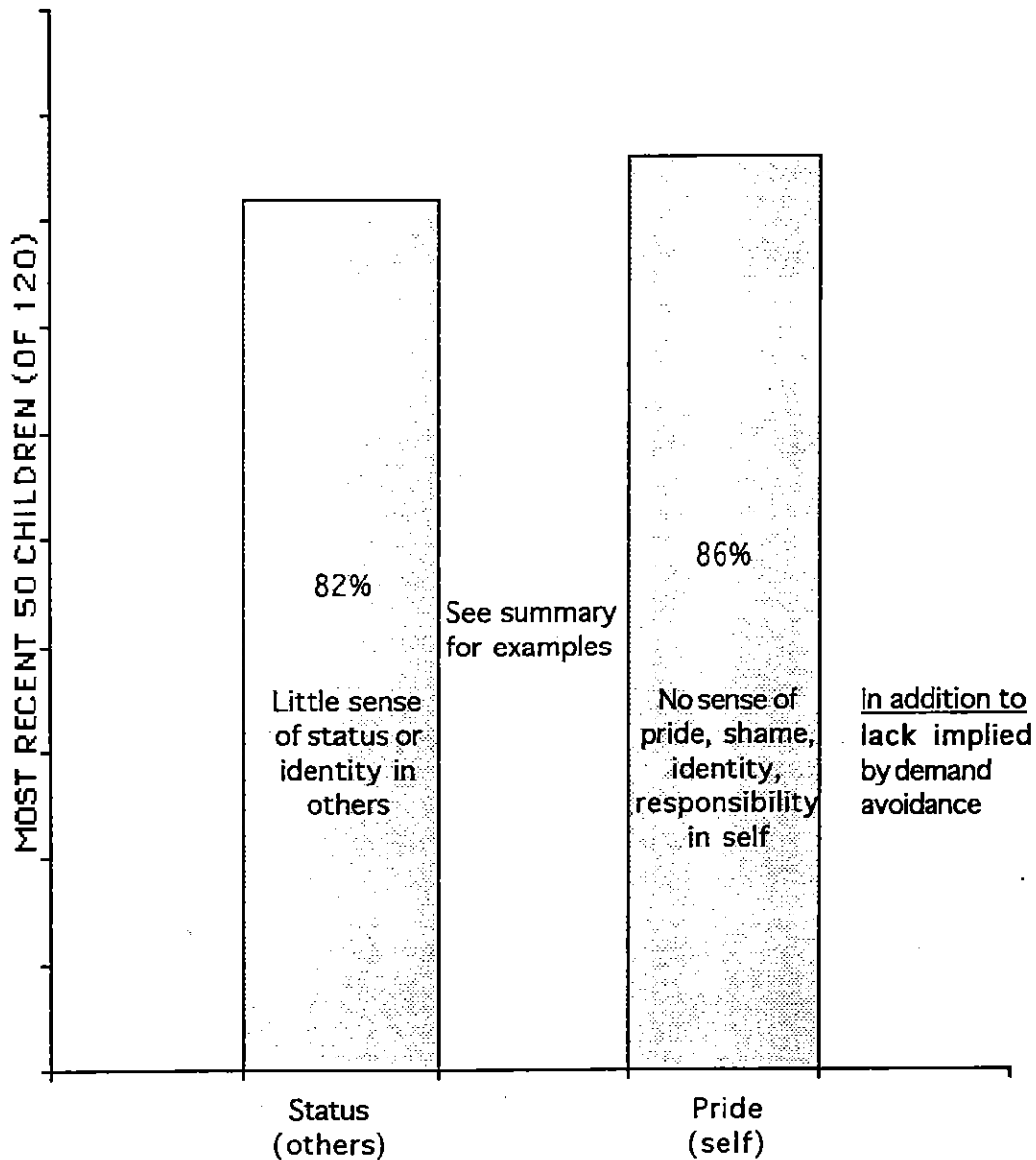
(‘Inappropriate’ excludes demand avoidance)



(Newson 1996)

Table 13

Pathological Demand Avoidance Syndrome :
CONFUSION of IDENTITY



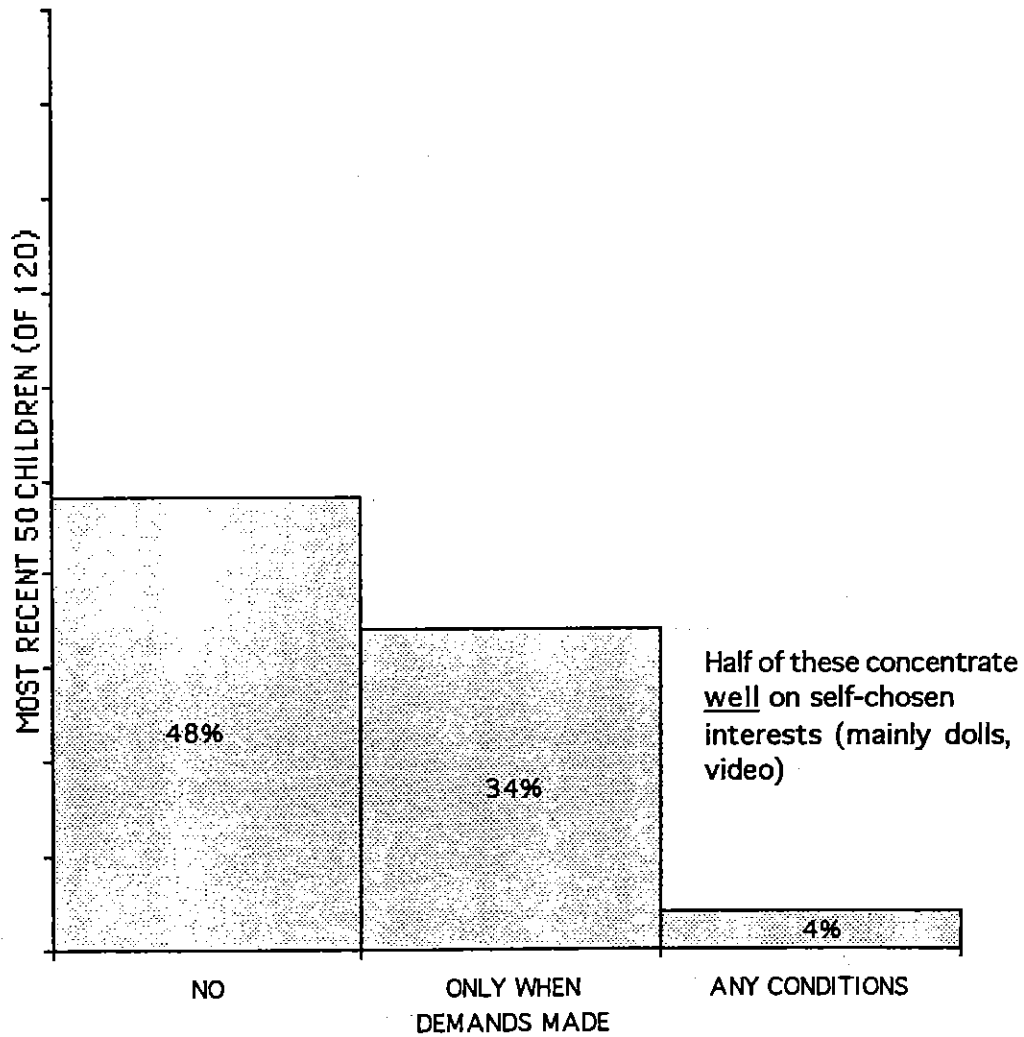
(Newson 1996)

Table 14

Pathological Demand Avoidance Syndrome :

FLITTING

(is this ADD?)



(Newson 1996)