The role of special schools for children with profound and multiple

learning difficulties: is segregation always best?

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Introduction: 'Education for all' and the segregation of a minority

Recent years have seen a shift in attitude in favour of inclusive education for children with various forms of learning difficulties and disabilities who have traditionally been located in special schools. Legislation in the form of the Special Educational Needs and Disability Act (2001) has enshrined children's access to mainstream provision

making the refusal of access on the grounds of disability/impairment of the child difficult. However, there is a general assumption that inclusive education can only go so far and that mainstream opportunity for some children is unrealistic. Chesley and Calaluce for example argue that those who support inclusive education for all have 'lost sight of practical reality' (1997, p318) and claim that some children are incapable of benefiting from lessons in a mainstream school as the workload and pace is pitched far too high for their abilities. They argue that, given the cognitive abilities of some children, a more appropriate approach would be 'to work intensively on skill development and remediation first…with the goal being to mainstream children' when the child is deemed to possess the basic skills required to keep up with mainstream life (ibid). Such an attitude towards the necessity of special education for some is also reflected in the Green Paper*: Excellence For All Children - Meeting Special Educational Needs* (DfEE, 1997) which, as Croll and Moses argue, falls into the pattern of emphasising the need for inclusion for most children whilst reinforcing the segregation of a selected few by 'protecting and enhancing specialist provision for those who need it' (2000, p9). More recently, these assumptions were reflected by the Special Educational Needs Code of Practice (2001) which stresses how local education authorities must comply with parents' preference of school *unless*:

'...the school is unsuitable to the child's age, ability, aptitude or special educational needs, or the placement would be incompatible with the efficient education of the other children with whom the child would be educated, or with the efficient use of resources' (Education Act 1996, in SENCOP 2001, p107).

Despite the above notions that special schools are the most appropriate educational setting for some children, the extent to which special schools actually meet the needs of children with the most severest of cognitive impairments – those with profound and multiple learning difficulties (PMLD) - is rarely questioned in the literature and a culture of 'faith in special schools' appears to be prevalent. Although the category of 'PMLD' is contested as a syndrome, it is often claimed that since such children operate at preverbal stages of development, in no way could mainstream schools contribute to 'growth' in such children as the lessons are far too advanced for their abilities (Foreman, Arthur-Kelly, Pascoe, & Smyth King 2004). This paper presents research from a different perspective which challenges the above assumptions. It highlights how the learning environment of one highly regarded special school for children with severe learning difficulties (SLD) in the Southwest of England provided an inappropriate learning environment for children with PMLD as a result of lack of staff knowledge and training. It emphasises the social limitations of the special school and considers these limitations in light of recent research by Foreman et al. al. (2004) and Simmons and Bayliss (2005) which suggests that the rich social milieu of mainstream schools could contribute towards the development of children with PMLD. The paper concludes by suggesting a more critical attitude towards special schools is needed as well as a reconsideration of the generalisation that children with PMLD cannot benefit from mainstream education.

Defining 'profound and multiple learning difficulties'

Children and adults with PMLD are seen as having the severest of cognitive impairments resulting in an extremely young mental age, often compared to that of an infant at the preverbal stages of development (Aitken and Trevarthen 1997; Trevarthen and Aitken 2001) resulting in the earliest forms of non-verbal communicative abilities (Burford 1988; Nind and Hewett 2001). The World Health Organisation (1992, in PMLD Network 2001) identifies such children as having an IQ below 20, giving a 10-year-old child a mental age of 6 months. In addition to their cognitive delays, children with PMLD also experience other forms of disability such as physical and sensory impairments. Such children are highly dependent on others for the most rudimentary care needs and deemed to require a lifetime of support (Carnaby and Cambridge 2002). Children labelled as having PMLD are often very diverse in their abilities and as such present as having very idiosyncratic behaviours. In order to understand the behaviour of children with PMLD, each child has to be considered in their own right since most have very individual ways of interacting with others.

Sharing a vision whilst understanding the 'detail'

The recent White Paper - *Valuing People* (Department for Health 2001) sets out the Government's commitment to improving the life chances of people with learning disabilities and reports how this commitment will be met by working closely with local councils, the health service, voluntary organisations and most importantly with

people with learning disabilities and their families to provide new opportunities for those with learning disabilities to lead full and active lives. However, the extent to which the White Paper addressed the needs of people with PMLD was criticised by the PMLD Network (2001) who argued that Valuing People fails to:

• 'use consistent terminology

• identify that children and adults with PMLD are amongst the most excluded people in our society

• identify children and adults with PMLD as a priority group

• make any specific objective or sub-objective for people with PMLD

• identify family carers of children and adults with PMLD as a priority group' (PMLD Network 2001, p2).

For people with disabilities, ~~T~~the White Paper ~~for people with learning difficulties,~~ outlined the four key principles of Rights, Independence, Choice, and Inclusion but for people with PMLD, 'whilst the overall vision is the same as for their more able peer group, the detail for children and adults with PMLD is often different. Children and adults with PMLD~~pmld~~ have specific needs that call for specific initiatives. All too often, their needs are lost within the wider agenda' (ibid, p3).

The Study

The aim of the research reported in this paper was to explore how children with PMLD could be 'included' in the general classroom life of a Southwest special school designated for children with severe learning difficulties (SLD) in order to illuminate the ways in which the 'detail' of inclusive education could be actualised for children with PMLD. For the purpose of this project, inclusion was understood in terms of the extent to which the children with PMLD engaged with their social and educational environments. Opportunities for mainstream school placements for children with PMLD are extremely rare in Southwest England, hence the research was undertaken in a highly regarded special school. The school has been praised by Oftsed and the Learning and Skills Council for its 'inclusive' provision for children with severe and profound and multiple learning difficulties (i.e. the children with PMLD are no longer located in a PMLD-specific class) and has strong links with the local community by providing popular holiday clubs for children of all ages and abilities.

The following Sseven key questions - related to themes of specific and generalised strategies for supporting children with PMLD guided the research process:

1. How does the school see the needs of children with PMLD?

2. What specific intervention strategies are adopted by the staff in order to support children with PMLD?

3. Have the teachers received any additional training to work with children with PMLD?

4. Are staff confident enough to work with children with PMLD?

5. Is peer interaction with children with PMLD facilitated? If so, how?

6. Are children with PMLD 'included' in the classroom?

7. To what extent do staff feel that children with PMLD could successfully be included in a mainstream school?

Methodology and Methods

Research methods were guided by an interpretive methodology and a grounded, ethnographic approach was adopted, making use of both participant and non-participant observations as well as informal and formal, semi-structured interviews adopted (Cohen, Manion and Morrison 2000, Crotty 2005, Randor 2002). The research was undertaken in two phases. The first phase was exploratory and illuminative, the purpose being to understand what inclusion meant for a child with PMLD within an SLD school. During this time participant and non-participant observations were undertaken for a period of 8 weeks. Acting as a learning support assistant in three different classrooms allowed one of the researchers to participate in the daily routine and life of the children in the school. The participatory role helped reduce notions of observer reactivity also. Periods of non-participatory observation

allowed the researcher to step back and observe how other LSA's and teachers interacted with the children, and to observe the skills, techniques and intervention strategies used by adults. Field notes provided a wealth of examples of practice, and were discussed with adults during suitable free periods (break time, after school etc) to ensure authenticity. The second phase of the research consisted of a final round of non-participant observations for a day in each of the classrooms followed by a series of semi-structured interviews, the questions being based on the original research questions and the observation notes being used to provide prompts and maintain conversation, whilst also acting a method for triangulating the notes with the opinions of the staff. Data analysis was undertaken through grounded methods and conclusions reached after submergence in the data to reveal themes and patterns (Ryan and Bernard 1994; Silverman 1993). The findings of this process are reported below.

Interpretivism, Participant observations, observations, field notes, informal interviews, semi-structured, open-ended interview.

I guess you need to write this bit! Or are you leaving it up to reader interpretation??

Findings

From observations it was evident that some teachers had strong expertise in a variety of areas such as curriculum differentiation for those with SLD, as well as behaviour management strategies and techniques for motivating the children in class. The treatment of children with SLD was impressive, with a variety of monitoring systems

and a wide range of intervention strategies. The staff were friendly and the newly built classrooms were large, bright and well resourced. Unfortunately, after observing various members of staff in action it became apparent that many struggled to meet some of the more serious needs of those children with PMLD.

1) School staff lacked a sufficient understanding of 'PMLD' stemming from little opportunities for additional training resulting in inappropriate educational experiences.

It was clear that some members of staff (including senior management, teachers and learning support assistants) lacked an understanding of what constituted 'profound and multiple learning difficulties'. Terminological inconsistency was revealed during informal discussions and semi-structured interviews with staff, where the terms 'brain damage', 'severe needs', 'PMLD', 'global delay', 'complex disabilities' and even 'cerebral palsy' were often used interchangeably. The need for clarity and consistency of terminology is essential so that 'the population of children and adults with PMLD can be counted and, more importantly, their needs can be fully understood' (PMLD Network 2001, p4). Lack of understanding of 'PMLD' was reflected during observations of lessons, which were often inappropriate for children with PMLD. For example, during observations of one numeracy lesson an LSA was supporting a child with PMLD to use number fans. The teacher would ask the class to find a number between 1 and 9, and the children had to find the number on the fan and show the number to the teacher. For the child with PMLD, the LSA would find the number for the child, put the fan in the child's hand and help the child raise the fan to show the teacher – a task completely beyond the cognitive capabilities of the

child and therefore a meaningless task. Similar observations were made in other classes also. ~~This is a good example~~

The distinct lack of understanding of PMLD could be attributed to the lack of appropriate training opportunities. Apart from the deputy head teacher, all the interviewed staff protested about the lack of external training opportunities and claimed that their prior education and mainstream experiences was insufficient preparation for SLD/PMLD school life. Despite the claim from the deputy head teacher that 'there is strong cross-fertilization within the school and so we don't have to go out and get certificates', the confidence of individual staff members about their own abilities to provide an appropriate learning experience for children with PMLD was low, one teacher claiming that 'if staff want to learn more, then it's up to them personally to join a course off their own back – though we don't have time to do that at the moment', whilst another member of staff expressed concerns that she was 'wasting the valuable time of the kids with more serious difficulties'. In addition to lack of support for external training by the school, two members of staff discussed in some detail the immense workload they faced and the lack of time to do their own research on the subject. It was felt that workload relief would allow more time for staff to look into 'different disabilities' and participate in self-directed learning.

2) Teacher expectations of the progress of children with PMLD were low.

Given the lack of understanding, it was not surprising to hear the low opinions staff had towards the development and progress of children with PMLD in their classes. Understanding 'gains' for children with PMLD requires a shift in perception insofar

as such gains could be very small (longer eye contact, increase in alertness etc) and take long periods of time, but are significant gains nonetheless. However, the attitudes of most interviewed members of staff towards some children were negative. One teacher claimed that a child with traumatic brain injury 'was unable to do anything' and questioned why such a child was in the school at all. Another teacher was also of the opinion that some children in the school required greater support than could currently be offered and suggested an even more specialist setting was needed. Interestingly, it was the LSA's who were the most optimistic towards the abilities of those with PMLD. During participant observations it was the support staff who allowed me to appreciate the subtle differences between particular sounds and movements of some children (i.e. recognising that for one boy gurgling sounds and extension of his arms and legs meant he was distressed).

3) Social interaction between children with PMLD and school staff/peers was minimal.

Despite the high number of adults in relation to students (most classes had approximately 3-4 adults and 10 children), the duration and quality of social interaction between children with PMLD and others (adults and peers) was low owing to difficulties with peer behavior, teacher pressure to complete whole-class projects and physical barriers to interaction. Observations revealed that LSA behavior strategies largely consisted of one-on-one 'marking' in which an adult would monitor and stay with a child who often presents challenging behavior. With the older, larger and stronger children it was common to observe two LSA's 'marking' a child. Whenever the child's behaviour became disruptive (i.e. attempting to run out of the

classroom, throwing chairs, hitting others, destroying materials such as displays etc) the LSA(s) would physically restrain the child. This behaviour (from both child and adult) was very common and much time was spent containing the behavior of some children, leaving the children with PMLD with little or no adult support for prolonged periods of time.

It was also common to see children with PMLD taking 'time out' in sensory corners in the classroom during busy periods whenre whole class displays had to be finished byby a set deadline (i.e. during 'literacy week') or when the lesson was deemed too complex for children with PMLD. Children with PMLD were placed in these sensory corners for entire lessons allowing staff to focus their efforts on supporting those children with SLD. Other barriers to social interaction included the physical design of the school. With a small playground, a climbing frame, a swing, a seesaw and little pavement space, the children with PMLD were left in the classrooms during break time since it was deemed that such children could not make use of the playtime facilities. During the interviews, when asked if social interaction of children with PMLD was facilitated, all members of staff, apart from the deputy head teacher, discussed the desire and attempts to facilitate social interaction, whilst stressing the difficulties such a task brings, the music therapist stating that: 'it depends on the class…the tinnies are only just learning about themselves and they do not know who others are. I think some children are not as accepted as much as they could be, especially when you see them on their own at play time', whilst a class teacher explained how: 'there are not enough hands and you sometimes are unable to include them as much as you would have liked'.

4) All staff questioned the extent to which inclusive education could be achieved for children with PMLD.

All members of staff ~~were~~were questioned ~~the questioned about~~about how far inclusive education could be achieved for children with PMLD. It is interesting to note however that the staff differed in their explanations over *why* including children in the mainstream sector was difficult.

The foundation teacher's concern was resource based and claimed that: 'I don't think it is realistic because a mainstream school doesn't have facilities to meet their needs and the variety of different things they need like physio, speech and medical needs'. She was also concerned about personal care, and claimed that 'you need more than one person with you for feeding and taking them to the toilet, and then there is the specialist equipment and winches and things'.

The music therapist questioned the ability of the mainstream teachers and claimed that: 'they're still struggling with autism and frightened of the not so major difficulties…the mainstream panic and ask for all the training in the world and sometimes it's just common sense'. This was a common opinion which interviewed staff adhered to and many discussed how the mainstream teachers found differentiating the curriculum difficult for moderate learning difficulties never mind PMLD.

Answers given by a newly qualified teacher focused on the reasons *why* children with PMLD should be included in mainstream schools. He asked the question: 'are we

trying to include them for our sake or for their sake…I think there is a place but at PMLD stage it is fairly minimal because I think we are looking at the benefits of other children than those with PMLD'. ——He argued that children with PMLD ~~need~~ need~~need~~ "'Intensive Interaction~~'~~' (Nind and Hewett 2001) and claimed that this was 'impossible' in ~~the m~~mainstream environment~~sector~~s.

It was the deputy head teacher who was the most optimistic of the interviewed staff. Although she claimed that ~~the~~ mainstream schools were~~sector was~~ reluctant to accept any children with 'communication difficulties' and argued that ~~and that the~~ staff struggled to differentiate the curriculum for the existing mainstream children, she argued that 'there is no reason why i~~I~~nclusion of all children shouldn't happen someday' and concluded: 'the future looks better'.

Discussion

Although the aim of the research was to illuminate how a reputable SLD school catered for children with PMLD within the 'regular' SLD class, the research found that the school struggled to provide an adequate learning environment for children with PMLD. Concerned staff expressed a wish to understand children with PMLD more, but explained how they had neither time nor training opportunities available to advance their knowledge and skills. The school was geared towards supporting children with SLD and, in general, the lessons were aimed at developing 'life skills' within the context of the National Curriculum. Although worthwhile for children with SLD, children with PMLD require alternative understandings and curricular

approaches which recognise the need to create an environment which supports *development* (in the form of moving the child through the preverbal stages of development) rather than trying to support skills which are beyond the comprehension of such children. By moving the children with PMLD into the SLD classes, staff explained how the children were now more visible, one teacher claiming that: 'the children with PMLD are no longer hidden but are seen by all and this mixing them all up is a good thing'. However, in order for such processes to move beyond a symbolic gesture of 'being seen', it is important that the needs of the children with PMLD are recognised and met rather than trying to appropriate an inappropriate SLD curriculum since, in the words of the PMLD Network (2001), although the 'vision' is the same for all children, the 'detail' for those with PMLD is often different. The research undertaken for this project highlighted how the vision was the same for all children in the school (i.e. that all children regardless of abilities should be educated together) but the 'detail' (that is, the route to providing an appropriate learning experience) was often different.

Observations and interviews revealed the distinct lack of social interaction between children with PMLD and others (adults/peers). Much time was spent on behaviour management and when PMLD-other interaction was observed, it was usual adult-based in order to expose the child to a meaningless sensory experience in order to appropriate the lessons (i.e. spraying water over the child's face to convey the impression that it is raining). The appeal to a variety of senses is important to children with (and without) sensory impairments but the centrality of social *interaction* to human development must not be overlooked. Decades of literature has shown how social interaction is prerequisite to human development. More recently,

the discovery of innate intersubjectivity (Trevarthen and Aitken 1997, 2001) and communicative abilities in children with PMLD (Nind and Hewett 2001), along with a deeper understanding of intentionality in people with PMLD (Pratchett 2005) has allowed the 'detail' of children with PMLD to be understood in terms of developing social and object awareness through interaction with others (parents, school staff, peers etc). Such an 'interactionist' model transcends the divide between the medical model (which views needs in terms of meeting individuals functional deficits described within pathological/remediative terminology) and the social model (which views needs in terms of environmental adaptation and access to mainstream schools) and sees individual development as contingent on the quality of social interaction. Such a view, which sees individual change in relation to quality social environments allows development to be supported in mainstream settings in which opportunities for rich, reciprocal interaction is great (.Arthur 2004; Foreman, Arthur-Kelly, Pascoe, & Smyth King 2004; Simmons and Bayliss 2005).

Recent research in Australia ref analysed the differential behaviour states of eight matched pairs of students with 'profound and multiple disabilities' ('PMD') within segregated and inclusive environments. The researchers found that those students with PMD observed in 'general' classrooms were involved in significantly higher levels of communicative interaction than their matched peers in special classrooms. In particular, students with PMD in general classrooms displayed 'desirable behavioural states' (i.e. 'awake-active-alert') more frequently than their peers in special classrooms, as well as lower periods of 'no communication'. Both adult and peer engagement was greater in the general classroom than the specialist classroom.

Research by Simmons and Bayliss (2005) yielded similar results, insofar as a nine-year-old boy with PMLD displayed more frequent displays of social activity ('other-active happy') in his mainstream school compared to his special schools, in which his dominant behaviour state was 'passive-happy'. The research sought to move beyond identifying behaviour states and measured social growth in terms emerging higher intersubjective states. The research showed that, over the period of an academic year, the child with PMLD displayed a strengthening of higher secondary intersubjective states (person-person-object awareness), whereas in his special school the child rarely displayed indication of higher intersubjective awareness. The research concludes that mainstream environments may be able to stimulate children with PMLD in a way that special schools, with their limited social capacity, may not. I am not sure that this discussion fits the data as you are discussing the outcomes of the Sam data here and relating it to more general data on staff interactions and training to deal with PMLD children. There seems to be a sudden shift into 'Sam' territory, which whilst I can see is highly relevant here, perhaps it needs more of an introduction. There is some assumed knowledge of the Sam research otherwise!

Conclusion

The difficulties the school in the study faced in providing appropriate educational opportunities for children with PMLD may not be unique to this school but reflect wider issues regarding knowledge of children with PMLD and attitudes towards their educational placements. Schools in our culture have developed, as a 'raison d'être', a competitive ethos based on 'standards' and place great emphasis on meeting academic

benchmarks. However, there are always going to be some children who are unable to compete and achieve the ~~allotted?such~~allotted benchmark given their special educational needs. Because of this, the general assumption is that some children (i.e. those with PMLD) require alternative educational experiences in the form of special schools. This ~~shift in gaze, from mainstream to special school provision for those with PMLD~~assumption is rarely challenged, but nor is the *quality* of special school placements for children with PMLD. This study highlights that, despite the best intentions of the staff, the quality of education ~~that~~that children with PMLD received was poor as a result of a lack of understanding of PMLD stemming from lack of training opportunities ~~and resources~~and resources?. Given the attitudes of the staff towards progress that children with PMLD can make, and the view that children with PMLD are in no way includable in mainstream schools, it was perhaps not surprising to see that social interaction between children with PMLD and their peers was largely unsupported and that interaction with adults was based on the adult providing sensory stimulation in order to 'differentiate' lessons designed for students with SLD. Given the practices of the special school – and ~~perhaps~~the lack of progress deemed to be made by children with PMLD within the special school – then perhaps attitudes against inclusion are ~~perhaps~~not surprising.

An alternative understanding, based on an interactionist perspective which sees the quality of social interaction as being central to the development of children with (and without) PMLD allows a shift away from the necessity of special schools and towards the development of strategies which support communities. An inclusive ethos which is based on interaction with adults and peers can foster the development of intersubjectivity as a foundation for learning, both in the academic sense, and in the

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sense ~~of learning to become human~~a developing personhood. Recent research has suggested gains in mainstream schools can be made in a way that special schools may not be able to offer. Given the limitations of special school interaction, and in light of the research reported here challenging the notion that special schools are always appropriate for children with PMLD – it is perhaps time to call into question the appropriateness of special schools for children with PMLD.

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Trevarthen, C. and Aitken, K. (2001) Infant intersubjectivity: research, theory and clinical application, in *Journal Child Psychology and Psychiatry. 42(1), pp.3–48*~~Just a thought….have you looked at any literature on non PMLD children deprived of social interaction? It may be an interesting backdrop to your claims.~~