

**Parents whose children with learning disabilities and challenging behaviour attend 52-week residential schools: Their perceptions of services received and expectations of the future.**

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## **Abstract**

This paper reports the findings of a survey of parents whose children attended 52-week residential schools. 73 parents completed a postal questionnaire which asked questions about three main areas: support and services received prior to their child's entry into residential education; perceptions of the quality of care and education provided by residential schools; and concerns for their child's future care and welfare. Telephone interviews were conducted with 14 parents, to obtain additional information on the topics addressed by the questionnaire. Parents were critical of services and supports received prior to their child's entry into residential education and reported high rates of exclusion from local services. Residential schools were generally perceived as providing a good quality of service, though considerable concern was expressed about their geographical distance from the family home and this had a significant impact on the frequency of visits. Parents expressed high levels of concern about the future care and support needs of their children. Further research is required to understand the relationship between the availability and quality of local services and the need for 52-week residential schools. The impact of distant residential education on parent-child relationships and on future demand for residential care is considered.

**Keywords:** learning disabled children, residential schools, parental views, challenging behaviour.

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## **Introduction**

The poor coordination of services for the families of children with learning disabilities and the lack of sufficient support for carers were clearly recognised by Valuing People (Department of Health, 2001) in its proposals for improvements in learning disability services. This recognition echoes research which has identified a range of problems of service provision including inadequate support from professionals (e.g., Beresford, 1995) and a lack of sufficient respite care (e.g., McGill, 1996)

Such problems are exacerbated for families of children with severe impairments (Beresford, 1995) such as challenging behaviour. Already inadequate services may become completely inaccessible or unsuitable (Mental Health Foundation, 1997) or may provide a very poor quality of care (Hubert, 1991). These difficulties extend to the child's schooling where the child may be no more than contained (Cooper, 1999) or, increasingly, may face exclusion (Male, 1998a).

Such a background has contributed to the development of specialist residential schools, many of which provide 52-week care. 52-week residential schools are provided for children with many different kinds of disability. Of particular interest in this study are children with learning disabilities and serious challenging behaviour. Only a small number of schools offer places to such children. By illustration, the most recent figures (South Central Regional Inclusion Partnership, 2004) suggest that there are approximately 194 children whose primary special educational need is "severe learning difficulties" attending 52-week residential schools at a total cost of £22.7 million, or £117,000 per child on average. Such figures should be seen as no more than indicative given that children with learning disabilities (as seen from a social care perspective) may be defined as having any of the twelve primary special educational needs by which these statistics are compiled. They may, for example, be coded as having "autistic spectrum disorder", "moderate learning difficulty", or "profound and multiple learning difficulty. The same statistics suggest that, overall, 46.4% of the costs of 52-week residential school placements are met from the Social Care budget (41.8% from Education, 8.7% from Health, 3.1% from Joint budget). Again, these statistics hide the very wide variation that exists between Local Authorities in both number of placements made and distribution of costs between agencies.

The decision to make a placement at a 52-week residential school typically is taken by a joint panel of Education and Social Services (and, sometimes, Health). Such panels are, unsurprisingly, known to be characterised by conflict over whether the placement is needed, whether its consideration reflects local educational deficits (e.g. failure to cope at school) or local social care resource problems (e.g. failure to provide sufficient family support) and, inevitably, over the proportion of funding that should come from each agency (Abbott et al., 2001).

The continuing use of such schools raises a number of concerns. First, they fly in the face of government policies that have recognised and legislated for the right to education in

mainstream and inclusive (and, by implication, local) schools (Male, 1998b). In contrast, an increasing number of children with learning disabilities and challenging behaviour attend special residential schools some distance from their families (Mental Health Foundation, 1997). Second, Morris (2002) has argued that the placement of disabled children in residential schools, without proper consultation and monitoring, may breach the United Nations Convention on the Rights of the Child. Morris draws attention, in particular, to Article 9, the rights of the child to live with their family unless it is not in their best interests; Article 12, that the child be consulted and listened to, Article 20 concerning the right to “special protection” if they are living away from home on a temporary or permanent basis and Article 25, the right to regular reviews of the placements where they live. The extent to which such rights are not upheld shows the anomalous position of such placements within the social care (as well as the educational) system. There has been a general decline in the placing of children without disabilities into residential care. This has resulted from the recognition that children should, where possible, be cared for by their families or, if that is not possible, by substitute families so that the child’s development is supported by the presence of stable attachment figures. Children in specialist residential schools, by contrast, may see little of their families and receive support from multiple caretakers. Third, in the absence of clarity about the “looked after” status of children attending residential schools, the care and education received by individual children may be inadequately monitored, especially where placements are arranged and funded entirely by Education Authorities (Abbott *et al.*, 2001). In such circumstances Education Authorities do not always notify the relevant Local Authority so that some children in residential schools will not receive the protection of the Children Act 1989. Even where notified, Local Authorities may not treat the children as “looked after” “perhaps because of the stigma and perhaps because parents have not asked social services to provide accommodation” (Department for Education and Skills/Department of Health, 2004, p.5). This is, clearly, of particular concern when the children involved are in 52-week placements and may have limited contact with their parents.

Additionally, as noted in Valuing People (Department of Health, 2001), we know very little about the children attending such schools, their and their families’ experiences and the outcomes of such placements. The available information is based mainly on two studies. Emerson (Emerson *et al.*, 1996; Robertson *et al.*, 1996) retrospectively reviewed the progress made by children who attended one of the first such schools to be established - Beech Tree School, a 52-week residential school in the North of England. The study combined a review of written records with parental interviews and found evidence of significant improvements in self-care, communication and challenging behaviour during the child’s stay at the school which were largely maintained after leaving. All the children (41 boys, 14 girls) had severe learning disabilities with 20% additionally suffering from autism and 40% from epilepsy. On average children were aged 12.1 years when they entered Beech Tree and remained there for 2½ years. 47% were previously living with their families with the remainder in residential care including other residential schools, hospitals and children’s homes. 3 had previously been excluded from special schools. When they left Beech Tree the largest number went to another residential special school with smaller numbers returning to their families or going into other forms of residential

care. At the time the study was carried out, 82% were in various forms of residential care. 72% of parents were very satisfied with Beech Tree and 76% were very satisfied with their child's current placement. Almost 1 in 5 parents reported that the main reason for their child going to Beech Tree had been their local special school's inability to cope with their child's behaviour. 41% gave the main reason as being their own difficulty coping.

In the second study Abbott, Morris & Ward (Abbott *et al.*, 2000, 2001; Morris, 2003); gathered information from 21 local authorities and explored the situation in more depth in 4 of these. This was a study of all disabled children attending residential schools so that some of the children did not have learning disabilities or challenging behaviour and did not have a 52-week placement. The study found wide variations between local authorities in the number of children placed and the extent to which placements were only for the normal school year or were of 48/52 week duration. There were mixed views of the reasons for residential school placements with many LEAs seeing them as entirely for social reasons but many parents noting bad experiences in local special and mainstream schools. There was considerable variation in the involvement of Social Services Departments in funding ranging from 9% to 78% of cases across the LAs. There was, generally, very little NHS involvement. Considerable confusion over the legal status of children in residential schools together with the frequently limited involvement of Social Services in funding resulted in widespread variation in the application of "looked after" children procedures and very limited financial support for family visits or visits home by the child. The children, themselves, had often not been consulted about their views or had been deemed to be too disabled to offer any. Interviews with some of the children by the researchers found mixed experiences with many expressing homesickness but some reporting that residential school allowed them to make friends and be more independent.

Other work (Department for Education and Skills/Department of Health, 2004; South Central Regional Inclusion Partnership, 2004) is, as noted above, difficult to interpret other than indicatively because of the range of special needs and types of residential placements that are included and the limits of the statistical information on which they are based. Hampford and Collins (2002) interviewed families and local authority representatives with a specific focus on children with learning difficulties who have "challenging and complex needs" but provide no information about the numbers involved, their characteristics or the methods used.

The study reported here aimed to gather information from parents of children with severe learning disabilities and challenging behaviour attending 52-week residential schools about three main topics:

1. The support they received prior to their child's placement at residential school.
2. The suitability and quality of their child's current residential school placement.
3. Their concerns and hopes for their child's future.

## Method

### *Procedure and Participants*

Parents of children in 52-week residential school placements were consulted early in the project. One parent (the third author) acted as co-supervisor of the researcher and was involved at all stages of conceptualization, design, measure development, analysis and dissemination. Two other parents also reviewed the pilot questionnaire and gave feedback on its ease of use, clarity, content, sensitivity and length. In line with local procedures, the researcher submitted an application for ethical approval to the Departmental Research Ethics Committee (incorporating external participants), which is charged with acting on behalf of the University Ethics Committee. Ethical approval was granted. Research participants were assured of confidentiality and all materials were kept securely and in line with the Data Protection Act 1998. All authors were subject to departmental policies on confidentiality. Participants were given the option to complete the questionnaire anonymously. A summary of the results was sent following completion of the research to all those who had participated and provided contact details.

A total of 16 schools were asked to facilitate the survey. At the time of the study these were all the schools known to the authors in the UK that provided 52-week residential placements for children with severe learning disabilities and challenging behaviour. Of the 16 schools approached, 11 agreed to help, 3 refused and 2 did not respond to either the initial letter or a follow up phone call. Subsequently, 217 questionnaires were distributed to parents/carers - 214 via the participating schools, 3 to parents who contacted the authors directly. 73 questionnaires (34%) were completed and returned. 90% of respondents to the questionnaire indicated their willingness to participate in a telephone interview. 14 telephone interviewees were selected in a manner that broadly retained the proportions found in the larger sample with respect to the school attended, the relationship to the child and ethnic origin.

Questionnaires were coded, entered onto the computer and analyzed, using Statistical Package for the Social Sciences (SPSS, version 12.0). The “free response” sections of the questionnaire were coded according to the themes raised. Telephone interviews were audio-recorded and transcribed. They were coded according to the themes raised.

Questionnaires were completed mainly by birth parents (97% in a 4:1 ratio of mothers to fathers), the remaining two being completed by a grandmother and an adoptive mother. Respondents had an average age of 45.3 years (range: 28-61). 90% of respondents were white, 6% Asian, 1% Black, 3% other. Telephone interviewees included 12 mothers, 1 father and 1 grandmother with 2/14 coming from a minority ethnic background. Telephone interviewees had an average age of 46.2 years (range: 35-57).

The rate of questionnaire return (at 34%) was lower than in some comparable studies of parents (e.g. 53% in Male (1998)) but higher than commonly found with postal questionnaires (20-30% according to Hayes (2000)). While the comparability of responders and non-responders cannot be completely assured, responses came via all the

schools that had agreed to participate. The ethnic background of respondents was comparable to the proportions found in the 2001 Census but had less people from ethnic minorities (6% vs 15%) than that found in Emerson et al's (1996) study. The comparability of the children of respondents with those in other studies is considered below.

### ***Measures***

The questionnaire included five sections

1. Information about the respondent (including age, gender, ethnic origin) and child (including disabilities, challenging behaviour).
2. Experiences before the child left home (including services provided, quality of advice and support received).
3. Previous schooling (including parental satisfaction, types of school attended and reasons for leaving).
4. Current residential school (including communication with school, family-child and family-school contact, staffing, extent to which child's needs met).
5. The future (including care required, opportunities and choices expected for their son or daughter).

Most questions asked respondents to provide ratings (e.g. of satisfaction) on 5-point Likert scales. Opportunities were also provided for qualitative responses. A copy of the questionnaire can be obtained from the authors.

The telephone interview schedule sought to obtain responses of greater depth to those gained in the questionnaire in respect of: services and supports received prior to current residential school placement; perceptions of the residential school; and expectations for the future. Review of the respondents' completed questionnaires allowed interviews to include questions following up parental responses on the questionnaire.

### **Results**

Results are presented in four main sections focusing on: the characteristics of the children; family experiences prior to placement, including reasons for placement; experiences of residential school placement; and expectations of the future. The figures presented refer to questionnaire responses but are illustrated by quotes both from additional information provided in questionnaires and from telephone interviews.

#### ***Characteristics of children and young people***

The children and young people (54 male, 19 female) had an average age of 15.2 years (range: 8-19, 86% 13 years or over). In most cases children had an identifiable diagnosis with the majority (59% of the total sample) having an autistic spectrum disorder. 66% of the children and young people were reported to have at least one additional disability or persistent medical problem including physical disability (26%), visual impairment (26%), epilepsy (19%), hearing impairment (14%). Many children (42%) had more than one additional disability.

Ratings of the occurrence and severity of challenging behaviour are shown in Table 1. Unsurprisingly, given the nature of the sample, all except two children were rated as displaying a number of challenging behaviours. Aggression, the most commonly reported challenging behaviour, was rated as a “serious” problem for 22 children. On average children were reported to be displaying 10.5 different forms of challenging behaviour (range: 0-14).

Table 1 about here

These figures are compared with three other studies (Emerson *et al.*, 1996; McConkey *et al.*, 2004; McGill *et al.*, submitted for publication) in Table 2.

Table 2 about here

### ***Family experiences prior to residential school placement***

Respondents rated how useful they found the help/advice given by various professionals prior to their child’s residential placement. The overall average rating on a 5-point scale (1=“very poor/not at all helpful”, 5=“excellent/extremely helpful”) was 2.8 with 31% of ratings being “very poor” and 22% “excellent”. Of additional qualitative responses, most described negative experiences. Commonly reported was an apparent lack of expertise in the management of challenging behaviour. One parent described the teacher’s reaction to an incident at her child’s local special school where he had pulled down curtains: “So I said when he pulled them down, what did you do? And she said well I got very close to him and pulled a horrible face”. A similar perceived lack of expertise and helpful advice was reported by another parent: “O.T. and Psychologist suggested ways to improve behaviour patterns, but suggested ideas do not work when trying to comfort hurt siblings or do domestic chores”. This lack of effective support to remediate or even manage their child’s challenging behaviour was, for other parents, manifested as a failure of support e.g. “Our daughter did not sleep more than an hour or two at night, we were awake and on duty 24/7, no help offered”. Often difficulties in coping with challenging behaviour led to services breaking down. Even though 50% of respondents gave an “excellent” rating to the usefulness of respite care (average rating of 4.0) many concerns were raised about its availability which over 30% rated as “very poor” (average rating of 2.7). Many parents described their child’s exclusion from respite care e.g., “respite care couldn’t cope with her, not sleeping, so constant phone calls to come and pick her up as she would self-injure”, or the poor quality of what was provided e.g. “respite was desperately needed, but staff were not knowledgeable about his behaviour. Consequently, his behaviour when he came home was much worse than before he went”. Other parents reported similar experiences at school both in terms of exclusion, “our child was excluded from day school four months before leaving home, during this time we received no help whatsoever”, and quality of provision, “day school only useful because it gave him a routine. His Statement was never implemented effectively with regard to behaviour.”

This sense that local professionals and services did not know what to do to help them or their child was sometimes exacerbated by apparent lack of understanding of their child's disability, especially where it included autism – “few agencies understand autism”, “they weren't teaching him in an autistic way”. Not surprisingly, parents with these experiences reported feelings of isolation and exclusion e.g., “nobody listens, I found out that professionals actually hold another meeting after I have attended an arranged meeting”. Other parents found themselves asked to pay for what they felt should have been provided by the authorities e.g. “They said that we can't teach him anything because we can't keep him still for long enough and they ask us to buy... a big chair for physically disabled children... they couldn't afford it because it was £500” and “we paid for someone to come in and give the whole school an INSET day”. Many parents reported frequent instances of neglect. One parent's experience of respite was that “he would come home with big lumps on his head where he had been head banging... [because]... they had only one member of staff on at night and... she had to check the other children and... he would start head banging”. Another reported her daughter “going missing” while in respite and being found undressed in an adjacent bungalow with an older learning disabled man. Most reported high rates of change amongst both carers in respite services and amongst professional staff such as social workers.

The process of obtaining a placement at residential school was also characterised by parents as a negative and stressful experience. Most reported a lack of knowledge amongst professionals about what schools were available and might be appropriate for their son or daughter. Consequently, parents often took on the task of “find[ing] out what provision was available on our own, no one offered direction or advice”. As a result the placement process took on an arbitrary element with clearly inappropriate placements being investigated – “so I went on my own with... and they took one look at her and said that it wasn't an appropriate placement and that was it, ... she just exploded and... I don't know how we got home in one piece” – and schools being investigated on a very informal basis e.g. “she suggested... School because she knew the clinical psychologist there or had been on a course that he had run”. Parents also frequently reported conflict with their local education authority over a residential school placement – “after lots of meetings and disagreements, funding was given at the very last minute, it was a nightmare”, “I took the Education Authority to the Ombudsman”. Many remarked on the apparent incompetence of the process e.g. “Then I would find out that the agency meeting met and that the wrong person would go with the wrong piece of paper for the wrong signature” and some suggested that such incompetence served a purpose – “basically I think the education department were not overly motivated because of the money”.

A small number of parents noted positive experiences with supportive and collaborative professionals e.g. one parent described her son's social worker, “she is just so hard working, so on the ball, so in tune, so supportive of me and my son, she takes people to task”.

Respondents were asked about the schools the child had attended prior to their current residential school placement. All children had attended at least one previous school, 45% had attended two schools and 15%, at least three (the questionnaire asked only about the three most recent schools). Further investigation of the group of 12 children who had attended at least three previous schools showed an increasing pattern of residential provision further away from the family home. Distances from home to school were recorded in ranges. In Figure 1 notional distances have been calculated using the mid-point of each range (e.g. 25 when the range is 0-50) and 250 when the range is 250+ miles. On this basis median distance from home to school increased from 25 to 125 miles over the four placements, with the percentage that were residential gradually increasing from 10% to 100%..

Figure 1 about here

Respondents gave a range of reasons (many more than one) for their child leaving their previous school and going to a 52-week residential school. 40% stated that 52 week/24 hour care was needed for reasons such as consistency of management, 33% reported that they were no longer able to cope with their child's behaviour at home, 27% referred to the severity of their child's challenging behaviour, 26% reported that their child had been excluded from school because of disruptive behaviour. The social and educational reasons underlying placement can be illustrated: "no school to meet his needs...excluded from the two schools identified by the council"; "we couldn't cope with him anymore...I had a breakdown and ended up in a mental ward".

### ***Experiences of 52-week residential school placement***

Respondents gave generally positive ratings of their child's current placement. They perceived it as generally meeting their child's needs (average rating of 4.1 on 5 point scale) and providing good quality direct care (average 4.2). For example, one parent said that "care staff have a good attitude and knowledge of our son's needs, they also phone us at home if unsure about his behaviour". Although positive overall, parents did express concerns, especially about the rate of turnover of care staff, the youth and inexperience of care staff, the quality of care (not education) and communication between the school and family. For example, "most of the staff are young and inexperienced. Unable to wash clothes let alone educate children"; "they are there looking after him...day and night and the next day they are gone and he might never see them again, so that must be difficult for him". The number of respondents per school was too small to allow any meaningful comparison in ratings made of different schools.

Figure 2 about here

As shown in Figure 2, the majority (73%) of placements were more than 50 miles from the family home. 84% would have liked their son or daughter to attend a school that was closer to home. One parent put this particularly graphically: "I wish my son could have stayed at the school that he was at with 1:1 and 52 week school and living at home but there was no provision. What a waste of money that my son has to go miles and miles away... and his social worker and goodness knows who else has to go visit him all paid

for by the tax payer. And he doesn't see me very much because of the logistics and it's just really, really sad". The further from home schools were, the very significantly more likely were parents to want their child educated more locally. Parents were asked how often they visited their child at the residential school. Parents of children who were further away from home visited very significantly less frequently ( $\chi^2 = 71.3$ ,  $df=30$ ,  $p<0.0001$ ) with almost half of children placed more than 100 miles away seeing their parents less than monthly while the majority of children placed less than 50 miles away saw their parents fortnightly or more frequently.

66% of parents reported that there were constraints on how often they could visit, the most common being distance from home (63% of those noting constraints), cost (35%), work (33%) and other family commitments (31%). While the issue of distance is self-explanatory there were various elements to the other constraints. Given the distance, the cost of visiting sometimes included accommodation – “sometimes we stay at a B&B, which makes it costly” – as well as travel. The duration and cost of travelling was exacerbated for a small number of parents by their need to use public transport. Only three parents mentioned having travel/accommodation costs paid or partly paid by their Local Authority. Other family commitments mainly related to the care of other children. One parent noted that she had to “organize the rest of the family when I visit”. Other parents were concerned about the impact of time away from home on their other children e.g. “guilty feeling of not being able to be with all my children as much as I would like, someone always has to suffer”. Time was often in short supply anyway because of work commitments. The residential placement of their child may have been expected to free up time to work – “because he is out of area, I was told by the employment office that I had to return to full time work” – but the time involved in visiting a school over 250 miles away on a regular basis may not sit easily with new work demands. One parent noted that she worked “nights in order to attend meetings and reviews”. All of these difficulties of cost, other family commitments and work were likely to be exacerbated by social and economic disadvantage. One parent said “I am on my own, I can't afford the fare...I wish my child could be closer to me and I could visit more often”. Others mentioned the difficulties arising from their own disability or poor health.

### ***Expectations of the future***

“It's like the Local Authority think that when they are 19 they are OK and they are going to get up and go off to University” (parent of 18 year old whose post-school placement has yet to be planned).

Parents rated their concern about a number of aspects of their child's future on a scale from 1 (“not worried”) to 5 (“extremely worried”). Responses on all ratings indicated high levels of worry. For example, 75% were “extremely worried” about the availability of suitable, future services. The worries described by parents related mainly to the absence of planning for the future, their concern that their son/daughter would be placed inappropriately because of funding limitations and concerns that it might be expected that their son/daughter returned to live with them. Many parents expressed their concerns very strongly. The mother of a 16 year old said “his future is just such a big, dark thing...so

many things that could go horribly wrong”, the mother of a 17 year old said that she “was terrified about the future”. Some parents’ concerns were related to the difficulties they had gone through in obtaining their child’s residential school placement: “I’m almost phobic about going through that process... because it was so traumatic last time”.

In many cases parents reported that no future placement had been arranged despite the date for the end of residential school being imminent. “We are concerned where she will be going” said the grandmother of a 19 year old due to leave school in 7 weeks. One mother reported the very recent planning of a new placement for her 17 year old son: “he has to leave his present placement in about a month and it’s been really hard to pin social services down but they got their finger out and he’s now got a flat”. Most had less happy experiences: “we have tried to get them on board since he has been 16½ asking why we had no input from the young adult team...he is 19 soon and we have heard nothing”. Such experiences were sometimes accompanied by parents’ fears that they would be left to pick up the pieces: “I do know children who haven’t been found a placement and they have gone home...and it was a horrendous experience for the family and the young adult”.

In the absence of a plan, or even where such exists, many parents expressed concerns about the nature of their son/daughter’s future placement. This was manifested in two, related forms. First, that the future placement would not be appropriate for or tailored to their child’s needs: “he might be lumped together with very challenging people of varying age”, “I have trolled around the country and I feel that the type of provision that would be right for him is thin on the ground”. Second, that their son/daughter would be placed in a “residential home”, this being seen by many as trying to fit their child into “something that he wouldn’t fit easily into” which would, at best, contain rather than promote further development and, at worst, would break down. Parents saw these kinds of outcomes as reflecting funding problems, especially in the context of social services now picking up the entire funding: “it’s the cost and now she’s an adult education are not involved”.

Despite these expectations, parents also expressed clear views about a more desirable future. This typically involved their son/daughter living closer to them, receiving continued educational input and living with or interacting with other young people. The mother of an 18 year old said “Ideally I would like him to be ½ an hour from home... in a very small home...looked after by familiar people where he is loved”. The mother of a 16 year old said: “My ideal scenario [would] be...living in a 52 week service close to home, that had highly skilled staff and that had an education component still within it...that constantly wanted to develop...and realise his potential”. The mother of a 19 year old whose future placement had not yet been arranged wanted somewhere that would “treat her like she’s 19”. A minority of parents hoped that their son/daughter would remain linked to their current residential school in one of the “college” developments that have been associated with them: “they have a college and stuff and if it’s anything like the school...then I’ll be happy”.

## Discussion

The findings of this study should be considered in the context of two main limitations. First, the views reported are those only of parents. These should not be interpreted as a proxy for the views of children and young people in 52-week residential schools especially in respect of direct experiences of such schools. Apparent parental satisfaction with residential school placements may reflect the substantial improvement in their family situation rather than, necessarily, being a comment on the school and may not be consistent with the experience of their children (Abbott *et al.*, 2001; Morris, 1997). Similarly, parental views may not concur with local authority and professional perspectives. Second, while the questionnaire sample is relatively large it is self-selecting and caution should be exercised in concluding that findings reflect the population of parents having children at such schools. Findings based on qualitative comments either to the questionnaire or by the much smaller sample of telephone interviewees should be treated with similar caution. Having said this, we believe that these samples have provided information that is broadly generalizable. The questionnaire sample included parents of children at all of the schools that agreed to take part, telephone interviewees were an essentially random sub-sample and, as we shall see below, where comparison was possible with other studies, findings were broadly consistent with those studies.

The “typical” child attending one of the schools considered in this study is a 15 year old male with a diagnosis of Autism, at least one additional disability and displaying numerous challenging behaviours that cause considerable problems of management. In the context of other studies a consistent profile emerges of predominantly teenage boys who, in addition to their learning disability, are frequently diagnosed with Autistic Spectrum Disorder, are likely to have additional sensory, physical or medical impairments and display many challenging behaviours including serious aggressive, destructive and self-injurious behaviour. Other studies have found higher rates of children from minority ethnic backgrounds. This was not found in the current study but may reflect the self-selecting nature of the parent sample. The other studies described in Table 2 have gathered demographic information through schools or their records rather than through parents.

Family experiences prior to the current residential school placement were, almost universally, extremely negative and stressful. Professional advice was reported to be often ill-informed (e.g. about specific disabilities) or not available. Advice and assistance with the child’s challenging behaviour were particularly problematic. Parents seldom appear to have encountered any effective or expert provision that helped them manage their child’s behaviour better. In contrast, many public services were themselves unable to manage the child’s behaviour with resulting frequent breakdown of respite and school arrangements. Perhaps related to these difficulties, parents reported frequent instances of their child being neglected. For parents, the impact over years of such difficulties was considerable. The over-riding sense is of their being isolated, excluded and left to get on with a task which is too difficult or beyond the expertise of qualified professionals. When the possibility of a residential school placement is suggested or sought it is not surprising

to find that the responsibility of identifying a particular school and convincing the (often reluctant) local authority and LEA of the case for funding also falls to parents.

These findings are entirely consistent with those of Abbott *et al.*(2001) and suggest that the parental experience of support prior to residential school placement is similar no matter the specific impairments of the child or whether the child has gone to a 52-week school or one from which they come home every weekend and/or in the school holidays. Reported experiences of exclusion and neglect also echo strongly the findings of Hubert's (1991) study of the families of children with severe learning disabilities and challenging behaviour. The effects of such experiences on the children involved should be considered. Children arriving at residential school following experiences such as their parents have described, have had traumatic personal and family histories in which their own experience is likely to have been, at best, one of discontinuity and exclusion. Such experiences will almost certainly have interfered with all aspects of their personal, social and emotional development and exacerbated their challenging behaviour. This is, unfortunately, a very striking example of a "vicious circle" in which the responses the child receives from the world around them amplify rather than remediate problems of development resulting from their original impairments.

Parents were generally very positive about their child's current residential school placement, albeit with some concerns about the quality of care, the extent of staff turnover and the training/experience of junior care staff. Their principal reservation regarding the current placement was its distance from home, this reducing the amount of contact that they were able to have with their child. They reported very limited assistance or support from their local authorities (both education and social services) to maintain higher levels of contact with their child. These findings are also consistent with those reported by Abbott *et al.*(2001). While such findings suggest a clear contrast between the quality of local supports and the quality of residential schools, it does need to be acknowledged that evidence of poor quality is likely to be much less salient for parents whose child is at a residential school. Its effects (e.g. on the behaviour of their child) will not have the immediate impact on their family that it might have when their child is living at home. The limited contact between parents and their child (arising principally from the distance from home to school) also means that evidence of poor quality may be much more difficult to detect. The evidence from Abbott *et al.*(2001) of children attending residential school reporting a mixture of negative and positive experiences draws attention to the importance of research that looks more directly at the quality of the experience of children in 52-week schools, especially where children, as a result of the severity of their disabilities, are unable to communicate clearly their own views and feelings.

Parents expressed great concerns about the future and reported a lack of local planning for their child. They anticipated that the child's reaching school leaving age might well be accompanied by a repeat of the difficulties associated with the original residential school placement. While some were worried that this would mean their being asked to look after their child at home (and felt they could not cope with this) most expected the problem to be of finding a local, appropriate placement for their son/daughter that would provide

continued access to education and would be age-appropriate. By contrast, they thought it was more likely that an inappropriate “residential home” would be identified as a way of saving money and that this would not work in the long term for their child. A recent small-scale study (Smart, 2004) of parents of young people who had recently made the transition from residential special school to adult services suggests that parents’ concerns are justified. The majority of parents surveyed by Smart (2004) reported disputes about the funding of services and uncertainties and delays in arranging placements. Further, 1/3<sup>rd</sup> of young people had already changed placements, most often as the result of a placement breakdown resulting from difficulties in managing the young person’s challenging behaviour. There has, also, been a proliferation of “residential college” developments often linked to, or on the same site as, existing residential schools. This may reflect the staff of residential schools taking responsibility, by default, for the planning of future placements. Irrespective of the quality of these developments, they clearly remain inconsistent with the aspirations of most parents and seem likely to lead to permanent long distances between young people and their immediate families.

The nature of the residential schools attended by the children of parents in this study remains unclear. Such schools serve, perhaps, three main functions. First, they provide an intensity of educational support not typically available in local SLD schools (McGill *et al.*, submitted for publication), the absence of which may have led to the children’s exclusion or the school’s acceptance that their needs are better met elsewhere. Second, they provide year-round respite for the families of children and young people who, in a context of inadequate or non-existent local support, may have found their situation unsustainable. Third, and more controversially, by providing a 24-hour service or “curriculum” they ensure a consistency of provision which facilitates the development and management of their pupils. They provide these functions at considerable financial and social cost and it is appropriate to ask whether they are the best available alternative. Would it be possible to provide for these children in their local communities? Addressing such a question requires a good knowledge of the characteristics of the children involved and the experiences of their families. It is clear that, in general, the children present a range and complexity of need that some local services currently struggle to meet. At the same time the evidence that there is wide variation between local authorities in use of residential school placements (South Central Regional Inclusion Partnership, 2004) suggests that local educational support may be possible for at least some of the group. This is also consistent with the view expressed by many LEAs that residential school placements occur more for social than educational reasons. Given the widespread poor quality of family support we simply do not know if better quality support would allow families to maintain their child at home. The evidence presented in this study suggests that if such support included, much more than it does currently, focused and effective approaches to managing and improving behaviour at school and at home this may help to prevent the need for residential school.

But why would we want to prevent residential school placement? To suggest its prevention is not, of course, to say anything about the quality of its provision. As noted above, the only study to have looked at outcomes found that the children attending one residential school had generally benefited (Emerson *et al.*, 1996). But the costs associated

with its provision should also be considered. We will mention two main (non-financial) costs here. First, the current study shows the considerable impact of distance between residential school and family on the maintenance of family contact. Further, this distance may increase over a succession of failed placements. Second, this reduction in family contact which is, of course, a cost in itself, also increases the vulnerability of children to abuse and neglect. Children attending 52-week residential schools share an amalgamation of factors that have been shown to increase the risk of abuse. Their personal characteristics (e.g. challenging behaviour, poor communication, social impairment etc), their social situation (e.g., limited family contact) and their service situation (relatively isolated, “total” institution, use of physical intervention) all have been associated with abuse (Rusch et al., 1986; White et al., 2003). If such placements are to continue to be made safely, therefore, they must be accompanied by a significant increase in the clarity, quantity and quality of arrangements for ensuring the safety and protection of some of our most vulnerable children.

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Table 1 Parent/carer ratings of occurrence and severity of challenging behaviours (ratings of severity made on 5 point scale where 1= “displays the behaviour but causes minimal problems” and 5 = “displays the behaviour and causes a serious problem”)

Behaviour	% sample reporting	Mean rating	Behaviour	% sample reporting	Mean rating
Aggression	90%	3.4	Sleeping problems	79%	2.8
Social Disruption	88%	3.6	Hyperactivity	78%	3.0
Destruction	85%	3.0	Rituals	77%	3.1
Non compliance	84%	3.2	Wandering	73%	3.2
Temper tantrums	82%	3.0	Inappropriate sexual behaviour	73%	2.4
Self injury	80%	3.3	Stereotypy	68%	3.0
Physical disruption	79%	3.1	Other	15%	4.3

Table 2 Comparison of characteristics of children/young people in current and three other studies

Study	Sample	Sample size	Gender (M/F)	Ethnic background	Reported prevalence of autism	Percentage serious aggression
Current study	Children with learning disabilities and challenging behaviour in 52-week residential schools	73	74%/26%	90% White, 6% Asian, 1% Black, 3% Other	59%	30%
Unpublished (McGill <i>et al.</i> , submitted for publication)	Children with learning disabilities and challenging behaviour in 52-week residential schools	156	77%/23%	82% White, 7% Asian, 6% Black, 5% Other	75%	24%
Emerson et al. (1996)	Children with learning disabilities and challenging behaviour in one 52-week residential school	55	75%/25%	85% White, 11% Asian, 4% Black	20%	66% (at point of entry)
McConkey et al. (2004)	Children with a disability looked after away from home	108	59%/41%	Not known	19%	Not known (but 45% with challenging behaviour)

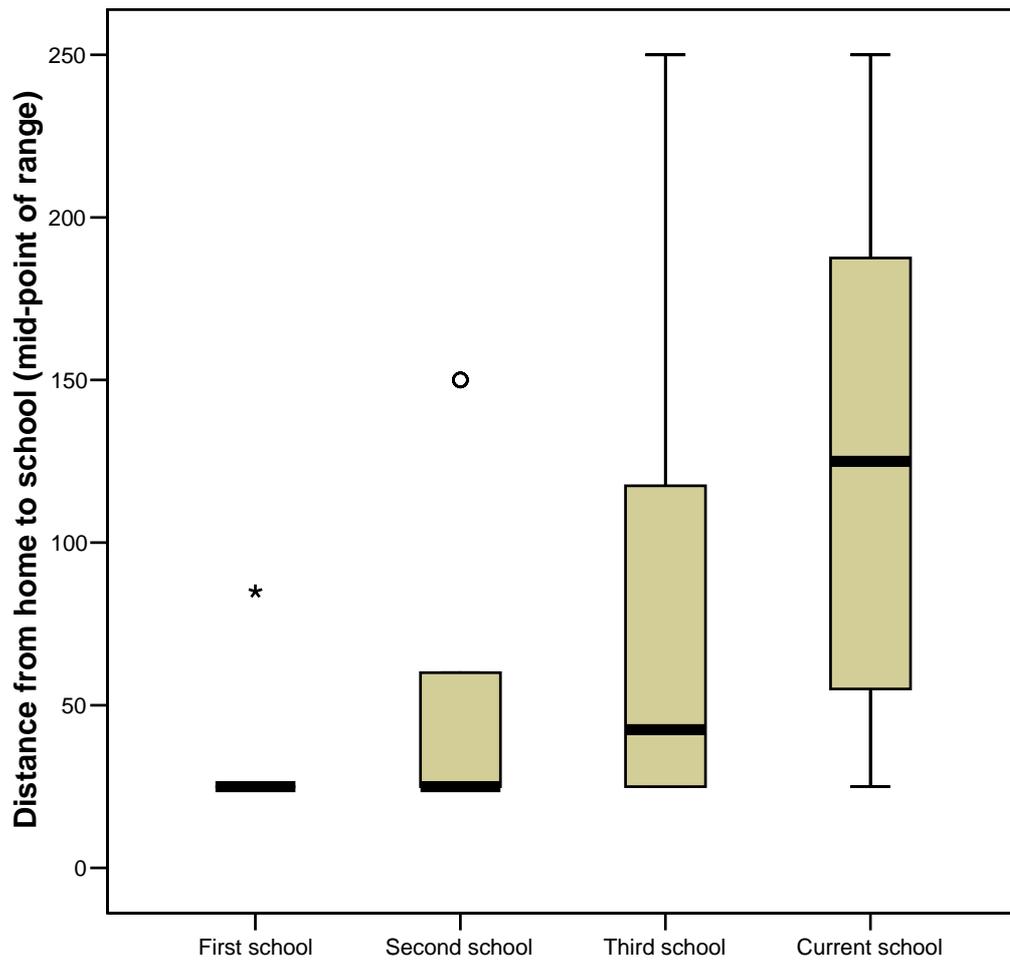


Figure 1 Box plot (showing median, range, semi-interquartiles and outliers) of distance from home to school in current and three most recent placements (N=12)

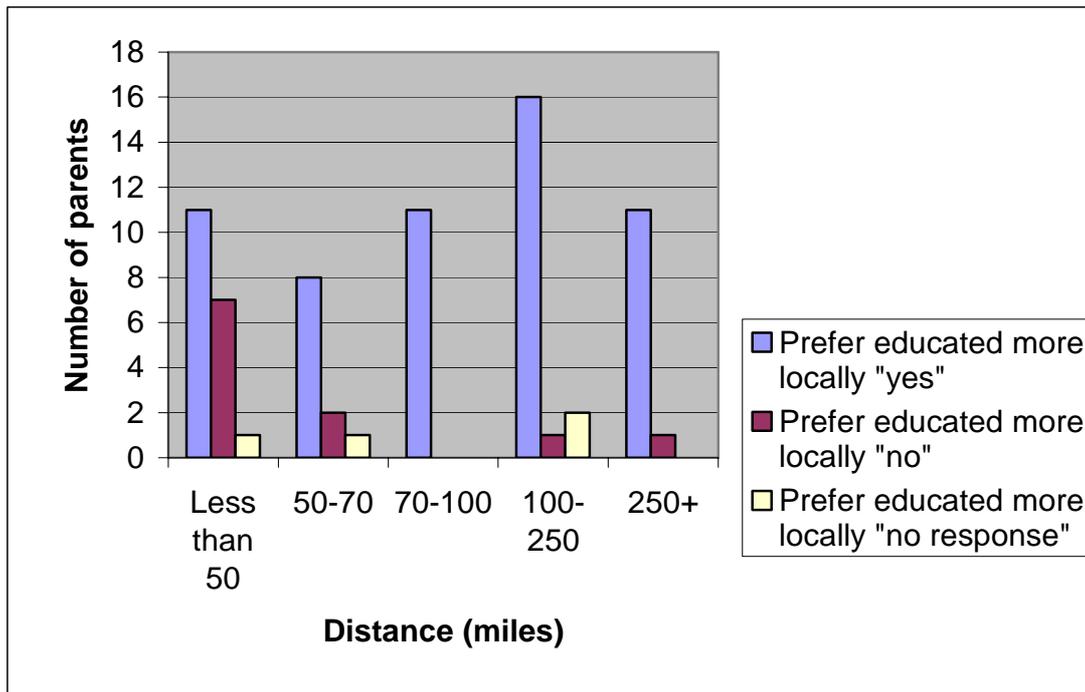


Figure 2 Distance from home to school and parental preference for more local placement (The further the distance the more likely parents express preference for local placement,  $\chi^2 = 27.1$ ,  $df=10$ ,  $p<0.003$ )