School for Social Care Research

Residential school placements for children and young people with intellectual disabilities

Their use and implications for Adult Social Care

Nick Gore, Serena Brady, Magnus Cormack,
Peter McGill, Jacqui Shurlock,
Freddy Jackson-Brown, Caroline Reid,
Rosey Singh, Alexandra Legge,
Maria Saville and Sarah Wedge

Scoping Review

Improving the
evidence base for
adult social care
practice

The School for Social Care Research

The School for Social Care Research was set up by the National Institute for Health Research (NIHR) to develop and improve the evidence base for adult social care practice in England in 2009. It conducts and commissions high-quality research.

About the authors

Nick Gore is a Lecturer in Learning Disability at the Tizard Centre, University of Kent

Serena Brady is a Research Assistant and PhD student at the Tizard Centre, University of Kent

Magnus Cormack is a Psychologist at the NHS Greater Glasgow & Clyde

Peter McGill is Co-director and Professor of Clinical Psychology of Learning Disability at the Tizard Centre, University of Kent

Jacqui Shurlock is Early Intervention Project Manager at the Challenging Behaviour Foundation

Freddy Jackson-Brown is a Clinical Psychologist at the Psychology Solutions Partnership

Caroline Reid is a Clinical Psychologist at the Ealing Intensive Short Break Service

Rosey Singh is a Consultant Clinical Psychologist at the Sussex Partnership NHS Foundation

Alexandra Legge is based at the Leeds & York Partnership NHS Foundation Trust

Maria Saville is Principal Manager at the Halton Positive Behaviour Support Service

Sarah Wedge is a Clinical Psychologist at the Sussex Partnership NHS Foundation

CONTENTS

ABSTRACT

Out of area residential placements are associated with a range of poor outcomes for adults with intellectual disabilities and behaviours that challenge. In recent years there has been an increased drive to reduce such placements at as early a stage as possible. In this context the current review collates research and policy regarding use of residential schools for children and young people with intellectual disabilities and transition from these settings to adult services. The review highlights that relatively little is known about both use of, and transition from, residential schooling for children and young people with intellectual disabilities in the UK. Thirteen articles are identified: 7 examining the child or families' experiences before placement, 4 examining outcomes during the placement, and 4 examining the process of transitioning from the placement and longer term outcomes. The methodological quality of articles was often limited. A lack of control groups, independent samples, or adequate sample sizes was particularly notable. Results are discussed in relation to factors that lead to a child's placement in a residential school, children and families' experiences of the placement, and outcomes following placement, including the transition process. A number of research priorities are highlighted based on gaps in the literature. Examples of alternative forms of support from clinical practice are provided, with recognition that a multi-element model is likely to be needed to provide high quality support to this group of young people.

KEYWORDS

BACKGROUND

Out of area placements for adults who display behaviour that challenges

Individuals with an intellectual disability are at an increased risk of developing behaviours that challenge (Totsika *et al.* 2011a, Totsika *et al.* 2011b). These behaviours are known to be persistent across the life span (Murphy *et al.* 2005, Totsika *et al.* 2008) and are associated with a range of poor outcomes for both the individual themselves and their families (Allen *et al.* 2006, Baker *et al.* 2003, Emerson and Einfeld 2011, Hastings 2002, Naylor and Prescott 2004). The presence of behaviours that challenge is often cited as a major reason for placing an individual in an out-of-area residential placement (Mansell 2007, McGill *et al.* 2010, Perry *et al.* 2013) and figures suggest that 34% of adults with a learning disability in England who are in residential care are placed out of area (Emerson and Robertson 2008). This includes 3250 individuals who are inpatients in assessment and treatment units which may be a great distance from their family, with the most recent estimates suggesting that 18.2% of adults are placed in units over 100km from their home (Health and Social Care Information Centre 2013). Furthermore, out of area residential placements are often expensive and can cost up to £450,000 per year (Emerson and Robertson 2008).

In addition, out-of-area residential placements have been associated with poor outcomes in relation to care standards, wellbeing and quality of life (Beadle-Brown *et al.* 2006), and a recent review found that many such placements underperform across a range of domains (Barron *et al.* 2011), challenging the assumption that they provide 'specialist' care. Despite publications outlining how alternative local provision should best be structured for those who display behaviour that challenges (Mansell 1993, 2007), recent national scandals (e.g. Winterbourne View) highlight a continued reliance on out-of-area placement and the resultant vulnerability of individuals placed in these settings to abuse and poor care. In this context, there has recently been an increased drive to further reduce the number of people with intellectual and developmental disabilities placed out of area (Department of Health 2012a, 2012b). Significantly, this has included an emphasis on early intervention and prevention to reduce the likelihood that an individual will be placed out of area from as early as possible in the life course (LGA and NHS England 2014).

Residential placements for children and young people with intellectual and developmental disabilities

Historically, many children and young people with intellectual or developmental disabilities were educated in segregated schools, with those who had the most severe disabilities placed in hospitals or special care units (Male 1998). In 1974, around 4450 children and young people lived in long stay hospitals away from their families (National Development Group for the Mentally Handicapped 1977). Policy and guidance developments in the UK over the past 2-3 decades have tried to ensure that children with disabilities are not routinely placed in institutions and are educated in local mainstream schools where possible (see for example Children and Families Act 2014, Special

Residential school placements for people aged under 25 with intellectual disabilities

Educational Needs Code of Practice for Wales 2002, The Mansell Report 1993, 2007, The Children (Scotland) Act 1995, The Special Educational Needs and Disability (Northern Ireland) Order 2005) with the right to be cared for by their family (for example, The Children Act 1989).

Recent figures suggest that 87.5% of children with moderate intellectual disabilities, 70.7% of children with ASD, 21.7% of children with severe intellectual disabilities, and 17.4% of children with profound and multiple intellectual disabilities attend mainstream schools (Pinney 2014). However, despite this and guidance to develop more specialised local support and inclusive schooling (as set out in Aiming High for Disabled Children 2007, and Removing Barriers to Achievement 2004), estimates also suggest that 660 children with moderate to profound intellectual disabilities and 700 children with ASD attend a maintained residential school (not including those placed in independent schools). Of these children, approximately 230 with intellectual disability and 250 with ASD attend a school that is out of area (Pinney 2014). Placements at residential schools are costly (estimated at £167,268 per year at current prices (Clifford and Theobald 2012)), can be a considerable distance from the family home (McGill *et al.* 2006) and are often arranged in the context of crisis, following a history of local service breakdown and failure to support behaviour that challenges for children and their families (see Cooper 1999, McGill *et al.* 2010).

Links between out of area placements for children and adults

Behaviour that challenges often develops in childhood and without effective intervention is persistent, enduring into adulthood (Murphy *et al.* 2005, Totsika *et al.* 2008). A history of behaviour that challenges is the most frequently cited reason why residential school placements are sought for children and young people with intellectual disabilities (see McGill *et al.* 2006) and cited as the main reason for out-of-area placements for adults with intellectual disabilities (Mansell 2007, McGill *et al.* 2010, Perry *et al.* 2013). In this light, there is increasing recognition and concern that children and young people attending 52-week residential schools may be placed or remain in out-of-area placement following transition to adult services (LGA and NHS England 2014, McGill *et al.* 2010). Whilst there has been limited research in this area, Perry and colleagues (2013) found that 19% of a sample of adults placed out of area had previously attended a residential school, and McGill and colleagues (2010) reported as many as two thirds of adults had previously been placed in a residential school, many of which were run by the same provider as their current residential placement.

Aims of the current review

Despite high costs and high use of residential schools for children and young people with disabilities and potential links to out-of-area adult placements, there is little research concerning their use. Increasing knowledge in this area is essential if a preventative, lifespan approach is to be taken to increasing local service supports for those who display behaviour that challenges. The current review therefore brings key information from

research and policy together with examples of alternative forms of support from clinical practice with the aim of highlighting future research concerning wellbeing and support for children, young people and adults with intellectual disabilities. Information reviewed is structured around the following key questions in order to gain insight into a range of factors relating to residential schooling, which may inform research relating to circumstances that are likely to lead to out of area adult placement:

1. What leads to a child with intellectual or developmental disabilities being placed in a residential school?

2. What is the quality and experience of support received at residential schools?

3. What are the outcomes for children following placement in a residential school and/or transition to an adult service?

RESEARCH REVIEW

The following section provides a systematic review of peer-reviewed research that has focused on the use of residential schools for children and young people with intellectual disabilities and (where available) placements and outcomes following transitions to adult services.

Methodology

The review aimed to identify studies related to residential schooling (and the transition to adult services following residential schooling) for children and young people with intellectual/developmental disabilities in the UK. The inclusion criteria were as follows:

1. The study focussed on residential school placements (i.e. not residential respite or short term placements);

2. The study was related to individuals with an intellectual/developmental disability who were under the age of 25. If an article included participants with mixed diagnoses or ages, then it was included only if the results could be separated for participants of interest (and only these participants were included in the review);

3. The study included either quantitative or qualitative data (i.e. was not a review article or descriptive account);

4. The research was conducted in the UK (as the review aims to inform research relating to out-of-area adult placements in the UK, and practices in other countries may differ);

5. The research was published in a peer-reviewed journal.

There were no criteria related to the date when articles were published, as UK research in this area is scarce and it was felt important to include all relevant published articles. The majority of included articles were published within the last ten years; however, the implications of including older studies are highlighted in the discussion below. There were also no criteria related to challenging behaviour; however, it is important to note that a number of studies included only participants for whom challenging behaviour was a concern (as discussed below).

Initial searches were conducted on PsychINFO, Web of Science, and PubMed to identify relevant articles. Where possible, limiters were applied to searches to exclude articles related exclusively to participants over the age of 25. Search terms were split into two groups and each term from group one was combined with each term from group two (see Table 1 below for specific search terms). Terms related to short term or non-school care (denoted with 1 in Table 1) were initially included as part of a potentially broader review, but upon refinement of the inclusion criteria any articles related to these terms were excluded. The decision to exclude these articles was taken for three reasons: (1) there were only a small number of articles related to non-school based care (i.e. hospital

admissions) for children and young people with learning disabilities; (2) many of the articles related to foster care, the reasons for which may be variable; and (3) where non-school based articles were found, these mainly related to adult participants with only a small number of cases where data relating to children and young people was available. In order to ensure that the scope of the review was well defined, these articles were subsequently excluded.

Table 1. Databases and search terms used for identifying articles

Databases Searched	Group 1 Terms	Group 2 Terms
PsychINFO	Residential school	Learning disabilit*
Web of Science	Residential college	Intellectual disabilit*
PubMed	Residential provision	Developmental disabilit*
	Residential service	Autism
	Out of home placement	Autism spectrum disorder
	Out of area placement	Asperger syndrome
	Boarding school	
	Care home[1]	
	Foster placement[1]	
	Short breaks[1]	
	Respite[1]	
	Assessment and treatment centre[1]	
	Inpatient[1]	
	Hospital admission[1]	

1 = terms related to short term or non-school based residential placement which were later removed

Initial searches identified 5841 potentially relevant articles (including duplicates). The titles and abstracts of these articles were then examined and 108 articles were obtained for further screening. After applying inclusion and exclusion criteria, nine articles were retained. Following this, hand searches were conducted of the two journals which had published the highest number of included studies (*Journal of Intellectual Disability Research*, and *Journal of Applied Research in Intellectual Disabilities*) which identified a further 20 potential studies of which none met inclusion criteria. Finally, the reference lists of included articles were searched and 28 additional articles were identified of which four were included. The search process and reasons for exclusion of articles can be seen in Figure 1 below.

Figure 1. Flow chart demonstrating search process and reasons for exclusion of articles

PHASE 1

| PsychINFO 1,193 | PubMed 2,177 | Web of Science 1,751 |

Abstracts screened

108 articles retained

Abstracts assessed for inclusion criteria

Reason for exclusion
Short-term care: 4
Conducted outside UK: 68
Adult focus: 1
No data: 2
Did not related to schools: 24

Included 9

Excluded 99

PHASE 2

Specific journal hand search

Journal of Intellectual Disability Research 13 (0 included)

Journal of Applied Research in Intellectual Disabilities 7 (0 included)

PHASE 3

Reason for exclusion
Short-term care: 3
Adult focus: 1
Conducted outside UK: 15
No data: 2
Did not related to schools: 23

Reference lists searched 28 (4 included)

FINAL INCLUDED 13

Analysis

Thirteen articles met inclusion criteria and were retained for review. The articles were coded by two independent coders according to the following variables: article details (authors, year, and journal); methodology (type of study, design, focus, measures, aims/hypotheses); participants (number, participant role (i.e. family carer, teacher, professional, service user)), diagnosis (if participant was a service user), age, gender, additional characteristics; facility details (type of facility, additional characteristics); results; main discussion points; and methodological limitations (either identified by the authors of the study or by the coders). Following this, articles were grouped by their main focus (for example, characteristics of children and young people attending residential schools, reasons for placement, child/young person's experience of school, family carer views, outcomes from placement, and transition from placement) and common themes within the results of articles that had been grouped together were identified. These themes, along with the research questions for the review, were then used to structure the discussion and review of articles. This method was felt appropriate due to the small number of included studies and idiosyncrasy of methodologies used. Furthermore, this method allowed the researchers to review articles in detail and to discuss both quantitative and qualitative results in a meaningful way in relation to the research questions.

Methodological quality evaluation

The methodological quality of the included articles was assessed using the Mixed Methods Appraisal Tool (MMAT; Pluye *et al.* 2011). The MMAT contains two screening questions and five domains relating to different research methodologies (qualitative, quantitative – randomised controlled trial, quantitative – non-randomised, quantitative – descriptive, mixed methods). Each domain contains items which are rated as present, absent, or not known. If a study utilises one type of methodology only (e.g. only quantitative – non-randomised), the final rating is derived by summing the number of items rated as 'present' (i.e. a maximum score of 4). If the study utilised mixed methodologies, the relevant quantitative and qualitative domains are completed, as well as the mixed methods domain; the final score in this instance is taken as the lowest domain score. In this way, the MMAT allows for a common rating to be applied to studies utilising a range of methodologies.

The MMAT is a tool which is still in development[1]; as a result, the first two authors of this review discussed each item and reached a consensus on interpretation of the item (see Appendix 1 for details). An agreement was then reached on the score assigned to each study. The studies included in this review were categorised as qualitative or quantitative-descriptive for the purposes of quality appraisal. In each case a percentage score of total items marked 'yes' out of all applicable items was calculated. The MMAT has been pilot

---

1 see http://mixedmethodsappraisaltoolpublic.pbworks.com/w/page/24607821/FrontPage for more information

tested for reliability and achieved between moderate (k = .53) and perfect (k = 1) reliability for qualitative items, and good (k = .71) to perfect (k = 1) reliability for quantitative-descriptive items following discussion between raters (Pace *et al.* 2012).

Findings

The final thirteen articles that are included in the review are summarised in Table 2. Figure 2 displays the timeline of the included studies, which of the three aims each study addresses, and the main methodology used by each study. Most of the articles reviewed used more than one methodology. Many of the articles used mainly qualitative methods including: interviews with family carers (Abbott and Heslop 2008, Alborz 2003, Brown *et al.* 2011, Emerson *et al.* 1996, Heslop and Abbott 2007, 2008, McGill *et al.* 2006, Morris *et al.* 2002, 2003, Robertson *et al.* 1996), interviews with professionals (Abbott and Heslop 2008, Emerson *et al.* 1996, Heslop and Abbott 2007, 2008, Morris *et al.* 2002, 2003), interviews with children/young people with intellectual or developmental disabilities (Abbott and Heslop 2008, Heslop and Abbott 2007, 2008), or focus groups (Brown *et al.* 2011).

Some studies used mixed method postal questionnaires sent either to family carers or to residential schools (McGill *et al.* 2006, Pilling *et al.* 2007, Smart 2004). A small number of studies used quantitative methodologies such as reviewing records held about pupils by residential schools (Emerson *et al.* 1996) or administering a standardised measure of stress to family carers (Alborz 2003, Robertson *et al.* 1996). In addition, three articles used observations to assess the level of staff-student interaction in a residential school (Smith *et al.* 2007) or to gather information about placement panels held by Local Authorities (Morris *et al.* 2003, 2003).

The findings from the articles are discussed in relation to the three research questions below. Some studies are discussed in more than one section, as their findings provide information that spans question areas:

1. What leads to a child or young person being placed in a residential school?

2. What is the quality and experience of support received at residential schools?

3. What are the outcomes and experiences for children or young people during transition following placement in a residential school?

Residential school placements for people aged under 25 with intellectual disabilities

Table 2. Studies reviewed in alphabetical order

Author and Year	Focus	Method	Sample	Analysis	Findings
Abbott and Heslop (2008)	Experience of transitioning from residential school	Semi-structured interviews with young people, family carers and professionals; 1st initial interview and a 2nd interview one year later	13 young people with a learning disability in their penultimate year of residential school/college 16 parents 27 professionals NB parent/professional interviews related to 15 young people	Constant comparative approach	• It was a struggle to find post school options and families often had to find their child's next placement on their own. • Most of the young people returned home, at least initially, and very few entered employment or further education.
Alborz (2003)	Reasons for placing individual with intellectual disabilities in residential accommodation	Semi-structured interview with family carers Malaise questionnaire for maternal stress	18 mothers, 5 fathers, 1 grandparent (representing 18 individuals with intellectual disabilities, 11 of whom met inclusion criteria for the review)	Content analysis	• 7 different explanations cited for placing a child in a residential placement. • No difference in pre-move stress score between mothers whose child had left home and those whose child had not.
Brown et al. (2011)	Behaviour before residential school Child and family carer experience of school Impact on family life	Semi structured interviews and focus groups with family carers	26 family carers (representing 23 children)	Mixed quantitative and qualitative	• Child's behaviour had mostly improved since starting at the school. • Positive effects on family life since child had been placed at school.

Residential school placements for people aged under 25 with intellectual disabilities

Table 2. Studies reviewed in alphabetical order (continued)

Author and Year	Focus	Method	Sample	Analysis	Findings
Emerson et al. (1996)	Outcomes whilst at residential school Long-term outcomes once child had left residential school	Analysis of written records kept by school at child's entry and point of leaving Semi-structured interview with family carer or staff member working with individual	55 children who had attended Beech Tree School 44 parents/close family members 11 staff in residential/day services 1 advocate 1 social worker	Qualitative	Whilst at Beech Tree School • Significant improvements in self-care, communication and challenging behaviour • Significantly more behavioural programmes and written plans to manage challenging • Significantly less sedation and anti-psychotic medication used After leaving Beech Tree School • No additional improvements except in severity of aggression • Significantly less behavioural programmes and written plans • Significantly more sedation and anti-psychotic medication

Residential school placements for people aged under 25 with intellectual disabilities

Table 2. Studies reviewed in alphabetical order (continued)

Author and Year	Focus	Method	Sample	Analysis	Findings
Heslop and Abbott (2007)	Family perspectives of what makes a good transition pathway and outcome	Semi structured interviews with young people, family carers, and professionals	13 young people with intellectual disabilities in their penultimate year of residential school 16 parents 27 professionals NB parent/professional interviews related to 15 young people	Themes and subthemes identified	5 themes identified • Being well connected • Being proactive • Provision of information • Good forward planning and time to prepare • Good outcomes
Heslop and Abbott (2008)	Experience of transitioning from a residential school	Semi-structured interviews with young people, family carers, and professionals; 1st initial interview and a 2nd one year later	13 young people in their last or penultimate year of residential school 16 parents 29 professionals NB parent/professional interviews related to 15 young people	Qualitative	• Problems of transition included: lack of or insufficient transition plans, distance of school from home • Views of young people themselves rarely taken into account • Most individuals moved home initially • Forward planning and good information about options needed

Residential school placements for people aged under 25 with intellectual disabilities

Table 2. Studies reviewed in alphabetical order (continued)

Author and Year	Focus	Method	Sample	Analysis	Findings
McGill *et al.* (2006)	Characteristics of children and families before placement Experiences of placement Expectations of the future	Postal questionnaires sent to family carers Telephone interviews with family carers	73 family carers (14 also took part in interview)	Mixed quantitative and qualitative	• Children were mostly male. Nearly all displayed multiple forms of challenging behaviour • Parents dissatisfied with local services due to lack of availability and knowledge • Generally positive about residential school • Concerns about distance of school from home • Concerned about future services for child

Residential school placements for people aged under 25 with intellectual disabilities

Table 2. Studies reviewed in alphabetical order (continued)

Author and Year	Focus	Method	Sample	Analysis	Findings
Morris et al. (2002)	Process of decision making for residential school placement	Examination of Local Authority policies relating to residential school placement. Observation of professional panel meetings. Interviews with family carers, professionals, and teachers. Observation of children	53 interviews with professionals 34 interviews with families (representing 32 children, some of whom did not have an intellectual disability)	Qualitative	• Wide variations in number and type of residential school placements made across 4 LAs • Variation in how placements were funded, and the demographics of children who were placed across LAs • Range of reasons cited by professionals and parents for seeking a residential placement • Families felt they had to fight LA to get a residential placement. Little information or support given to them during this process, particularly in relation to choosing a school and assessing if it could meet their child's needs • Some advantages of residential schools identified

Residential school placements for people aged under 25 with intellectual disabilities

Table 2. Studies reviewed in alphabetical order (continued)

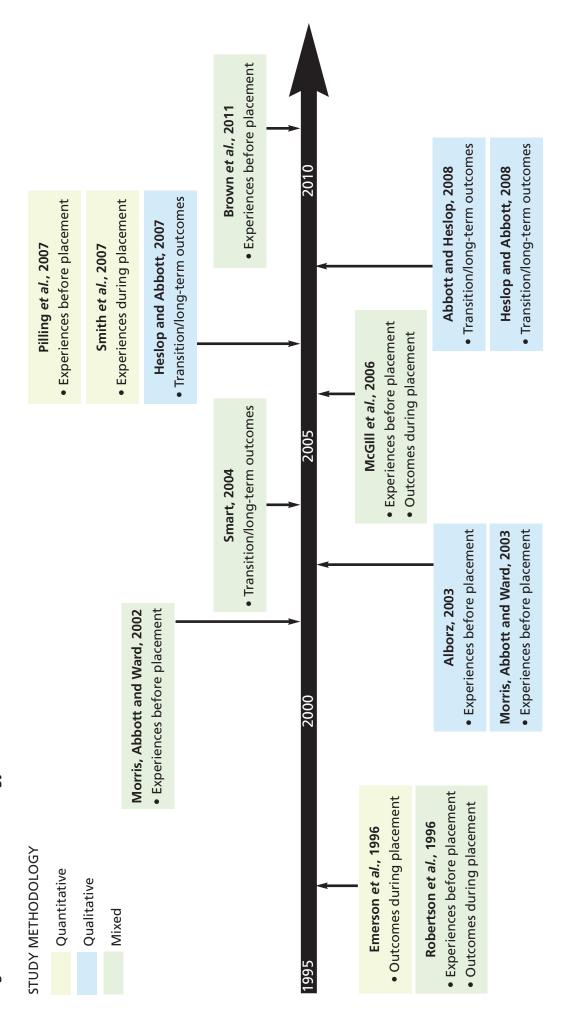| Author and Year	Focus	Method	Sample	Analysis	Findings
Morris *et al.* (2003)	Process of decision making for residential placement Experiences of residential placement	Interviews with family carers and professionals from local education authority or social services Observation of professional panel meetings	21 Local Authorities 52 interviews with professionals 34 interviews with families (representing 32 children, some of whom did not have an intellectual disability)	Qualitative	• Families reported generally poor experiences of LA's decision-making process when seeking a residential school • Parents received little information or help during process • There was often little involvement of social services or LEA professionals once the child had been placed at a residential school (and this varied depending on how the placement had been funded)
Pilling *et al.* (2007)	Identify characteristics of children in residential schools Describe experiences of children whilst in a school Make comparisons with other groups of children described in previous studies	Questionnaire about children attending the School	9 participating schools 156 returned questionnaires representing 156 pupils	Quantitative	• Children mostly male with ASD • Nearly all displayed multiple forms of challenging behaviour • Most children had written plan for physical interventions • Seclusion/sedation used more often than in day schools • Accessed health care, social care, and leisure activities at comparable rate to children in day schools

Residential school placements for people aged under 25 with intellectual disabilities

Table 2. Studies reviewed in alphabetical order (continued)

Author and Year	Focus	Method	Sample	Analysis	Findings
Robertson *et al.* (1996)	Child outcomes following placement at Beech Tree School	Semi-structured interviews Malaise questionnaire for family carer stress	44 parents or close family members of children who had completed placement at Beech Tree School	Mixed	• Significant improvements in self-care, communication and challenging behaviour whilst at the school. Changes attributed to services and support offered at school • Improvements continued after leaving school but attributed to maturity rather than service • 1 in 5 parents noted that challenging behaviour had got worse since leaving school
Smart (2004)	Family experience of their child's transition from residential school and current placement	Postal questionnaires	17 parents/carers of young people aged 19–23	Mixed	• Wide variation in experience of transition process with some families citing positive experiences whilst others were offered little support • Families identified positive and negative aspects of their son/daughter's current placement and concerns about the future

Residential school placements for people aged under 25 with intellectual disabilities

Table 2. Studies reviewed in alphabetical order (continued)

Author and Year	Focus	Method	Sample	Analysis	Findings
Smith *et al.* (2007)	Student and staff interaction and behaviour at a residential school	Observations	23 students with intellectual disabilities and challenging behaviour	Quantitative	• Students constructively engaged for 48.3% of the time in the main building and 17% of the time in the independent living unit • Most common interaction from staff was other conversation (neither positive nor negative interaction)

Residential school placements for people aged under 25 with intellectual disabilities

Figure 2. Timeline, methodology, and focus of included studies

STUDY METHODOLOGY

Quantitative

Qualitative

Mixed

Emerson et al., 1996
• Outcomes during placement

Robertson et al., 1996
• Experiences before placement
• Outcomes during placement

Morris, Abbott and Ward, 2002
• Experiences before placement

Alborz, 2003
• Experiences before placement

Morris, Abbott and Ward, 2003
• Experiences before placement

Smart, 2004
• Transition/long-term outcomes

McGill et al., 2006
• Experiences before placement
• Outcomes during placement

Pilling et al., 2007
• Experiences before placement

Smith et al., 2007
• Experiences during placement

Heslop and Abbott, 2007
• Transition/long-term outcomes

Abbott and Heslop, 2008
• Transition/long-term outcomes

Heslop and Abbott, 2008
• Transition/long-term outcomes

Brown et al., 2011
• Experiences before placement

1995   2000   2005   2010

Representativeness of study samples

Across the majority of the included studies, the representativeness of the study samples was low, as many of the articles presented data from related studies or from one school only. As a result, the generalizability of the findings is limited, highlighting a need for research with more representative samples. Table 3 below provides details of the sample size (of participants who met inclusion criteria for this review) and sampling strategy for each study. Studies that are related are outlined with a green border.

Table 3. Sample size, sampling strategy for each study

Study	Sample Size	Sampling Strategy
Abbott and Heslop (2008) Heslop and Abbott (2007) Heslop and Abbott (2008)	13 young people with intellectual disabilities 16 parents 27 professionals	Participants who were in their penultimate year of residential school/college were contacted from five Local Authority areas in England.
Emerson *et al.* (1996) Robertson *et al.* (1996)	44 parents of children with intellectual disabilities	64 families of children who had attended Beech Tree school were contacted after their child had left the school, 44 responded.
Morris *et al.* (2002) Morris *et al.* (2003)	53 professionals 34 parents/carers (representing 32 children, only some of whom had an intellectual disability)	Professionals and families from four Local Authority areas across England (which were chosen to be representative) were interviewed about their experiences of obtaining a residential placement.
Alborz (2003)	Parents/carers of 3 individuals with intellectual disabilities aged under 18, plus 8 aged between 18 and 25.	Participants identified as part of a total population survey conducted in 1988 relating to seven health authorities in the North West health authority in the UK.
Brown *et al.* (2011)	26 family carers (representing 23 children)	Participants were families of children who were attending Camphill School.

Studies contained within green borders present data from related studies.

Table 3. Sample size, sampling strategy for each study

Study	Sample Size	Sampling Strategy
McGill *et al.* (2006)	73 parents/carers	All schools that provided 52 week placements for children with intellectual disabilities were approached, 11 agreed to send out questionnaires to parents/carers of the children in the school (217 questionnaires sent out in total).
Pilling *et al.* (2007)	156 questionnaires returned relating to 156 students	All schools providing 52 week placements to children with intellectual disabilities were approached; 9 agreed to participate and completed questionnaires on 156 students.
Smart (2004)	17 parents/carers of young people aged 19–23	44 families of children who had attended one residential school were contacted, 17 responded.
Smith *et al.* (2007)	23 students with intellectual disabilities	Participants were all students at one residential school and lived in one of two residential units within the school.

Only one article recruited control group participants (Alborz 2003) and in one case (Pilling *et al.* 2007) comparisons were made to known data on a sample of children from specialist day schools.

Methodological quality of included articles

As discussed above, the first two authors used the MMAT (Pluye *et al.* 2011) to rate the methodological quality of each of the included studies. The final ratings (presented as a percentage with higher percentages indicating greater methodological quality) can be seen in Table 4 below, and further details on the interpretation and rationale relating to the ratings can be found in Appendix 2. Where studies presented related data from the same research project (as outlined in Table 3), the same rating was given to each study.

The methodological quality of the qualitative and descriptive quantitative designs used by the nine sets of studies was variable. Three of the nine studies received a rating of 50% or less. Only two studies met all criteria with the remaining studies scoring between 66 and 75%.

Table 4. MMAT ratings (expressed as a percentage) given to each included study

Article	Rating
Abbott and Heslop (2008), Heslop and Abbott (2007), Heslop and Abbott (2008)	100%
Alborz (2003)	50%
Brown *et al.* (2011)	75%
Emerson *et al.* (1996), Robertson *et al.* (1996)	75%
McGill *et al.* (2006)	75%
Morris *et al.* (2002), Morris *et al.* (2003)	50%
Pilling *et al.* (2007)	100%
Smart (2004)	25%
Smith *et al.* (2007)	66%

What leads to a child or young person being placed in a residential school?

Seven articles provided information about factors and processes that lead to a child or young person being placed in a residential school (Alborz 2003, Brown *et al.* 2011, McGill *et al.* 2006, Morris *et al.* 2002, 2003, Pilling *et al.* 2007, Robertson *et al.* 1996). These articles examined the characteristics of children and families before the child/young person was placed in a residential school, the perceptions of family carers and professionals about the reasons for seeking a residential placement, and the decision-making processes of professionals. These factors are discussed below and include: the characteristics of the child/young person, the impact on the family of caring for the child and managing behaviour that challenges, factors related to resource and service needs and the process of obtaining a residential placement. None of the articles compared the experiences of families of children who were and were not subsequently placed in a residential school; therefore results presented here reflect only the experiences of families of children who were placed in a residential school.

Characteristics of the child/young person

Five studies discussed the characteristics of the child or young person who was subsequently placed in a residential school (Alborz 2003, Brown *et al.* 2011, McGill *et al.* 2006, Pilling *et al.* 2007, Robertson *et al.* 1996). Pilling and colleagues (2007) found that

children/young people who were placed in a residential school were likely to have a diagnosis of Autism Spectrum Disorder, were aged on average 15.1 years old and were more likely to be male than children/young people attending specialist day schools. This finding was supported by McGill and colleagues (2006) who found that in a sample of 63 children attending a residential school, 59% had ASD, 54 were male, and their average age was 15.2 years.

In addition to gender, age and ASD diagnosis, in some studies, behaviour that challenges was frequently mentioned by family carers and was highlighted as an important factor when seeking a residential school placement for their child. It is important to note, however, that whilst the search criteria for this review did not focus on behaviour that challenges, it was the case that some studies only focused on participants for whom these behaviours were a concern. Behaviour that challenges was therefore frequently highlighted by family carers. Studies reported that children/young people displayed multiple forms of behaviour that challenges before being placed in a residential school, including self-injury, aggression and property destruction (Brown *et al.* 2011, Pilling *et al.* 2007). Families reported that their child's behaviour was severe (Alborz 2003, McGill *et al.* 2006) and difficult to manage both at home and at school (Brown *et al.* 2011, Robertson *et al.* 1996, McGill *et al.* 2006), which contributed to their decision to seek a residential placement (Alborz 2003, McGill *et al.* 2006).

Impact on the family

Three articles highlighted impacts on the family relating to their child (Alborz 2003, Brown *et al.* 2011, Robertson *et al.* 1996). Families in some studies felt that caring for their child, both in terms of the child/young person's general wellbeing and in relation to behaviour that challenges, had significantly affected their own wellbeing. Families reported sleep difficulties as a result of the need for constant vigilance around their child and this in turn impacted upon their employment (Brown *et al.* 2011). Additionally, family carers described impacts on their emotional wellbeing, such as feeling stressed, guilty, and experiencing low self-esteem (Brown *et al.* 2011). In two studies, the Malaise Inventory stress measure was used to examine the level of stress experienced by family carers. In both cases, family carers scored highly (i.e. a score of 6 or more), indicating that they were experiencing significant distress (Alborz 2003, Robertson *et al.* 1996).

Family carers also felt that caring for their child had negatively impacted on their ability to plan for themselves, have personal goals, and take part in activities they enjoyed (Brown *et al.* 2011). They reported feeling socially isolated (e.g. due to losing friends or being unable to go out) and having little social support outside of their immediate family (Brown *et al.* 2011, Robertson *et al.* 1996). They felt that their relationships with their partners had often suffered due to having no time to spend together and frequent disagreements about how to manage their child's behaviour (Robertson *et al.* 1996). Three of the 44 family carers stated that the impact of caring for their child had directly led to divorce or separation from their partner (Robertson *et al.* 1996).

Families in some studies were also concerned about the impact of behaviour that

challenges on other children in the family. Siblings were reported to be the victims of assault, were bullied at school and were described as being resentful of their brother or sister (Robertson *et al.* 1996). In some cases, siblings took on a caring role for their brother or sister and experienced social isolation themselves due to not being able to have friends visit (Robertson *et al.* 1996). Family carers also felt that the sibling's quality of life overall had been negatively impacted by the behaviour of their child (Brown *et al.* 2011).

Resources and services

Two studies reported that the difficulties described by family carers were often exacerbated by poor service support and a lack of resources (McGill *et al.* 2006, Robertson *et al.* 1996). In many cases, families described poor quality services (both for the family carer and their child/young person) that were characterised by a lack of professional advice and expertise about behaviour that challenges (Robertson *et al.* 1996, McGill *et al.* 2006). Furthermore, families expressed concerns about the quality of services that were provided due to high staff turnover, a lack of understanding about disability, and issues of neglect (McGill *et al.* 2006). As a result of this poor quality support, families reported that they found the process of seeking a residential placement stressful, with little support or knowledge available from professionals (McGill *et al.* 2006).

In addition, families described significant resource implications of caring for their child. They reported needing adaptations to their house (e.g. additional locks on doors), frequent repairs to items due to their child's destructive behaviour, and having to pay for services and resources themselves (e.g. adapted furniture for use at school) (McGill *et al.* 2006).

Factors and processes leading to a residential school placement

One article examined the process used by LAs to make decisions regarding whether a child or young person should be placed in a residential school in addition to families' experiences of this process (Morris *et al.* 2002). A further article by Morris *et al.* (2003) summarises findings from three related studies (including Morris *et al.* 2002) regarding the process of placing children or young people in a residential school.

Taken together, these two articles highlighted wide variation in practices across the four case-study LAs in relation to the number of placements made, the types of placements made, and the demographics of children and young people who were placed in residential schools. In addition, the perspectives of professionals and families about the reasons for seeking a residential placement were reportedly often in conflict, with families citing failure of local schools and their child's social or emotional wellbeing, whilst professionals felt that families were pushing for a placement due to not being able to cope with their child's behaviour or support needs.

The studies found that there was also variation in the placement panels held within each of the LAs. The panels commonly included professionals from education, health, and social care (however, the role of health was felt to be underdeveloped). There were often a large number of children/young people discussed in one meeting (with those discussed at

the end receiving less attention than those discussed at the beginning), only incomplete assessments relating to children/young people to base decisions on, and rarely anyone on the panel who had personal involvement with and knowledge of the child and families' needs (or the needs of children and young people with disabilities more generally).

Families reported that the process of obtaining a residential placement was stressful due to receiving little information or support. They highlighted that they often had to visit and assess schools for themselves with no input from the LA. Following placement, families reported that they were offered little support to attend meetings or visit their child, and LAs were often poor at monitoring the progress and wellbeing of the child/young person, particularly if the placement had not been jointly funded by education and social services.

What is the quality and experience of support received at residential schools?

Six studies examined the experiences that children/young people and families had whilst the young person attended a residential school (Brown *et al.* 2011, Emerson *et al.* 1996, McGill *et al.* 2006, Pilling *et al.* 2007, Robertson *et al.* 1996, Smith *et al.* 2007). These studies included findings related to the child's experiences and treatment while at the school, families' perceptions of the child's experience, the impact on family life, and the outcomes for the child/young person whilst at the school. Two of these studies report findings from related studies (Emerson *et al.* 1996, Robertson *et al.* 1996).

Types and quality of support received at a residential school

Only two studies examined the type and quality of support received by the child whilst attending the residential school (Pilling *et al.* 2007, Smith *et al.* 2007). Pilling and colleagues (2007) found that of 156 children and young people who were placed in 52-week residential schools, a quarter were prescribed medication to manage their behaviour and most (but not all) had plans in place for physical interventions, although these types of restrictive interventions (e.g. seclusion, physical interventions, sedating medication) were used more frequently than in specialist day schools. Pilling and colleagues also reported that while at a 52-week residential school, children and young people had good access to frontline health and leisure services and nearly all had had a designated keyworker for over a year. Additionally, the majority of children and young people took part in class activities and received extra educational support, which was provided at a higher staff-student ratio (5.2:4.8) than in specialist day schools

One study examined the level of staff-student interaction in a residential school (in both the main building and an independent living unit (ILU)) as an indicator of the young person's experience while at the school (Smith *et al.* 2007). Interaction levels were found to be low, with total staff-student interactions encompassing 19.9% of the time in the main building and 8.7% of the time in the ILU. Students were engaged (i.e. in social, domestic, leisure or educational activities) for 48.3% of the time in the main building and 17% of the time in the ILU.

Family perceptions of the residential school and impact on family life

Families involved in three studies spoke about their perceptions of the residential school and its impact on their family life (Brown *et al.* 2011, McGill *et al.* 2006, Robertson *et al.* 1996). Some families reported that they were very satisfied with the school (Robertson *et al.* 1996) and felt that the school provided a good quality of care and met their child's needs (McGill *et al.* 2006). However, others also highlighted concerns about the school. These concerns often related to the distance of the school from the family home (McGill *et al.* 2006, Robertson *et al.* 1996), which prevented family carers from visiting their child regularly due to time and cost (McGill *et al.* 2006), and the quality of the care at the school due to staff turnover, inexperienced staff, and inadequate communication between the school and family (McGill *et al.* 2006). Additionally, family carers reported that they sometimes disagreed with the methods used by the school and were concerned about their child copying behaviours from other students or being injured by them (Robertson *et al.* 1996).

One study reported that family carers perceived a range of positive impacts that their child/young person's attendance at a residential school had on the family. These included feeling relieved and more relaxed, improved family relations, positive effects on siblings, more enjoyable time spent with their child when they were home, and ease of restrictions on family life due to the child/young person's support needs (Brown *et al.* 2011)

Outcomes while at the school

Three articles examined outcomes for the child following their attendance at the residential school (Brown *et al.* 2011, Emerson *et al.* 1996, Robertson *et al.* 1996). Family carers involved in the studies reported a range of positive and negative changes in their child or young person. Many family carers felt that their child's behaviour had improved (Brown *et al.* 2011, Robertson *et al.* 1996) and was easier to manage, less damaging, less frequent, shorter, and occurred in fewer situations (Robertson *et al.* 1996). In some cases, however, the child/young person's behaviour had reportedly become more frequent or severe and the child had developed new forms of behaviour that challenges (Robertson *et al.* 1996).

In some cases, families also highlighted that their child/young person appeared more sociable, happier and calmer, and had improved communication (Brown *et al.* 2011, Robertson *et al.* 1996). Some families also thought that the child was more attentive, tolerant of change, had improved sleep or feeding (Brown *et al.* 2011), and had learnt new skills or was more willing to learn (Robertson *et al.* 1996).

One study examined records kept by a residential school upon a child's entry and at the point of leaving the school as a measure of outcome for the child/young person during their attendance at the school (Emerson *et al.* 1996). Children were found to have made significant improvements in self-care, communication and reductions in behaviour that challenges. In addition, there was a significant increase in the number of behavioural programmes and written plans used to support children and young people who displayed

behaviours that challenge and a significant reduction in the use of sedation and anti-psychotic medication for individual children/young people throughout this period.

What are the outcomes and experiences for children or young people during transition and following placement in a residential school?

Five articles examined the process of transitioning from a residential school to a new placement (Abbott and Heslop 2008, Heslop and Abbott 2007, Heslop and Abbott 2008, McGill *et al.* 2006, Smart 2004). Three of these articles report findings from a series of related studies (Abbott and Heslop 2008, Heslop and Abbott 2007, 2008).

Support for transition

Five articles examined support provided to families relating to the child's transition from a residential school (Abbott and Heslop 2008, Heslop and Abbott 2007, 2008, McGill *et al.* 2006, Smart 2004). Families interviewed by McGill and colleagues (2006) highlighted anxieties about the future for their child concerning lack of adult services, placements being inappropriate or unable to meet the child/young person's needs due to funding limitations, and the possibility of the child returning to live with the family. In addition to these concerns, families reported generally poor experiences of the transition process. The transition to adult services from a residential school was often not smooth and was made more difficult by the considerable distance of the school from the family home (Abbott and Heslop 2008, Heslop and Abbott 2007, 2008). In a number of studies, families noted that their son or daughter was not given a transition plan or that these lacked detail (Abbott and Heslop 2008, Heslop and Abbott 2007, 2008, McGill *et al.* 2006); as a result, families reported that they were often left to find their child's next placement on their own. Families felt that this was exacerbated by the transition process being initiated late in the child/young person's current placement (Abbott and Heslop 2008, Heslop and Abbott 2007, 2008).

Studies also found variations in the amount of involvement the children and young people themselves had in the transition process. Families reported that their child's views were often not sought during transition planning (Abbott and Heslop 2008, Heslop and Abbott 2007, 2008, Smart 2004), and some schools lacked capacity to support the child or young person to visit future placements (Abbott and Heslop 2008, Heslop and Abbott 2007, 2008). In contrast, one study found that some students from a residential school were enabled to take part in a range of preparatory transition activities (e.g. visiting new placement, spending time with new peers etc) (Smart 2004).

Studies also highlighted mixed experiences of the transition process for families, with some feeling well prepared due to being involved in a range of ways during transition (e.g. attending meetings, visiting services etc.), while others felt that they were unprepared and unsupported by the school (Smart 2004). Additionally, some families reported that the process had been handled adequately; however, others experienced difficulties such as professional disagreements or disputes about funding, uncertainty of

placements (including delays), organisations failing to work together, inappropriate services offered, and too few planning meetings (Smart 2004). Some studies found that families felt they needed more information, for the transition process to begin earlier, and reassurances that their child would be cared for, funded, and supported through their transition (Smart 2004).

Families also identified a range of factors that they felt would contribute to a good transition. For example, being well connected with other families and professionals was seen as important for emotional support, networking, and ensuring continuity of support during the transition process. Being proactive as a parent was also seen as an important factor in facilitating a successful transition and was reported by both family carers and professionals, although family carers felt that this was not something they should have to do themselves. Family carers highlighted the importance of receiving adequate information during their son or daughter's transition period and that being able to visit and see potential placements first-hand was felt to be important in particular. Finally, forward planning and allowing time for families and young people to prepare for transitions was linked to a good experience of transition. Families suggested that the transition process should last between one and five years in order to ensure that there was adequate time to prepare and explore options, as well as to ensure that the necessary equipment and support are in place before the young person moves to their new placement (Heslop and Abbott 2007).

Outcomes following transition

Four studies examined outcomes for the child or young person following transition from their residential school (Abbott and Heslop 2008, Emerson *et al.* 1996, Robertson *et al.* 1996, Smart 2004). Nearly a quarter of individuals were placed more than 100 miles from home (Emerson *et al.* 1996) and in some studies children or young people initially moved home, onto further residential schools (due to the school only providing support for children/young people for up to 2.5 years), or to a residential placement (Abbott and Heslop 2008, Emerson *et al.* 1996). In other studies, however, nearly all students had been able to move to supported living services (Smart 2004). Despite this, individuals were reportedly very rarely able to access employment or further education following transition (Abbott and Heslop 2008, Smart 2004), and a quarter of individuals experienced subsequent placement breakdowns (Abbott and Heslop 2008, Smart 2004).

In their new placement, studies found that individuals did not make additional improvements in self-care, communication, or behaviour (the only improvement being less severe aggression), and significantly fewer behavioural programmes or written plans were in place to manage behaviours that challenge (Emerson *et al.* 1996); instead, the use of restrictive management strategies (i.e. medication or sedation) was found to be significantly increased (Emerson *et al.* 1996). Individuals reportedly still had good access to frontline health and social services but were less likely to have input from specialist services (Emerson *et al.* 1996).

Studies also examined families' perspectives of their child/young person's new placement. Family carers in one study reported that they were happy with various aspects of the service and felt that their child was also happy (Smart 2004). They were also found to be significantly more likely to find a particular staff member or the service in general more helpful (Robertson *et al.* 1996). Despite this, some families were significantly less likely to find staff approachable, to receive training, or to have their child home than when their child was in a residential school (Robertson *et al.* 1996). Additionally, families in one study highlighted concerns similar to those raised about residential schools (e.g. the distance from the family home, staff turnover, methods used to manage behaviour) (Smart 2004).

DISCUSSION

Whilst for a number of decades policy and guidance has advocated reductions in out-of-area placements for children, young people and adults with intellectual disabilities, surprisingly little research has examined the use of residential schools for this population and possible associations with placements and outcomes in adulthood. Only thirteen studies were identified by this review that examined the use of residential schooling and transition experiences for children with intellectual/developmental disabilities in the UK. All of the studies were published between 1996 and 2011, with the majority published within the last ten years. Older studies were included due to the small number of studies identified that were related to residential schooling; however, it is important to note that there may be key differences in policy and practice between studies published more recently and older studies. For example, the recognition and diagnosis of developmental disabilities (such as Autism Spectrum Disorder) has changed over time (Rutter 2007), and educational support may also have changed in line with developments in policy (see Appendix 1). Whilst still relevant, findings from older articles must be interpreted in light of these potential factors.

Many of the studies were published, however, after important policy developments asserting the right of children with disabilities to live with their families and receive local mainstream education wherever possible (such as The Children (Scotland) Act 1995, The Special Educational Needs and Disability (Northern Ireland) Order 2005, Special Educational Needs Code of Practice for Wales 2002) and the Mansell report (2007).

It is also important to note that recent policy developments may influence future placement practices (such as the Children and Families Act 2014, Special Educational Needs Code of Practice: 0 to 25 years 2014). While these developments may have the potential to influence the practice of placing children with disabilities in residential schooling, it is not yet clear to what extent this potential will be realised; therefore, the results of this review are likely to be relevant to current practices.

The majority of included studies focussed on factors that lead to a child or young person being placed in a residential school. Very few studies examined children's and families' experiences of the school and the outcomes for the child/young person whilst at the school, during or following transition. Strengths of available studies include first-hand accounts of the experiences of family members and (to a lesser degree) professionals; the identification of common characteristics of children and young people who are at risk of residential placement and some indication of the systemic complexities relating to entry to and transition from a residential school. The nature and quality of studies was, however, variable. Many relied on mainly qualitative methods of data collection, with few using quantitative methods or consulting or observing children and young people directly. Only two studies met full criteria for methodological quality of these designs and, in the vast majority of cases, data was drawn from pre-existing data or retrospective accounts of informants with a notable lack of control group comparisons. Finally, three groups of

articles (seven articles in total) reported findings from related studies/data sources and/or focussed on factors related to a particular school (see Brown *et al.* 2011, Emerson *et al.* 1996, Robertson *et al.* 1996) that are therefore difficult to generalize to other settings. Due to the large number of studies (approximately half of all included studies) presenting data from related data sources or relating to one school, the applicability of the results to residential schooling more generally is limited. Conclusions are therefore made tentatively in light of the need for studies utilising more representative samples and varied methodologies.

As a result of these limitations, it is concluded that the state of evidence relating to residential schooling in the UK is very limited and more research of high quality is undoubtedly needed. While findings from the review must be interpreted with caution, tentative conclusions summarising what is known in relation to each question area are presented below:

What leads to a child or young person being placed in a residential school?

Factors contributing to a child's placement in a residential school appear to include:

- A diagnosis of ASD, age (i.e. 15 years), and gender (i.e. male)

- Frequency, severity and management difficulty of behaviours that challenge and the impact of these on the family

- Non-residential schools being unable to cope with the child/young person's behaviour and the child/young person subsequently being excluded

- Lack of good quality service support and insufficient resources

- Lack of expertise from professionals about behaviours that challenge and the needs of children and young people with disabilities and their families

- Difficulties faced by the family, e.g. increased stress and negative emotions, relationship difficulties, concern for siblings, etc.

The factors and processes leading to a residential school placement appear to be characterised by:

- Poor support and a lack of expertise from professionals before placement

- Poorly co-ordinated placement panels in LAs

- A lack of support for family carers to visit their child/young person and attend reviews following placement

- A lack of adequate progress monitoring by professionals following placement

Residential school placements for people aged under 25 with intellectual disabilities

What is the quality and experience of support received at residential schools?

Positive outcomes and experiences of residential school placements may include:

- Good access to frontline health and social services

- Good access to leisure activities

- A high level of extra educational support including a higher staff-student ratio than found in day schools

- Child/young person being calmer or happier

- Improvements in the frequency, duration, or severity of behaviours that challenge

- Improved attention, communication, sleep, or physical functioning

- Child/young person learning new skills or being willing to learn

Negative outcomes and experiences of residential school placements may include:

- Poor levels of staff-student interaction and time spent engaged in meaningful activities

- A high use of restrictive practices (e.g. physical interventions, seclusion, and sedation)

- Dislocation from the community

- Discontinuity of care and support

- Methods used by the school that conflict with the families' wishes

- Risk of injury to child/young person from other students

- The development of new forms of behaviours that challenge

- Behaviours that challenge getting worse

What are the outcomes and experiences for children or young people during transition and following placement in a residential school?

The process of transition for children and young people at residential school may raise concern for families regarding:

- A possible lack of services

- Inappropriate services being offered

- Funding limitations meaning that placements may not be able to meet their child/young person's needs

- The possibility of the child/young person moving home

Families' experience of transition may vary in relation to:

- Their involvement and involvement of their child or young person

- How much support they are offered and how well prepared they are for transition

In addition, the transition process may be experienced by families as:

- Being initiated too late and not properly coordinated

- Characterised by delays and professional disagreements

A good transition experience may include:

- Being connected with other parents and professionals throughout the process

- Being proactive as a family carer

- Receiving adequate information about potential placements and the transition process

- Adequate time for the young person and family to prepare for transition (i.e. 1 to 5 years) and good forward planning to ensure that equipment and support are in place when the young person moves to their new placement

Following transition from a residential school, young people and adults may be placed in:

- Residential community settings

- Supported living settings

- A hospital based setting

- A new residential educational placement

In their new placement, individuals may experience the following **positive** outcomes:

- Good access to frontline health and social services

And the following **negative** outcomes:

- Very few opportunities to enter employment or further education

- No additional improvements in communication, self-care, or behaviours that challenge

- A reduction in good support for behaviours that challenge and increased reliance on restrictive practices

- Limited access to specialist services

- Living at distance from the family home

FUTURE QUESTIONS FOR RESEARCH

Future questions and directions for research are presented in relation to each of the question areas approached in the review of literature. These suggestions stem from limitations and gaps in the current evidence base and focussed discussions between the authors, reflecting perspectives from clinical practice, research and policy.

What leads to a child being placed in a residential school?

1. **What are the characteristics of children or young people who are at risk of attending a residential school?** Whilst there is a good suggestion of these characteristics from available research, these need to be confirmed (and potentially expanded) by studies that employ a larger sample size. Whilst this may in part be done by making use of existing data and records, prospective studies are also required.

2. **What are the early indicators for risk of attending residential school placement?** To date, those studies that have considered characteristics of children and young people at risk of residential placement have done so based primarily on the presentation of the child/young person just prior to attendance of the school. More research is required to identify the characteristics and needs of children and young people at an earlier stage to support early intervention and preventative service developments.

3. **What are the systemic factors and system failings that lead to a residential school placement?** Relatively little research has examined in detail processes of professional decision-making that precede placement in a residential school or how professionals, commissioners and families have drawn upon available guidance and policy to explore an alternative to such a placement. Furthermore, variation in placement practices between LAs was highlighted in the literature and the reasons for this could be explored by further research. These areas may be usefully (though in no way exclusively) approached via action research methodologies.

4. **What are the alternatives to residential school placements?** There is a major need to identify alternative forms of local support for children and young people who might be at risk of out-of-area residential placement. Appendix 3 provides an overview of intensive support teams in the UK as examples of emerging good practice. While in no way providing the complete solution to early prevention of out-of-area placement, these services suggest particular promise in preventing use of residential-school placement for those who are at imminent risk. The clinical effectiveness, cost-benefit and development of services of this nature might therefore usefully be considered in future research. At a further level, interventions and service supports that reduce risk of later residential placement from an even early stage (i.e. during preschool years and early childhood) need development and investigation.

5. **What supports resilience amongst family carers who support children and young people at risk of placement in a residential school?** High rates of emotional difficulty

and the impact of supporting a child or young person who presents with behaviour that challenges were reported by many family carers within studies in the current review. Further research is however required to consider factors that relate to the resilience of families facing such challenges and the support required to maintain such resilience if alternatives to residential school placements are to be sustained. Where families have been able to maintain a home placement for their child/young person, what has facilitated this and supported them to do so?

What is the quality and experience of support received at residential schools?

1. **What is the quality of support available to children and young people attending residential schools?** Despite the high costs of residential school placements, very few studies overall have examined the quality of support provided. Future studies in this area need to consider a range of domains, including best practice approaches for supporting behaviour that challenges, educational attainment and skills acquisition, support for family contact and quality of life more broadly across representative samples of schools and colleges in the UK. Comparisons should be considered between children and young people who present with similar levels of complexity in both local and out-of-area school placements.

2. **How effective are residential schools in supporting positive outcomes for the children and young people they support?** Related to the above research question, there is a paucity of research examining the extent to which residential schools actually achieve positive outcomes for children/young people in relation to behaviour that challenges, educational attainment and skill development and quality of life. Again, studies should ensure adequate sample sizes and incorporate comparisons to children/young people supported in alternative settings.

3. **What are the direct experiences of children and young people attending residential schools?** The direct involvement of children and young people with disabilities should be considered as a priority for future studies either through accessible interview and focus groups or direct observation.

4. **How do families experience life and support following residential school placement for their child?** While there has been some research examining life for families during this period, more detailed studies are required to determine the impact of such placements on family functioning, relationships with the child/young person, experience of contact and support offered by the local and out of area service.

5. **How might transitions from residential school best be supported?** A more detailed and comprehensive account of transition is needed. Studies should examine transition procedures and practices in place across a range of residential schools and the experience of families, young people and professionals during the period of transition and how quality of transition planning relates to outcomes and support for young people and adults longer term.

Residential school placements for people aged under 25 with intellectual disabilities

What are the outcomes for children and young people following residential schools?

1. **What are the long term outcomes for individuals who have attended a residential out-of-area placement?** There have been very few follow up investigations of individuals who have attended a residential school following transition to adult services. Future studies in this area should ideally track school leavers to assess outcomes over time but may also identify individuals in adulthood who attended a residential school in the past. Key outcomes should include cost, quality and locality of adult service, indicators of emotional, behavioural and physical wellbeing and a range of quality of life variables more broadly.

2. **What are the long term outcomes for individuals with complex needs who are supported by a local alternative to residential schooling?** Where alternatives to the use of residential school placements are identified (for instance via intensive support teams) the longer term outcomes for individuals and their families need to be assessed as they transition into adulthood. Again variables here should consider service quality and effectiveness, individual and family wellbeing and quality of life.

APPENDIX 1: OVERVIEW OF POLICY AND GUIDANCE

This Appendix provides an overview of key policy and guidance related to local alternatives to out-of-area residential placements at an early stage of the life course. Although this summary is inclusive of policy relevant to England, Wales, Northern Ireland, and Scotland, it is not intended to be a comprehensive overview of policy and guidance in each of these countries.

The Children Act 1989 defined children with disabilities as "Children in Need" with Local Authorities given a duty to "promote the upbringing of such children by their families, by providing a range and level of services appropriate to those children's needs". Subsequent policy and legislation under successive Governments, and, since devolution, across England, Scotland, Wales and Northern Ireland, has been consistent with the principle underlying this duty.

In 1993, the Department of Health published 'Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs', a review chaired by Professor Jim Mansell, which set out a number of key areas for improvement in the provision of support for children, young people, and adults with learning disabilities. This report was updated in 2007 and found that challenging behaviour may be an important factor in the placement of children in residential schools. The report also highlighted that these placements "are often disruptive of ties with family and community, so that families face particular problems getting local services which can provide the level of support needed when responsibility passes from children's to adult services". The report recommended that "continued use of residential special schools away from people's homes needs to be re-examined in the light of these problems, to expand the provision of local services which offer at least as good education and care".

In 1997, a committee of The Mental Health Foundation published 'Don't Forget Us: Children with Learning Disabilities and Severe Challenging Behaviour'. The report provided an overview of provision in the UK, made recommendations for the future development of services, highlighted the need for children to be viewed as 'children first', and emphasised that families require access to child focussed services. The report describes the need for a comprehensive, co-ordinated range of services including very specialist interventions and suggests that, without this provision, children and young people with learning disabilities and severe challenging behaviour risk exclusion from local services, schools, playgroups, play and leisure activities, and family life itself. 'Valuing People: A New Strategy for Learning Disability for the 21st Century' (2001) aimed to transform the delivery of support for people with learning disabilities by outlining four key principles of rights, independence, choice and inclusion. These principles, aligned with the practical changes set out in standard eight of the National Service Framework (2004), focused on children and young people with disabilities and those with complex needs. This ten-year strategy promoted the development of "appropriate local educational support and provision so that parental requests for residential education are not made on the basis of

lack of support and practical help in their community."

In line with this, across England, Scotland, Wales and Northern Ireland, parents of children or young people with a statement of special educational needs have the right to express their preference for a school. The local authority must comply with this "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 resource." (SEN Code of Practice 2001). In Scotland, the concept of additional support needs was introduced in the Education (Additional Support for Learning) (Scotland) Act (2004; revised in 2009) and aimed to clarify procedures for families to seek assessments, make requests relating to their child's school placement, resolve disputes and access tribunals. Furthermore, the right to local mainstream education for children with disabilities is enshrined in policy and guidance across England, Wales, Ireland, and Scotland (e.g. The Children (Scotland) Act 1995, The Special Educational Needs and Disability (Northern Ireland) Order 2005, Special Educational Needs Code of Practice for Wales 2002, Children and Families Act 2014).

In response to this, The Education and Skills Select Committee held an inquiry on the special educational needs system in 2006, which examined decisions about admissions to school and parental choice. The committee found that, in reality, families felt that they did not have a choice about where the child/young person was educated, highlighting that if appropriate services are not available, it is not possible for parents to choose or express a preference for them.

Despite this, reforms over the past ten years have significantly changed the system of support for children and young people with disabilities with a focus on better integrated local support. Removing Barriers to Achievement (2004) reformed the special educational needs system and encouraged more joint working between mainstream and special schools in support of greater inclusion. It highlighted a need for "joint investment by local authorities and other agencies in the development of specialist provision that can provide outreach and tailored packages of support for children".

Aiming High for Disabled Children (2007) demonstrated a clear commitment to making better local support a reality with a £340m investment underpinning reforms, including funding for short breaks, better early intervention, more responsive services and timely support underpinned by good quality data about disabled children and young people. 'Valuing People Now' (2009), the three year delivery strategy for the Valuing People commitments, proposed opening up mainstream services so that people with learning disabilities should have the same opportunities as other people to lead full and active lives and should receive the support needed to make this possible.

The report of the World Health Organisation - Better health, better lives: children and young people with intellectual disabilities and their families (2010) identified ten priorities for action which need to be addressed in order for children and young people with intellectual disabilities and their families to live healthy, fulfilled lives. These priorities include enabling children/young people to grow up in a family environment, transferring

Residential school placements for people aged under 25 with intellectual disabilities

care from institutions to the community and ensuring good quality mental and physical care is co-ordinated and sustained.

Despite these longstanding commitments from Government and significant reforms to the system, a recent Department of Health Review (2012), following the abuse of people with learning disabilities and behaviours that challenge at Winterbourne View hospital, found "a widespread failure to design, commission and provide services which give people the support they need close to home, and which are in line with well-established best practice."

In 2011, DfE published a Green Paper *Support and Aspiration: A New Approach to Special Educational Needs and Disability* (2011) to consult on a radical transformation of the SEN system. The progress and next steps document (2012) acknowledged that it is still the case that:

> too many children and young people who are disabled or identified as having special educational needs (SEN) have poor outcomes in life and they and their families can struggle to get the support they need.

The subsequent Children and Families Act (2014) now provides an opportunity for fundamental change in commissioning practice. The Act aims to reform the system of support across health, education and social care to ensure that services are organised with the needs and preferences of the family and their child firmly at the centre. The Act replaces statements with Education, Health and Care plans which set out how services will work together to meet outcomes. The Act includes a duty for local authorities to set out the provision that should be available in a "Local Offer" and introduces joint commissioning arrangements designed to improve outcomes, secure assessment and provision and agree personal budgets. The Act also requires local partners to identify any gaps in provision that need to be addressed. Similar legislation in Scotland (i.e. the Children and Young People (Scotland) Act 2014, linked to Getting it Right for Every Child) also aims to promote partnership working and a stepped care approach for supporting children and young people across universal, specialist, and target services.

The reforms introduced by the Children and Families Act in England provide a vehicle for local authorities, health commissioners and their partners to deliver on the commitments to improve support for children with learning disabilities whose behaviours challenge, as set out in the Transforming Care Concordat (2012). Alongside the revised SEN and Disability Code of Practice for England (2014), key guidance for local areas includes the LGA and NHS England publication *Ensuring quality services: Core principles for the commissioning of services for children, young people, adults and older people with learning disabilities and/or autism who display or are at risk of displaying behaviour that challenges* (2014). This guidance is based on a Positive Behavioural Support (PBS) approach and sets out principles that provide a foundation for commissioners to review services and develop more detailed local plans and specifications for future service delivery. Further advice for local areas is provided in *Market facilitation: guidelines for children and young people's services*, published by the Children's Improvement Board in 2011.

APPENDIX 2: METHODOLOGICAL QUALITY APPRAISAL

As discussed above, all of the articles were categorised as either qualitative or quantitative-descriptive in methodology (based on their dominant methodology) for the purposes of methodological review. The relevant MMAT (Pluye *et al.* 2011) items for these methodologies can be seen in Table A1 (below) with notes relating to how the item was interpreted for the purposes of the review. All of the items were interpreted in relation to the aims of the current review (e.g. questions on representativeness of the sample were interpreted in relation to the representativeness of children with intellectual disabilities who attend residential schools), however it is important to note that the aims of the original studies may been different (e.g. the sample may be representative of the population which was targeted in the study, but not of the population for the current review). As a result, these ratings can be used only for the purposes of this review and do not reflect the methodological quality of the articles more generally.

Table A1: MMAT domain items and interpretation used for current review

MMAT domain	Item	Interpretation
Screening questions	Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	N/A
	Do the collected data address the research questions (or objective)?	N/A
Qualitative	1.1 Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (or objective)?	Studies scored yes on this question if their sample was thought to be representative (e.g. inclusive of both genders, a range of ability/ communication levels, varying aetiologies etc.).
	1.2 Is the process for analysing qualitative data relevant to address the research question (or objective)?	Studies scored no on this item if the method for analysis was not described.
	1.3 Is appropriate consideration given to how findings relate to the context, e.g. the setting, in which the data were collected?	Studies scored yes on this question if sufficient detail was given about the context within which the data was collected (e.g. the specific school).

Residential school placements for people aged under 25 with intellectual disabilities

Table A1: MMAT domain items and interpretation used for current review

MMAT domain	Item	Interpretation
Qualitative	1.4 Is appropriate consideration given to how findings relate to the researchers' influence, e.g. through their interaction with participants?	Studies scored yes on this question if there was evidence of: two separate individuals contributing to analysis of the results, reflexivity if only one individual analysed results, or an independent individual (i.e. not the same person who collected the data) analysed the results.
Quantitative-descriptive	4.1 Is the sampling strategy relevant to address the quantitative research question?	Studies scored no on this question if their sample was too small or had been taken from only one source (i.e. one school).
	4.2 Is the sample representative of the population under study?	Studies scored yes on this question if there was no evidence of bias in their sampling strategy (i.e. no inappropriate exclusion of participants) or in the final sample obtained.
	4.3 Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Studies scored yes on this question if they described where the measures had been obtained, or if the measures were standardised/tested for validity.
	4.4 Is there an acceptable response rate (60% or above)?	Studies scored yes on this question if their response rate was above 60%.

Table A2 displays the scores given to each study by individual item, and, where studies scored no, the reasons for this scoring. All studies scored yes on both screening questions.

Table A2: Ratings given to each study by item and reason (if study scored no)

Study	Domain used	Item	Score	Reason
Abbott and Heslop (2008)	Qualitative	1.1	Yes	N/A
		1.2	Yes	N/A
Heslop and Abbott (2007)		1.3	Yes	N/A
Heslop and Abbott (2008)		1.4	Yes	N/A

Table A2: Ratings given to each study by item and reason (if study scored no)

Study	Domain used	Item	Score	Reason
Alborz (2003)	Qualitative	1.1	No	Small sample of participants who met inclusion criteria
		1.2	No	Unable to separate results for participants who met inclusion criteria
		1.3	Yes	N/A
		1.4	Yes	N/A
Brown *et al.* (2011)	Qualitative	1.1	No	Participants taken from one school only
		1.2	Yes	N/A
		1.3	Yes	N/A
		1.4	Yes	N/A
Emerson *et al.* (1996) Robertson *et al.* (1996)	Quantitative-descriptive	4.1	No	Participants taken from one school only
		4.2	Yes	N/A
		4.3	Yes	N/A
		4.4	Yes	N/A
McGill *et al.* (2006)	Quantitative-descriptive	4.1	Yes	N/A
		4.2	Yes	N/A
		4.3	Yes	N/A
		4.4	No	Response rate = 34%
Pilling *et al.* (2007)	Quantitative-descriptive	4.1	Yes	N/A
		4.2	Yes	N/A
		4.3	Yes	N/A
		4.4	Yes	N/A
Smart (2004)	Quantitative-descriptive	4.1	No	Participants taken from one school only, and small sample obtained
		4.2	Yes	N/A
		4.3	No	Not enough detail given on measures
		4.4	No	Response rate = 36%
Smith *et al.* (2007)	Quantitative Descriptive	4.1	No	Participants taken from one school only
		4.2	Yes	N/A
		4.3	Yes	N/A
		4.4		Item not applicable to the methodology used

APPENDIX 3: ALTERNATIVE FORMS OF SUPPORT IN CLINICAL PRACTICE

This Appendix provides service examples of alternative support for children and young people at risk of placement in a residential school due to behaviour that challenges. In recent years, Intensive Support Teams have been highlighted as best practice examples (Reid *et al.* 2013, DoH Concordant on WV 2012b) for supporting children and young people with behaviour that challenges who are at imminent risk of such a placement due to family or school breakdown. Examples of services based on this model of practice are provided below. The systems and factors related to residential school placement are, however, multiple and complex and it is stressed that, whilst promising, such services are likely to relate to only one possible aspect of preventative or alternative support. Early intervention is also needed to support families based on known risk factors in order to prevent a crisis from occurring and to reduce the need for specialist support.

Intensive Support Teams

The following services incorporate values, processes and approaches that are consistent with components of Positive Behavioural Support (Carr *et al.* 1999), a multi-component framework for providing evidence-based support to people who display behaviour that challenges (see Gore *et al.* 2013). This includes partnership working with stakeholders (e.g. involving families in assessment and intervention procedures and providing direct therapeutic and training support to families), the use of holistic functional assessments (i.e. structured assessments that highlight how behaviours that challenge allow the focal person to get their needs met or to exert some control over their environment) to develop constructive, proactive and non-punitive supports (i.e. interventions that focus primarily on increasing quality of life) and to support wider systems development (e.g. via training and mentoring to other professionals).

These teams were developed primarily to work with children and young people with disabilities (and their families) at high risk of residential placement (either as a specific service or as an aspect of a broader service) with the aim of providing a local alternative. In the majority of cases, these teams adopt an intensive model, working with a small number of families at any given time but with a high frequency of contact. In addition to the use of PBS, the teams typically also facilitate short break provision for children and young people in the local community.

The teams are generally small, and in most cases, professionals have worked in partnership with commissioners to develop and maintain the service. Evidence for the effectiveness of these teams currently exists in relation to a small number of practice-related publications and outcome data routinely collected in the service pathway.

Ealing Intensive Therapeutic and Short Break Service (ITSBS), Ealing, London

Development and aims	In the summer of 2008, approximately 7 young people in the London Borough of Ealing with severe learning disabilities who displayed behaviour that challenges were placed in residential placements. This number was significant and raised concerns with both commissioners and clinicians. The Ealing CAMHS-LD service offered to pilot an 'intensive' service for one young person at risk of family placement breakdown and their family. After demonstrating success in working at a more intensive level and providing an extended therapeutic break (3 weeks) in a local respite setting, commissioners agreed to fund the ITSBS. Since 2009, the service has grown each year with increases in staffing and numbers of young people seen.
	The service aims to prevent family placement breakdown and a move to residential placements for young people with moderate to severe learning disabilities and/or autism who display behaviours that challenge. The service aims to support 8 new young people each year. Typically there are 2–4 young people each year that require more longer-term intervention (but less intensive and more on a monitoring level offering consultation and training to the network) and therefore a typical service caseload is 10–12 individuals. The service also aims to develop skills in local short-break staff to ensure high quality short breaks can be provided locally to support young people and their families within Ealing.
Team members	Band 8a Clinical Psychologist 0.6wte
	Band 7 Clinical Psychologist 0.4wte
	Band 5 Assistant Psychologist 1.0wte
	Social Worker 1.0wte
	(From May 2014 – Band 7 Occupational Therapist 0.2wte)
	ITSBS staff members are nested within the CAMHS-LD team which consist of Psychology (2.2wte), LD Nursing (1.4wte) and Psychiatry (0.1wte).
Outcomes and indicators of effectiveness	Since setting up, 27 young people have been referred to the service, 19 of whom met intake criteria and were supported. To date, all young people seen in the service are still living at home with their families (except one who is in a 38 week residential school placement in Ealing). Early service outcomes are described by Reid *et al.* (2013).
	The service currently implements the following outcome measures at intake and repeats some of these at 3 month intervals and point of discharge:
	- Developmental Behaviour Checklist (for parents, carers and teachers) (Einfeld and Tonge 2002)
	- Three Concerns (goal based measure)
	- Emotional Reaction to Challenging Behaviour Scale (Mitchell and Hastings 1998)
	- Attitudes towards Challenging Behaviour Scale (CHABA) (Hastings 1997)
	- Beech Centre Family Quality of Life Scale (Park *et al.* 2003)
	- GHQ-12 (Goldberg 1972)

Ealing Intensive Therapeutic and Short Break Service (ITSBS), Ealing, London (continued)

Outcomes and indicators of effectiveness	The service also collects data to inform cost-benefit analysis, including: - Services accessed by this group of young people - Number of young people in Ealing placed in residential care since 2006 and reasons for this - Population of young people in Ealing with mod-severe LD who either are on school action plus or have a statement of SEN.
Contact	Dr Caroline Reid: caroline.reid1@nhs.net

Positive Behaviour Support Service (PBSS) Bristol

Development and aims	The service was initially commissioned as a single intervention programme in response to a crisis. In 2005, an 11-year-old child with severe learning disabilities had been excluded from school due to high levels of aggressive behaviour. At this point there were no other local educational provisions able to offer a placement and an Out of Authority residential placement was being considered. In response to the family's request for a local alternative, the school made a referral to the community NHS learning disability clinical psychology service to assess the child's needs and consider the viability of a support programme. The initial assessment (including a functional analysis) indicated a PBS programme was viable and the Local Authority agreed to fund a three month trial period. Two graduate assistant psychologists were recruited to work under the direction of a senior clinical psychologist and the young person was successfully supported to remain living at home. Following the success of the initial PBS programme, the Primary Care Trust (PCT) and Local Authority jointly funded an extended service and the PBSS was formed. The PBSS's purpose remains to support school placements at risk of breakdown by developing and enhancing pro-social, independence and educational skills. In addition the service supports school and family systems and provides training to relevant professionals. The service has capacity to work with four children at any one point in time.
Team members	The PBSS is hosted with the Specialist Service for Children with Learning Disabilities (SSCLD), the community team for supporting children with learning disabilities and families. There are also close links with special schools and disabled children's social workers. The PBSS is led by a 0.7 full-time equivalent clinical psychologist. The clinical psychologist is responsible for designing, implementing and evaluating the intervention programmes. The clinical psychologist recruits, trains and supervises graduate assistant psychologists to deliver the programmes on a case by case basis. As the number of children referred to the PBSS varies from year to year, the number of assistant psychology staff also varies. For instance, some children require a 2:1 staff ratio throughout the day and other children need only 1:1 support for part of the day.

Positive Behaviour Support Service (PBSS) Bristol (continued)

Outcomes and indicators of effectiveness	Over 8 years the PBSS has worked with 12 children and supported 10 of them to stay in their local community and school
	The service routinely delivers the following outcome measures
	- VB- MAPP (Sundberg 2008) for child development data
	- Vineland Adaptive Behaviour Scale (Sparrow et al. 1984)
	- Discrete Behaviour recording for behaviours of interest e.g. aggression, SIB, class participation
	The service also gathers data to support cost-benefit analysis and has produced a number of case studies for publication (Jackson-Brown and Brown 2012, Jackson-Brown et al. 2014, Jackson-Brown and Peace 2011, Jackson-Brown 2006).
Contact	Dr Freddy Jackson-Brown: freddy.jacksonbrown@nbt.nhs.uk

Family Intervention Rapid Support Team (FIRST),York

Development and aims	Professionals recognised that a number of children with disabilities were required to move into out-of-area residential school placements, often in crisis situations, as a result of services being unable to provide the intensity of support required more locally.
	A major trigger for FIRST was a young person needing to access a hospital placement over 100 miles away from home. It was felt that this could have been avoided if intensive support could have been placed into the family home. Clinicians within York CAMHS-LD initially trialled an intensive form of support to prevent residential support for one young person. A sub-group of clinicians in the team made special arrangements (clearing all other appointments) and were able to support the young person to remain living at home. This success was presented to local commissioners.
	Funding from Aiming Higher was later used to secure a one year pilot service. This involved the recruitment of one Consultant Clinical Psychologist (August 2011) who would be responsible for developing and leading the pilot service. It was agreed that outcomes from the pilot would be used to determine whether the service should be extended. To date the FIRST service provision has been extended twice; one extension of 6 months (to February 2013) and one of three years (February 2016). The service has capacity to work with between 6 and 10 young people at any one time.
	In addition to aiming to reduce the need for out of area residential and hospital placements for young people who present with behaviour that challenges, the service also aims to increase multi-agency working and holistic support and influence broader systems through consultation and training to improve the patient/ family journey.

Family Intervention Rapid Support Team (FIRST), York (continued)

Team members	The service is physically based within the Child and Family Unit alongside the CAMHS team. The Consultant Clinical Psychologist also has strong connections to the Child Development Centre, the Children's Health and Disability Team, as well as local education services. This is through FIRST inclusion on a number of local panels, as well as multi-agency working with tier-one professionals - One whole time Consultant Clinical Psychologist - Currently recruiting a full time Child Behaviour Support Worker (Band 3), this post will predominantly be for supporting the implementation of FIRST interventions.
Outcomes and indicators of effectiveness	Since development of the service, only one hospital stay and temporary residential placement has been required for young people supported. In addition, two young people have been supported to return to York from out of area residential placements in their transition to adult services. The service routinely attempts to deliver the following outcome measures pre and post intervention: - Developmental Behaviour Checklist (Einfeld and Tonge 2002) - Parenting Stress Index (Abidin 1990) - Children's Global Assessment (Shaffer et al. 1983)
Contact	Dr Alexander Legge: a.legge@nhs.net

Child and Adolescent Mental Health Service – Learning Disability/Family Intensive Support Service (East Sussex)

Development and aims	A proposal for a small demonstration project to work with children with severe learning disabilities and their families where the child was displaying challenging behaviour was made in 1996. The proposal focussed on maintaining children in their families and communities and preventing residential placement. A local commissioner used the proposal to apply for Challenge Fund monies that up until then had only been used to prevent residential placement in older people. Funding was identified for three years to set up a specialist team and demonstrate that children and families could be supported to remain living with their family and local community. After three years, substantive funding was secured from the Primary Care Trust to provide to the West of East Sussex; in 2008, the service was reviewed and achieved further funding to expand to deliver to the whole of East Sussex. Whilst the service initially had a specific remit to support young people at imminent risk of residential placement, the service has since evolved to provide support to children and young people with disabilities and their families more broadly. The service has however maintained a commitment to preventing residential placements both within and out of area by responding to the needs of children and family proactively. The wider remit of this service is reflected in a higher capacity than other services described here (the service typically hold a caseload of over 100 and provides support to families for an average of 4.5 years).

Child and Adolescent Mental Health Service – Learning Disability/Family Intensive Support Service (East Sussex)

Team members	The service are a specialist team within Community Adolescent Mental Health Services (CAMHS), and have strong links with other CAMHS teams colleagues, the Early Years Care Co-ordination Scheme, the local social care disability teams and local special schools. The team consists of: - Team Leader (Social work): 0.8 wte - Clinical Psychologists: 3.2 wte - Assistant Psychologist 1.0 wte - Speech and Language Therapy: 2.4 wte - Family Support Workers: 2.8 wte
Outcomes and indicators of effectiveness	The service estimate that they support a high number of children and young people who are at risk of out of area residential placement but have been supported to maintain a local alternative. In the last 5 years only one child worked with is believed to have been placed in an out of area residential school. The service routinely deliver the following outcome measures throughout the care pathway: - Strengths and Difficulties Questionnaire (Goodman, 1997) - Developmental Behaviour Checklist (Sparrow et al., 1984) - Alliance tool - Behaviour Grids - Session Rating Scale Outcomes for the service have been published by Mulligan et al. (2014).
Contact	Dr Rosey Singh: Rosey.Singh@sussexpartnership.nhs.uk

REFERENCES

Abbott D, Heslop P (2008) Where next? Transition pathways for young people with learning difficulties in U.K. residential schools and colleges, *Journal on Developmental Disabilities,* 14, 1, 52–58.

Abidin RR (1990) *Parenting Stress Index (3rd Ed.),* Pediatric Psychology Press, Charlottesville, VA.

*Alborz A (2003) Transitions: Placing a son or daughter with intellectual disability and challenging behaviour in alternative residential provision, *Journal of Applied Research in Intellectual Disabilities,* 16, 1, 75–88.

Allen D, Hawkins S, Cooper V (2006) Parents' use of physical interventions in the management of their children's severe challenging behaviour, *Journal of Applied Research in Intellectual Disabilities*, 19, 4, 356–363.

Baker BL, McIntyre II, Blacher J, Crnic K, Edelbrock C, Low C (2003) Pre-school children with and without developmental delay: behaviour problems and parenting stress over time, *Journal of Intellectual Disability Research,* 47, 4–5, 217–230.

Barron DA, Hassiotis A, Paschos D (2011) Out-of-area provision for adults with intellectual disabilities and challenging behaviour in England: Policy perspectives and clinical reality, *Journal of Intellectual Disability Research,* 55, 9, 832–843.

Beadle-Brown J, Mansell JL., Whelton B, Hutchinson A, Skidmore C (2006) People with learning disabilities in 'out-of-area' residential placements: 2. Reasons for and effects of placement, *Journal of Intellectual Disability Research*, 50, 11, 845–856.

*Brown RI, Geider S, Primrose A, Jokinen NS (2011) Family life and the impact of previous and present residential and day care support for children with major cognitive and behavioural challenges: A dilemma for services and policy, *Journal of Intellectual Disability Research*, 55, 9, 904–917.

Carr EG, Horner RH, Turnbull AP, Marquis K, Magito-McLaughlin D, McAfee ML, Doolabh A (1999) *Positive Behavior Support for People with Developmental Disabilities: A Research Synthesis,* American Association on Mental Retardation, Washington, DC.

Children's Improvement Board (2012) *Market Facilitation: Guidelines for Children and Young People's Services*, Children's Improvement Board, London.

Cooper V (1999) My son with learning disabilities and challenging behaviour: Adapting to meet his needs, *Tizard Learning Disability Review*, 4, 3, 13–18.

Clifford J, Theobald C (2012) *Summary of Findings: Extension of the 2011 Cost Comparison Methodology to a Wider Sample.* Retrieved from http://www.nasschools.org.uk/

Department for Education (2011) *Support and Aspiration: A New Approach to Special Educational Needs and* Disability, Department for Education, London.

Department for Education (2012) *Support and Aspiration: A New Approach to Special Educational Needs and Disability: Progress and Next Steps*, Department for Education, London.

Department for Education and Department of Health (2014) *Special Educational Needs and Disability Code of Practice: 0 to 25 Years.* Retrieved from www.gov.uk/government/uploads/system/uploads/attachment_data/file/342440/SEND_Code_of_Practice_approved_by_Parliament_29.07.14.pdf

Department for Education and Skills (2001) *Special Educational Needs Code of Practice*, Department for Education and Skills, London.

Department for Education and Skills (2004) *Removing Barriers to Achievement: The Government's Strategy for SEN*, Department for Education and Skills, London.

Department for Education and Skills (2007) *Aiming High for Disabled Children: Better Support for Families*, Department for Education and Skills, London.

Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21*st *Century*, Department of Health, London.

Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services*, Department of Health, London.

Department of Health (2009) *Valuing People Now: A New Three Year Strategy for People with Learning Disabilities*, Department of Health, London.

Department of Health (2012a) *Transforming Care: A National Response to Winterbourne View Hospital*, Department of Health, London.

Department of Health (2012b) *DH Winterbourne View Review: Concordat: Programme of Action*, Department of Health, London.

Einfeld SL, Tonge BJ (2002) *Manual for the Developmental Behaviour Checklist: Primary Carer Version (DBC-P) and Teacher Version (DBC-T)* (2nd Ed.), Monash University Centre for Developmental Psychiatry and Psychology, Clayton, Melbourne.

Emerson E, Einfeld S (2011) *Challenging Behaviour* (3rd Ed), Cambridge University Press, Cambridge.

Emerson E, Robertson J (2008) *Commissioning Person-Centred, Cost-Effective, Local Support for People with Learning Disabilities,* Social Care Institute of Excellence, London.

*Emerson E, Robertson J, Fowler S, Letchford S, Jones M (1996) The long-term effects of behavioural residential special education on children with severely challenging behaviours: Changes in behaviour and skills, *Journal of Applied Research in Intellectual Disabilities*, 9, 3, 240–255.

Residential school placements for people aged under 25 with intellectual disabilities

Foundation for People with Learning Disabilities (1997) *Don't Forget Us: Children with Learning Disabilities and Severe Challenging Behaviour*, Mental Health Foundation, London, UK.

Gore NJ, McGill P, Toogood S, Allen D, Hughes JC., Baker P, Hastings RP, Noone SJ, Denn LD (2013) Definition and scope for positive behavioural support, *International Journal of Positive Behavioural Support, 3*, 2, 14–23

Goldberg D (1972) The Detection of Psychiatric Illness by Questionnaire: A Technique for the Identification and Assessment of Non-psychotic Psychiatric Illness, Oxford University Press, London, New York.

Goodman R (1997) The strengths and difficulties questionnaire: A research note, *Journal of Child Psychology and Psychiatry*, 38, 581–586.

Hastings RP (1997) Measuring staff perceptions of challenging behaviour: The Challenging Behaviour Attribution Scale (CHABA), *Journal of Intellectual Disability Research*, 41, 6, 495–501.

Hastings RP (2002) Parental stress and behaviour problems of children with developmental disability, *Journal of Intellectual and Developmental Disability*, 27, 3, 149–160.

Health and Social Care Information Centre (2013) *Learning Disabilities Census Report*, Retrieved from http://www.hscic.gov.uk/catalogue/PUB13149

*Heslop P, Abbott D (2007) School's out: Pathways for young people with intellectual disabilities from out-of-area residential schools or colleges, *Journal of Intellectual Disability Research*, 51, 7, 489–496.

*Heslop P, Abbott D (2008) Help to move on – but to what? Young people with learning difficulties moving on from out-of-area residential schools or colleges, *British Journal of Learning Disabilities*, 37, 1, 12–20.

Jackson-Brown F (2006) Maintaining long-term therapeutic programmes: a qualitative case study, *British Journal of Learning Disabilities*, 34, 117–121.

Jackson-Brown F, Brown M (2012) Increasing spontaneous requests using a time delay procedure with a learning disabled child with challenging behaviour, *International Journal of Positive Behavioural Support*, 2, 19–25.

Jackson-Brown F, Pearce N (2011) Teaching a child with challenging behaviour to use the toilet: A clinical case study, *British Journal of Learning Disabilities*, 39, 321–326.

Jackson-Brown F, Gillard D, Brown M, Anderson A Stewart J (2014) Supporting special school placements at risk of breakdown: behavioural and financial outcome, *International Journal of Positive Behavioural Support*, *4*, 24–37.

Local Government Association and NHS England (2014) *Ensuring Quality Services,* Local Government Association, London.

Male DB (1998) Who goes to SLD schools? *Journal of Applied Research in Intellectual Disabilities*, 9, 4, 307–323.

Mansell JL (1993) *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs: Report of a Project Group*, Department of Health, London.

Mansell JL (2007) *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Need*, Department of Health, London.

McGill P, Cooper V, Honeyman G (2010) *Developing Better Commissioning for Individuals with Behaviour that Challenges Services – A Scoping Exercise*, Tizard Centre/Challenging Behaviour Foundation, Canterbury/Chatham.

*McGill P, Tennyson A, Cooper V (2006) Parents whose children with learning disabilities and challenging behaviour attend 52-week residential schools: Their perceptions of services received and expectations of the future, *British Journal of Social Work*, 36, 4, 597–616.

Mitchell G, Hastings RP (1998) Learning disability care staff's emotional reactions to aggressive challenging behaviours: development of a measurement tool, *British Journal of Clinical Psychology*, 37, 441–449.

*Morris J, Abbott D, Ward L (2002) Residential school placements and disabled children: the contrasting views of local education authorities and of parents, *Journal of Research in Special Educational Needs*, 2.

*Morris J, Abbott D, Ward L (2003) Disabled children and residential schools: the implications for local education professionals, *British Journal of Special Education*, 30, 2, 70–75.

Murphy G, Beadle-Brown J, Wing L, Gould J, Shah A, Holmes N (2005). Chronicity of challenging behaviours in people with severe intellectual disabilities and or autism: A total population sample, *Journal of Autism and Developmental Disorders,* 35, 4, 405–418.

Mulligan B, John M, Coombes R, Singh R (2014) Developing outcome measures for a Family Intensive Support Service for Children presenting with challenging behaviours, *British Journal of Learning Disabilities*, published online.

National Development Group for the Mentally Handicapped (1977) *Mentally Handicapped Children: A Plan for Action*, HMSO, London.

Naylor A, Prescott P (2004) Invisible children? The need for support groups for siblings of disabled children, *British Journal of Special Education*, 31, 4, 199–206.

Pace R, Pluye P, Bartlett G, Macaulay AC, Salsberg J, Jagosh J, Seller R (2012) Testing the reliability and efficiency of the pilot Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review, *International Journal of Nursing Studies,* 49, 1, 47–53.

Park J, Hoffman L, Marquis J, Turnbull AP, Poston D, Mannan H, Wang M, Nelson L (2003) Toward assessing family outcomes of service delivery: Validation of a family quality of life survey, *Journal of Intellectual Disability Research*, 47, 4/5, 367–384.

Perry J, Allen DG, Pimm C, Meek A, Lowe K, Groves S, Cohen D, Felce D (2013) Adults with intellectual disabilities and challenging behaviour: the costs and outcomes of in- and out-of-area placements, *Journal of Intellectual Disability Research*, 57, 2, 139–152.

*Pilling N, McGill P, Cooper V (2007) Characteristics and experiences of children and young people with severe intellectual disabilities and challenging behaviour attending 52-week residential special schools, *Journal of Intellectual Disability Research*, 51, 3, 184–196.

Pinney A (2014) *Children with Learning Disabilities whose Behaviour Challenges: What Do We Know from National Data?* [Data Supplement]. Retrieved from www.challengingbehaviour.org.uk/cbf-articles/latest-news/eip-briefing-paper-published.html

Pluye P, Robert E, Cargo M, Bartlett G, O'Cathain A, Griffiths F, Boardman F, Gagnon MP, Rousseau MC (2011) *Proposal: A Mixed Methods Appraisal Tool for Systematic Mixed Studies Reviews.* Retrieved from http://mixedmethodsappraisaltoolpublic.pbworks.com/w/page/24607821/FrontPage

Reid C, Scholl C, Gore NJ (2013) Seeking to prevent residential care for young people with intellectual disabilities and challenging behaviour: Examples and early outcomes from the Ealing ITSBS, *Tizard Learning Disability Review*, 18, 4, 171–178.

*Robertson J, Emerson E, Fowler S, Letchford S, Mason H, Mason L, Jones M (1996) Residential special education for children with severely challenging behaviours: The views of parents, *British Journal of Special Education*, 23, 2, 80–88.

Rutter M (2007) Incidence of autism spectrum disorders: Changes over time and their meaning, *Acta Paediatrica*, 94, 2–15. doi: 10.1111/j.1651-2227.2005.tb01779.x

Shaffer D, Gould MS, Brasic J, Ambrosini P, Fisher P, Bird H, Aluwahlia S (1983) A children's global assessment scale (CGAS), *Archives of General Psychiatry,* 40, 1228–1231.

*Smart M (2004) Transition planning and the needs of young people and their carers: the alumni project, *British Journal of Special Education*, 31, 3, 128–137.

*Smith K, Powlitch S, Little D, Furniss F (2007) Social ecology of a residential special school for young people with challenging behaviours: A preliminary report, *Journal of Applied Research in Intellectual Disabilities,* 20, 2, 99–104.

Sparrow SS, Balla DA, Cicchetti DV (1984) *Vineland Adaptive Behavior Scales*, American Guidance Services, Minneapolis, MN.

Sundberg ML (2008) *Verbal Behavior Milestones Assessment and Placement Program: The VB-MAPP*, AVB Press, Concord, CA.

Totsika V, Toogood S, Hastings RP, Lewis S (2008) Persistence of challenging behaviour in adults with intellectual disability over a period of 11 years, *Journal of Intellectual Disability Research*, 52, 5, 446–457.

Totsika V, Hastings RP, Emerson E, Berridge DM, Lancaster GA (2011a) Behavior problems at 5 years of age and maternal mental health in autism and intellectual disability, *Journal of Abnormal Child Psychology*, 39, 8, 1137–1147.

Totsika V, Hastings RP, Emerson E, Lancaster GA, Berridge DM (2011b) A population-based investigation of behavioural and emotional problems and maternal mental health: Association with autism spectrum disorder and intellectual disability, *Journal of Child Psychology and Psychiatry*, 52, 91–99.

Welsh Assembly Government (2002) *Special Educational Needs Code of Practice for Wales,* Retrieved from http://learning.wales.gov.uk/docs/learningwales/publications/131016-sen-code-of-practice-for-wales-en.pdf

World Health Organisation (2010) *Better Health, Better Lives: Children and Young People with Intellectual Disabilities and their Families*, World Health Organisation, Copenhagen, Denmark.

* = articles included in the review

School for Social Care Research

Phase I (2009-2014) of the NIHR School for Social Care Research (SSCR) was a partnership between the London School of Economics and Political Science, King's College London and the Universities of Kent, Manchester and York. Phase II (2014-2019) of SSCR is a partnership between the London School of Economics and Political Science and the Universities of Bristol, Kent, Manchester and York, and is part of the National Institute for Health Research (NIHR) www.nihr.ac.uk/.

NIHR School for Social Care Research
London School of Economics and Political Science
Houghton Street
London
WC2A 2AE

020 7955 6238
www.sscr.nihr.ac.uk
sscr@lse.ac.uk