

Managing behaviour and sleep problems in disabled children: An investigation into the effectiveness and costs of parent-training interventions

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The views expressed in this report are the authors' and do not necessarily reflect those of the Department for Education.

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Chapter 1

Introduction

Background

The research reported here is the second, and larger, element of a project on behavioural interventions for parents of disabled children regarding their child's sleep or day-time behaviour.

The first element of this project comprised two rapid, systematic reviews of the evidence on the effectiveness of behavioural interventions to help parents of disabled children manage their child's sleep or day-time behaviour problems (McDaid and Sloper, 2008; Beresford, 2009). The reports of these two reviews can be found in Appendix A. Both reviews concluded that there was evidence to suggest that parent-training interventions based on behaviour theory and behaviour modification principles may, for at least some parents of disabled children, be effective.

The conclusions drawn regarding the state of existing evidence by these two reports are also similar: the current evidence base is weak, and particularly compared to the very substantial evidence-base regarding the parenting interventions for parents of non-disabled children. In particular, there is a lack of studies with a control or comparison group, and which have sought to measure longer-term intervention effects. The report also called for studies to test the clinical, as well as statistical, significance of their findings. Finally, they note the absence of qualitative evidence on parents' experiences of receiving such interventions.

The second element of this project, and the focus of this report, was informed by the findings of these reviews. The following aims were identified for this second element:

- To evaluate the effectiveness of four different parent-training interventions for parents of disabled children with sleep problems.
- To evaluate the effectiveness of four different parent-training interventions for parents of disabled children (learning difficulties and/or autistic spectrum disorders) with behaviour problems.
- To identify the costs of these interventions and explore their cost effectiveness.
- To explore the factors which hinder or support the effectiveness of these interventions.
- To describe parents' experiences of receiving these interventions.
- To describe professionals' experiences of delivering these interventions.

Why study parent-training interventions for parents of disabled children?

Disabled children, and particularly those with learning disabilities and/or autistic spectrum conditions (ASC), are more likely to have problems with their sleep or behaviour than non-disabled children.

Sleep problems are common among all children but more common among disabled children (Bartlett *et al.*, 1985; Richdale and Prior, 1995; Quine, 2001). For these children sleep problems appear to be very persistent, and are not likely to disappear without intervention (Wiggs and Stores, 1996; Lancioni *et al.*, 1999). Figures for children with severe learning disability are particularly high. Bartlett *et al.* reported problems in over 80 per cent of children aged up to 11 years and 77 per cent of 12 to 16 years, and Richdale and Prior (1995) reported prevalence of 34-80 per cent in children with autistic spectrum conditions. A number of reasons have been suggested for the high prevalence of sleep problems in disabled children. Physical and medical conditions associated with disability may affect

sleep (Heaton *et al.*, 2006). Problems in learning may hinder the establishment of appropriate routines for settling and staying asleep, and parents may also have low expectations of the child's ability to learn such routines (Wiggs and Stores, 2004). Sleep problems can have a number of effects on the child and family. For parents, they are associated with high levels of stress and irritability (Quine, 1991) and, it is thought, increase parents' needs for other services such as short breaks. For children, they are associated with poor concentration and increased probability of daytime behaviour problems (Wiggs and Stores, 1996a; Lancioni, 1999). However, only a minority of families who have a disabled child with a severe sleep problem appear to receive help in dealing with the problem (Wiggs and Stores, 1996(b)).

Behaviour problems are also more common among disabled children than among their non-disabled peers, with studies finding rates of behaviour problems to be three to four times higher compared to non-disabled peers (for example, Baker *et al.*, 2002; Volmar and Dykens, 2002; Baker *et al.*, 2003; Emerson, 2003a;). Such behaviours can be difficult to manage, anti-social, distressing, and/or interfere with family routines and activities. These problems also typically continue to persist into later childhood and adolescence (Emerson, 2003a) and, as the child increases in size, strength and speed, become more severe. Behaviour problems can threaten children's safety and well-being, and can interfere with, or prevent, their participation in school, community and social activities. Severe behaviour problems are also one of the main reasons why disabled children and young people are placed in residential schools (Abbott *et al.*, 2000), and can also act as a barrier to accessing services such as short breaks (Kahng and DeLeon, 2008). For families, behaviour problems are associated with increased levels of stress among mothers and parental mental health difficulties (Frombonne *et al.*, 2001; Hastings, 2002; Emerson, 2003b; Glidden and Schoolcraft, 2003; Hastings, 2003; Bitsika and Sharpley, 2004; Herring *et al.*, 2006; Whitaker and Read, 2006). Sibling relationships can suffer long-term negative consequences (Rossiter and Sharp, 2001). Over the years a number of studies found parents reporting high levels of unmet need for skills to manage their child's behaviour (Quine and Pahl, 1989; Beresford, 1995; Chamba *et al.*, 1999; Baker *et al.*, 2003; Bromley *et al.*, 2004).

However, it is also clear that the relationship between behaviour problems and the risk of poor outcomes for children, parents and other family members is moderated by a number of factors (Blacher *et al.*, 2005; Plant and Sanders, 2007; Neece and Baker, 2008;). Current evidence suggests that access to early/preventive interventions which help parents better manage the behaviours they find difficult or problematic may be an important factor here. There is no evidence to suggest that the argument for early/preventive interventions for daytime behaviour problems does not equally apply to 'night-time' behaviour, or sleep, problems.

Behavioural approaches to managing behaviour problems

Behavioural theory and principles of behaviour modification have been used to inform and determine interventions to address problem behaviours (daytime and night-time). The approach involves identifying what provokes or causes the behaviour and current parental (or other parties') responses to the behaviour. This information is then used to develop a behaviour management strategy which seeks to change or modify factors precipitating the behaviour and responses to that behaviour.

The history of using behavioural approaches to manage problem behaviours

Until the 1960's, the management of problem behaviours in children was seen as the preserve of professionals and there was no or very little parental involvement in the delivery of an intervention. Two significant changes in thinking occurred in the late 1960s and early 1970s and resulted in a different approach being adopted (Wyatt Kaminski *et al.*, 2008). First, Bandura's work (for example, Bandura, 1969) revealed the significant role parents'

play in shaping their child's behaviours. Second, clinicians realised that parents could be trained to deliver behavioural interventions.

Since then, behavioural interventions which have involved parents in the delivery have been shown to be highly effective in a range of child behaviour problems among non-disabled children (for example, Campbell, 1995; Taylor, 1998; Barlow, 2000). Indeed, in light of this growing body of evidence, parent-training programmes have been incorporated in governments' family support strategies in this and other countries across the world (for example, Lindsay *et al.*, 2008).

In 2008, the then Department for Children, Schools and Families (DCSF) established the Parenting Early Intervention Programme (PEIP) in which well-established, evidence-based parenting programmes were delivered across all local authorities in England. An evaluation of the programme ran alongside and found that such interventions can have a positive impact on at least some parents and their children (see Lindsay *et al.*, 2011).

However, all these programmes were developed for use with normally developing children, and existing research suggests that these are not necessarily appropriate, nor may not be as effective, for parents of disabled children. Practitioners report modifying and adapting their content to respond to the particular needs of parents of disabled children (for example, McIntyre *et al.*, 2008; Lindsay *et al.*, 2011; see also Chapter 5 of this report). Some generic interventions have responded to this issue and developed disability-specific programmes (for example, Stepping Stones Triple P (Sanders, 2004)).

Parent-training programmes for parents of disabled children

The evidence presented above makes a clear case for the need to ensure parents of disabled children – particularly those with learning disabilities and/or autistic spectrum conditions – receive support to help them better manage their child's day- or night-time behaviour problems. Indeed, preventive or early interventions have the potential to prevent behaviours becoming more challenging and more entrenched, the management of which inevitably places higher demands on statutory services as well as compromising child and family outcomes. Given the paucity and weakness of the existing evidence base reported at the beginning of this chapter, there is a strong argument for the need for further robust research on the effectiveness of parent-training programmes which have been developed specifically for parents of disabled children.

The structure of the report

Chapter 2 provides an overview of the research design and methods. The interventions which were subject to investigation in this study are detailed in Chapters 3 (behaviour interventions) and 4 (sleep interventions). In Chapter 5 we move on to report the practitioners' experiences of developing and delivering the interventions studied, including their views on issues around take-up and engagement. This is complimented in Chapter 6 by a report of parents' experiences of views on the factors which affect take-up and engagement with parent-training interventions or programmes.¹ Chapters 7 to 10 report the findings from the quantitative data on the effectiveness of the behaviour-focused programmes. We follow these chapters with a report of parents' views of the outcomes they have achieved through participation in one of these programmes (Chapter 11), and the factors which hinder or support the achievement of these outcomes (Chapter 12). We then move on to looking at the sleep interventions. Chapter 13 describes the factors which parents say they take into account when considering accessing a sleep intervention, it also reports parents' experiences of receiving that intervention. Chapters 14 to 16 report the evidence from the quantitative data on the effectiveness of the sleep programmes included in this study. These are followed by a chapter describing parents' views on the factors which

¹ We use these terms interchangeably throughout this report.

impact on the effectiveness of sleep interventions (Chapter 17). The following chapter (Chapter 18) is concerned with both behaviour and sleep interventions and, specifically, practitioners' views on the factors which mediate or moderate the effectiveness of parent-training programmes. Chapter 19 presents a discussion of the key findings from this study and considers its implications. Study limitations and suggested future research conclude the report.

At the outset we would stress that comparison of findings between the behaviour or sleep interventions should not be undertaken. The demographics of the samples across the interventions differ on key variables (see Appendix O) which are likely to affect the impact of a parent-training interventions on child day-time or sleep behaviour and/or parents' sense of competence including: child's age, the nature of the child's disability; severity of disability, parental level of education. In addition, there are sometimes differences of emphasis between interventions as to the main outcomes or primary purpose (for example, the two ASC-specific interventions devoted different proportions of time to supporting parents to better understand autism). Further research, using a randomised controlled design, is required to explore the relative effectiveness of interventions.

Appendices and annex

A number of separate volumes accompany this report. Appendix A contains the two rapid systematic reviews which were the first element of this study. Appendices B to S are presented in a separate volume. Finally, exemplars of all the research materials can be found in Annex A.

Chapter 2

An Overview of the Study Design and Research Methods

2.1 Introduction

This study can be usefully conceived as a suite of investigations into the effectiveness of interventions currently being delivered by health, education and voluntary sector services to help parents better manage their disabled child's behaviour or sleep problem. These interventions were selected as representing best practice, as it was currently understood at the outset of the study. A key criterion of best practice was that behaviour theory and behavioural approaches to managing problem behaviours were a fundamental element of the design and delivery of the intervention.

Principles of realistic evaluation (Pawson and Tilley, 1997) underpinned the study design. Thus effectiveness was investigated using traditional, psychometric outcome measures, parent-identified goals, and parents own reports. Interviews with parents and practitioners were used to understand the processes underlying the outcomes parents' experienced and the facilitators and barriers to achieve positive outcomes. The practitioner interviews also explored their experiences of developing and delivering the interventions.

2.2 Identifying the programmes or interventions

The interventions were selected following a national, voluntary, mapping exercise in which practitioners working in health, education and voluntary sector services were invited to report the interventions they were delivering to manage behaviour or sleep problems in disabled children, including any 'manualised'² parent-training interventions being delivered to parents of disabled children who needed support to better manage their child's sleep or behaviour problems (see Appendix B). One hundred and twenty-one services completed the mapping questionnaire (65 behaviour interventions; 56 sleep interventions). Pre-determined inclusion criteria were used to develop 'long-lists' of services which could, potentially, be invited to take part in the study.

Twenty behaviour and sleep interventions achieved this long-list. Detailed information about each of these interventions was then collected via telephone and email contact. A short-listing process then ensued using the following criteria: intervention embedded in routine practice; behavioural theory a key element; projected potential sample size; comparator group opportunities; representation of generic disability; and ASC-specific interventions. Final selection of the interventions was carried out in consultation with the project's research advisory group.

Ten parent-training programmes³ were selected for inclusion in the study (five behaviour interventions and five sleep interventions). However, at an early stage a behaviour intervention was removed as it emerged practitioners would not have the capacity to deliver the intervention a sufficient number of times to achieve the required sample size. A sleep intervention was removed from the study somewhat further into the project when difficulties with long-term staff sickness meant that delivery of the intervention had been curtailed and,

² By this we mean the intervention had a set procedure of delivery. This was either set out in an 'intervention manual', or intervention adherence was monitored using a checklist completed by the practitioner.

³ We use the term intervention and programme interchangeably throughout this report.

thus, recruitment to the study dwindled. Thus, in the end, four behaviour interventions and four sleep interventions were investigated.

The interventions selected to the study

A brief description of each of the behaviour and sleep interventions selected to the study is provided in Figure 2.1. Further details of each intervention are provided in Chapters 3 (behaviour) and 4 (sleep). Additional details about the content of each programme are provided in Appendix C.

Figure 2.1 The interventions

The behaviour parent-training programmes	
Programme A	An 11 week group-delivered programme for parents of children with autistic spectrum conditions (ASC). Seeks to improve parents' understanding of ASC and parents' abilities to manage behaviour and support the child's development
Programme B	A 6 week group-delivered programme for parents of disabled children. Seeks to empower parents to confidently manage their child.
Programme C	A 6 week group-delivered programme for parents of children with ASC. Seeks to increase parental understanding of ASCs and parent's abilities to understand and manage difficult behaviour. Also seeks to signpost parents to relevant local ASC resources, and to meet with other local parents/carers.
Programme D	A 10 week group-delivered programme for parents of children with ASC and other disabilities. Seeks to enable parents to understand and manage their child's behaviour in the context of additional needs, and to encourage parental confidence and emotional well-being.
The sleep parent-training programmes	
Programme E	An individually delivered intervention, typically lasting 6-8 weeks, involving an initial assessment, development of a sleep strategy and support to parents as they implement the strategy using (weekly) home visits or phone calls.
Programme F	An individually delivered intervention, typically lasting 12-14 weeks, involving an initial assessment, development of a sleep strategy and support to parents as they implement the strategy using (fortnightly) clinic appointments, home visits and phone calls.
Programme G	A 4 session (over 5 weeks) group-delivered programme. Seeks to help parents better manage their child's sleep difficulties.
Programme H	A one-day workshop for parents with disabled children. Seeks to support families of children with sleep difficulties through raising awareness of good sleep practice and basic strategies to support parents in establishing new routines.

2.3 The study design

The preferred design of the evaluations

The aim was, for each intervention, to use a controlled trial design to investigate the effectiveness of a behaviour- or sleep-focused parenting training programme in terms of child and parent outcomes. Comparator groups were to be either a waiting list/declined intervention control group or different modes of delivering the intervention. Practitioner-completed checklists would to be used to record and measure intervention integrity for group-delivered interventions (see Appendix D for an exemplar).

Child outcomes (presence and severity of sleep or behaviour problems), parent outcomes (parenting self-competence), and progress towards parent-set behaviour or sleep goals were to be measured pre-intervention, post-intervention and at one or more follow-up intervals (12 week (3 months), 24 week (6 months)). Power calculations suggested a minimum sample size of at least 50 (i.e. 25 in both intervention and comparator groups) was required.

Parents' experiences of receiving the intervention, and their experiences of implementing and generalising newly learnt skills and strategies were to be explored through interviews with subsamples of parents receiving each intervention.

Practitioners delivering the interventions were to be interviewed regarding their experiences of delivering the intervention, its perceived effectiveness, strengths and weaknesses. Programme authors would, in addition, be asked about the rationale and development of the intervention.

An economic component would estimate the costs of the each of the interventions (to services and families), and then combine costs and outcome data to ascertain the relative cost-effectiveness of the interventions

The final designs of the quantitative outcomes element of the evaluations

The final design of each evaluation is set out in Figure 2.2. Deviations from the 'gold standard' design are described. The areas of deviation were: the lack of a comparator group; sample size; the time at which parent-set goals were set; and baseline ratings collected. For the comparator groups, data was not collected at the 24 week follow-up time point. 24 week follow-up data collection was not possible for the intervention groups for Programmes E and F. All other elements of the investigations were achieved as planned. However, the extent of the costs work was governed by the sample size and the presence (or not) of comparator groups.

Figure 2.2 The evaluations

	COMPARATOR GROUP	SAMPLE SIZE (PRE-INTERVENTION)	BASELINE TIME POINT FOR PARENT-SET GOALS	
Behaviour parent-training programmes				
Programme A	Waiting list control	41	21	Week 7/11 of the intervention
Programme B	No intervention convenience community sample	20	20	Week 1/6 <u>or</u> 3/6 of the intervention
Programme C	Waiting list control	35	33	Week 5/6 of the intervention
Programme D	Waiting list control (pre- and post-intervention time points only ⁴)	48	28	Week 1 of intervention
Sleep parent-training programmes				
Programme E	Treatment arms: home visit vs. 'phone support	Home visit=6 'Phone support=7		Pre-intervention
Programme F	No comparator group	12		Pre-intervention
Programme G	No comparator group	23		Week 1 of intervention
Programme H	No comparator group	26		Pre-intervention

As noted earlier, this programme of work consisted of a suite of investigations conducted on services currently being delivered across a number of health, education and voluntary sector settings. These interventions were selected as examples of what, on the basis of existing evidence, is regarded as 'best practice'. The conduct of non-clinical effectiveness research in 'real-life' settings almost inevitably involves compromises in the proposed research design. It is important to bear in mind that, despite clear limitations in some of these investigations, each has generated new evidence which make an important contribution to what, as has already been noted, is a very limited evidence base. Throughout, the research team has been careful and conservative in the statistical analyses conducted and in the presentation of the findings (see Appendix E).

The specific issues encountered with an investigation are listed below:

- Programme B: take-up of the intervention lower than anticipated by practitioners delivering the intervention.
- Programme E: intervention suspended on two occasions during the study period due to long-term staff sickness, this impacted on achieved sample size.
- Programme F: no waiting list operated and staff unable/unwilling to create one for the purposes of the study; forecasted rates of referral provided to the research team incorrect; difficulties engaging some sleep practitioners to the study affected recruitment.

⁴ Waiting list control parents moved on to intervention by 12 week follow-up time point.

- Programme G: staff capacity issues restricted the number of times the programme was run and hence sample size; no waiting list operated and staff unable/unwilling to create one for the purposes of the study.
- Programme H: planned comparator group⁵ left the study at an early stage; not possible to replace with another comparator group.

Limitations of the quantitative element

Two key issues need to be highlighted: study design and sample size. First, for three of the four sleep interventions it was only possible to adopt a ‘before and after’ study design. This is a weaker design than a controlled trial because it does not allow the researcher to separate changes or improvements in child or parent outcomes which have occurred as a result of the intervention from those which may have occurred ‘naturally’, or without any intervention.

Second, *a priori* ‘power’ calculations indicated that the desired sample size for each evaluation was at least 50 (or, n=25 in the intervention and comparator groups, or each trial arm). This size of sample was required in order to be sure that the effects of the intervention on outcomes would be detected. Where the target sample size was not achieved, it is not possible to attribute whether a non-significant finding is the result of a small/negligible effect of the intervention or insufficient power. In addition, it should be noted that lower response rates at the follow-up time points means that the desired sample size was not always achieved at each time point.

Thus, across this suite of investigations there is a range in the strength of the findings. Findings from before and after studies and/or those with small sample sizes need to be interpreted with caution. Across the whole project, the most robust data, and where we can be most confident with the conclusions drawn, was achieved for the evaluations of three of the behaviour support interventions (A, C and D). All the evaluations of the sleep interventions should be regarded as exploratory in nature. At the same time, it is important to note that the findings across all these studies, drawing on both the quantitative and qualitative datasets, are consistent in terms of indicating a positive impact for sleep parent-training programmes.

2.4 Measures and other data collection methods

The outcome measures

Quantitative data on child and parent outcomes were collected using parent report measures of:

- Child outcomes
 - Child behaviour: the Eyberg Child Behaviour Inventory; the Child’s Challenging Behaviour Scale
 - OR: Sleep: the Children’s Sleep Habits Questionnaire
 - Parent-set behaviour or sleep goals
- Parent outcomes: the Parenting Sense of Competence Scale.

Detailed information about the measures is provided in Appendix F.

⁵ An individually delivered sleep management intervention provided by the same service.

Overview of the child outcome measures

The Eyberg Child Behaviour Inventory (ECBI) (Eyberg and Ross, 1978) measures both the frequency of behaviours (the Intensity Scale, ECBI-IS) and whether or not parents perceive the behaviours as a problem (the Problem Scale, ECBI-PS).

The Child's Challenging Behaviour Scale (Bourke-Taylor *et al.*, 2009) is a newly developed 11-item parent rating scale. It was designed to assess a mother's observation of home based behaviours of their disabled child that were difficult to manage. It is entirely derived from parents' accounts of the behaviours they find difficult to manage in the home. It generates a single score.

The Children's Sleep Habits Questionnaire (CSHQ) (Owens *et al.*, 2000) assesses the severity of sleep problems in children aged 4-10 years. Parents are asked to respond about the child's sleep over a 'typical' recent week. Scores are combined to calculate a Total Sleep Disturbance Score. Items can also be grouped into eight domains for further analysis: bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night wakings, parasomnias, sleep disordered breathing, daytime sleepiness and scores for each of these calculated.

Parent-set behaviour or sleep goals

Monitoring the extent to which an intervention achieves the specific outcomes desired by parents was an important part of the evaluation. A simple method of recording outcomes for individually set goals was used and is similar to the method used by Quinn *et al.* (2007) in their evaluation of a parent-training intervention for parents of children with learning disabilities. It was emphasised that the goals parents set needed to be realistic within the time period observed, be precise and measurable (as recommended by Becker *et al.*, 2000). A 10 point scale was used to indicate goal attainment (1=very far from this goal; 10=I have achieved this goal).

Overview of the parent outcome measure

The Parenting Sense of Competence Scale (PSOC) (Gibaud-Wallston and Wandersman, 1978; Johnson and Mash, 1989) is a 16 item scale with two subscales. Parents are asked to respond to a series of questions about parenting, indicating their level of agreement or disagreement on a 6-point Likert scale. The Satisfaction Subscale (PSOC-Satisfaction) measures the extent to which parents are satisfied with their role as a parent, thus it captures the affective dimension of parenting competence including the extent of parental frustration, anxiety and motivation. The Efficacy sub-scale (PSOC-Efficacy) measures the extent to which parents feel they are managing the role of being a parent, thus capturing competence, problem solving ability and capability in the parenting role (Plant and Sanders, 2007).

The costs element

The following descriptive information was collected from each service: numbers, professional qualifications and grades of staff involved in delivering the intervention; time and other resource costs associated with delivering the intervention. Practitioners recorded parents' attendance at sessions. (See Appendix G for a sample costs data collection sheet.)

Parents completed a short version of the Client Service Receipt Inventory (CSRI) (Beecham and Knapp, 2001) (see Appendix H). This collected data on the services and supports used by their child and the impact of the child's disorder on parents' service use and employment patterns. The plan of analysis for the costs data is set out in Appendix I.

Interviews with practitioners

Practitioners involved in developing and/or delivering the intervention were interviewed on one occasion. The interview explored their experiences of delivering the intervention, its perceived effectiveness, strengths and weaknesses, and factors perceived to impact on its effectiveness. With participants' permission, the interviews were audio-recorded. A copy of the interview topic guide can be found in Appendix J. A total of 39 practitioners were interviewed (behaviour interventions n=24; sleep interventions n=15). Further details of this element of the study and details of the sample are provided in Appendix K.

Interviews with parents

Across all the behaviour and sleep interventions a purposive sampling frame was used to select parents for interview in order that parents from the different interventions and varying levels of progress in achieving parent-set goals were represented. In addition, we sampled to ensure fathers, parents with English as a second language, working parents, level of school-leaving qualification, type of disability and whether or not the intervention had been received by both or one parent were represented. A total of 103 parents were interviewed (65 parents had received a behaviour intervention; 38 parents had received a sleep intervention). Further details on the sample and the execution of this phase of the project can be found in Appendix L.

The interviews with the parents explored: deciding to accept the invitation to accept the intervention; accessibility and acceptability of the intervention; and experiences of implementing, generalising and maintaining behaviour management strategies, including factors which support or impede these processes. With participants' permission, the interviews were audio-recorded. Face-to-face, telephone and focus group interviews were used. Exemplars of the topic guides we used can be found in Appendix M.

Recruitment of parents to the study

Intervention groups

Initial contact with parents about the study came from the services delivering the interventions. Individualised recruitment strategies were developed with each service.

The core strategy was that project information sheets and letters of invitation to participate in the research were sent out by the services in advance of the intervention. Parents were treated as being recruited to the study if they completed the research instrument pre-intervention. Administration of the pre-intervention research instrument took place at the start of, or immediately before, the intervention commenced. Practitioners and/or the research team carried this out. The research team assumed full responsibility for administering the research instrument at subsequent time points.

In order to maintain high levels of retention to the research, a small incentive was used comprising a £10 high street shopping voucher. This was sent to parents on receipt of a completed questionnaire at post-intervention, 12 week and 24 week follow-up time points. Reminder letters and phone calls were used to support a high response rate.

Comparator groups

The no-intervention comparator groups were almost all recruited from waiting lists. Here a similar process to recruitment to the intervention group was used, though administration of the pre-intervention time point questionnaire was always done postally. The comparator group for programme B was a convenience sample drawn from a local primary special school. Here the school mailed out a recruitment pack (letter of invitation, project information sheet, research instrument, reply paid envelope) to parents. Incentives were also used with the comparator groups.

Parents could request support with completing the research instrument. The research team was available to support parents over the phone as they completed it. Where requested, an interpreting service was used to assist parents. In these instances, the research team booked an interpreting service to arrange a home visit.

Copies of examples of all research materials can be found in Annexe A. Research recruitment and retention rates are reported in the chapters detailing the quantitative analyses (Chapters 7-10; Chapters 15-17). Details of samples recruited for each of the programmes under investigation are reported in Appendices N (behaviour interventions) and O (sleep interventions).

Chapter 3

Description of the Behaviour Management Interventions

3.1 Introduction

This chapter presents a brief overview of the behaviour management programmes which were investigated in the research study.

We provide a description of each programme, and then, using the data collected over the course of the study period, report on how the programmes were accessed, take-up, and parent demographics.

3.2 The group-based parent-training programmes

Tables 3.1, 3.2, 3.3 and 3.4 provide an overview of the four behaviour-management parenting programmes that took part in the study. General intervention details are provided in Appendix P. For details of the programme contents, see Appendix C.

Table 3.1 Overview of programme A: ASCEND

PROGRAMME A: ASCEND (Autistic Spectrum Conditions – Enhancing Nurture and Development)	
Aims	To increase understanding of children with ASC, to empower parents to address specific behaviours and to support their child's behavioural development.
Mode of delivery	Group (up to 20 participants per programme).
Venue	No specific requirements. In this investigation CAMHS facilities were being used.
Disability	Autism Spectrum Conditions (ASCs). Separate groups for Autism and Asperger's with appropriate adaptations.
Age range	From pre-school to 19 years.
The programme	11-weekly 2 ½-hour sessions.
Structure and approach	Manual sets out session structures and content, also contains handouts and other teaching materials. Training approach includes: recap of themes introduced in previous week; introduction of new topic with demonstrations and case examples; group exercises to reinforce key messages of week's theme; group discussion drawing on parents' experiences of topic.
Homework	Handouts from sessions provided. Optional homework exercises used to reinforce learning.
Participants	Open to parents, grandparents and professionals. Courses can be run for both small and large groups of participants but the course is most successful when run for the parents of around eight to ten children, which usually translates to around 12-15 people.
Facilitators	Qualified therapists, including child psychiatrists, clinical psychologists, community psychiatric nurses, or any other therapist with experience of working with families of children with ASCs. The number of facilitators per session depends upon the group size. For a group size of up to 10, two facilitators are recommended, and for more than 10, three to four are recommended. The sessions exploring individual problems and strategies work best with one individual facilitator per child represented but if this is not possible parents can share a facilitator when discussing a similar behaviour issue. Any additional facilitators will also need a good understanding of behavioural techniques and ASCs.
Follow-up	Ad hoc follow-up workshops/informal social reunion meeting may be arranged. Attendance at the programme may result in referral within the CAMHS team for individual work.

Table 3.2 Overview of programme B: Confident Parenting

PROGRAMME B: Confident Parenting	
Aims	To empower parents to confidently manage their child.
Mode of delivery	Group.
Venue	No specific requirements. In this investigation the programme was being delivered at local special schools.
Disability	Any. In this investigation a range of learning and complex disabilities were represented as well as children with autism spectrum disorders.
Age range	Children aged between 3-11 years.
The programme	6-weekly 2-hour sessions.
Structure and approach	No prescribed format. A facilitator's handbook sets out the approach and core elements which should be addressed during the programme. Training approach includes the use of video footage of parent/child and teacher/child interaction to provide feedback, modelling and generate discussion. Rating scales of child's behaviour and parent's sense of control. The specific focus of each session is driven by the needs and experiences of the group. One or two additional 'parent pampering' session(s) (for example, relaxation techniques, aromatherapy) may be delivered at the end of course.
Handouts and homework	Handouts including 'top tips' and a summary of themes discussed each week and advice given. Homework tasks are not assigned though parents are encouraged to think about, and report back on, one area each week where they are going to try and make a change.
Participants	Generally, it is difficult to manage a group of more than eight families or 12 participants. Parents, other family members (grandparents, aunts, uncles) and friends of the family (childminders, foster parents) can attend.
Facilitators	In this investigation three facilitators drawn from education and clinical psychology (community based learning disability health service) were involved.
Follow-up	No routine follow-up session is delivered. However, in the site where this research was located, parents are welcome to attend the programme again.

Table 3.3 Overview of programme C: Cygnet

PROGRAMME C: Cygnet	
Aims	To increase understanding of ASCs and what is behind behaviours, to provide strategies to manage difficult behaviours, to signpost to relevant local ASC resources, and to meet with other local parent/carers.
Mode of delivery	Group
Venue	No specific requirements. In this investigation the programme was being delivered in CAMHS and voluntary sector community facilities.
Disability	Autistic Spectrum Conditions.
Age range	Children aged 7 to 18 years.
The programme	6-weekly 2½-hour sessions.
Structure and approach	Manual sets out session structures and content. It also contains handouts and other teaching materials. Training approach includes a formal teaching element, supported by PDF slides/video-clips, small and whole group exercises and discussions.
Homework and handouts	Parents are given copies of the teaching materials used during each session. At the end of each session parents are encouraged to carry out an activity or task before the next session which is designed to embed the learning achieved. This 'homework' is reviewed at beginning of the following session.
Participants	It is recommended that there are no more than 12 parents/carers attending a group. Open to both parents, grandparents and professionals working with the child. Particularly targets hard-to-reach groups, e.g. South Asian parents, fathers, and parents/carers who find groups difficult.
Facilitators	Two to three facilitators working in field of autism drawn from range of professional groups including clinical psychology, education and the voluntary sector and parents.
Follow-up	Parents are invited to an informal social reunion three months after completing the programme.

Table 3.4 Overview of programme D: Riding the Rapids

PROGRAMME D: Riding the Rapids	
Aims	To enable parents to understand and manage their child's behaviour in the context of additional needs, using functional analysis, communication and behavioural approaches. To encourage parental confidence and emotional well-being.
Mode of delivery	Group.
Venue	Manual advises the use of community-based facilities for example, local schools, children's centres.
Disability	Any. In this investigation children with ASC severe learning disabilities and physical impairments were represented.
Age range	Children aged 4 – 10 years.
The programme	10-weekly 2-hour sessions.
Structure and approach	Manual sets out session structures and content. Also contains handouts and other teaching materials. Training approach incorporates weekly ratings of child's behaviour and parental coping; some formal teaching, modelling; problem-solving exercises; and extensive role play to support parents' learning. Parents' own 'self-care' is emphasised and small 'gifts' are used to encourage parents to look after themselves.
Handouts and homework	Parents receive handouts at each session. Parents are encouraged to complete homework tasks between sessions to reinforce learning.
Participants	Up to 12 adults can be accommodated in a group. Open to both parents. Particularly encourages attendance from parents from low SES backgrounds and BME groups.
Facilitators	A clinical psychologist leads the group. Co facilitators include nurses from the Disabled Children's Team or teaching staff, with input in some sessions from speech and language therapists. A co-facilitator in one of the groups is also a parent of a disabled child.
Follow-up	Parents are invited to an informal social reunion three months after completing the programme.

Both single research sites and multiple research sites were used in the investigation, see Table 3.5.

Table 3.5 Research sites in each programme

Programme	Number of research sites ¹	Original authors/programme developers participating?
A	3	Yes
B	2	Yes
C	2	Yes
D	1	Yes

¹ A research site was an organisation delivering the programme. For example, a CAMHS Learning Disability Service, a voluntary sector organisation.

3.2 Accessing the programmes

The routes by which parents accessed the programmes varied within and between programmes.

Programme A

In two research sites, a diagnosis of an autistic spectrum condition by a multi-disciplinary team triggers a referral to the CAMHS service which delivers the programme. Clinicians involved in diagnosis discussed the course with parents soon after diagnosis, and gave them a leaflet explaining the course's aims and structure. Parents were then sent a formal letter of invitation, with course dates and additional information. In the final research site, the programme was being offered to parents on their waiting list as a 'stop gap' or as an alternative therapeutic approach when one-to-one work did not appear to be having an impact.

Programme B

All parents in the schools where this parenting programme was run were sent an invitation 'leaflet' shortly before the programme was going to be run. This was colour-printed with photographs and basic information about the course (time, location, how to join, etc). Individual parents, who had made it known to school staff that there was a behavioural difficulty at home, were targeted at the same time. Teachers contacted them directly by phone, letter or a note in the home-school diaries, encouraging them to attend. Parents at the school also found out about the parenting groups following referral to the CAMHS Learning Disability Team (LD), or whilst awaiting referral. Additionally, some parents learnt about the group at a pre-course coffee morning held at the school, or from publicity on the school website. Parents accepting the invitation are visited in advance by one of the facilitators. The primary purpose of the visit is to obtain video footage of the child and parent interacting. This is used as a teaching tool in the programme.

Programme C

In research site 1 self-referral was possible and the programme was publicised using voluntary sector mail outs. In addition, parents could be referred to the programme by health, education or social care practitioners. Many parents self-referred. After completing an enrolment form, parents were put on a waiting list, and informed in writing when the next local group was taking place.

In research site 2 most parents accessed the programme following an invitation from the CAMHS LD team following diagnosis of their child's autism. A discussion with the diagnostic team/clinician about the programme was followed up by a letter of invitation when the programme was about to be run.

Programme D

Parents accessed this programme in a number of ways. When it was being delivered in a school, all or 'targeted' parents (identified by teachers, members of the CAMHS LD team) received a letter of invitation to attend the programme. Those that 'opted in' were then invited to attend a pre-course 'interview' with a course facilitator (held either at a community venue or in the family home). At this meeting the facilitator gathered background information about the child (condition, behaviour problems, etc.), ascertained that the programme would be an appropriate intervention and, where necessary, tried to dispel concerns and anxieties and encourage the parent to attend.

In addition to school specific delivery, the programme is also delivered in community venues. Parents registered on a multi-agency database of disabled children receive regular information about the programme and can request to be put on a waiting list. These parents are then contacted when the programme next runs in their area. As above, parents who opted had a pre-course meeting with one of the facilitators.

3.3 Take-up

Table 3.6 Take-up

Programme & 'lead organisation'	Total no. parents offered programme over 12 months	No. of parents expressing an Interest	No. of parents taking up offer	Take-up rate
Programme A				
Site 1 (CAMHS)	49	n/a	29	60%
Site 2 (CAMHS)			<i>Not available</i>	
Site 3 (CAMHS)			<i>Not available</i>	
Programme B				
Site 1 (Special school)	125 ^a	18	13	10%
Site 2 (Special school)			<i>Not available</i>	
Programme C				
Site 1 (Vol. sector)		No data: primarily self-referral		
Site 2 (CAMHS)		<i>Not available</i>		
Programme D				
Site 1 (CAMHS)	317	n/a	49	18%

^a Programme offered on a rolling basis in this school so some of these parents will have already accessed the programme.

'Take-up rates' varied considerably. However, this is primarily because of differences in the routes by which parents accessed the programme. Thus, it was highest among parents who had been formally introduced to a programme (Programme A) shortly after their child's diagnosis with an autistic spectrum condition. A looser, more informal recruitment approach (for example, a generic letter received through school), used by programmes B and D will, inevitably, yield a lower take-up rate. It should also be noted that these two interventions are run on a rolling basis and so parents may well be aware that another opportunity to attend the programme will present itself. In addition, Programme B had been running in the same school for a number of years and the research team learnt that take-up had inevitably dropped over that period. That said, a take-up rate of almost one in five parents (Programme D) would suggest a high level of unmet need.

3.4 The demographics of the parents attending the programmes

We have used the data collected in the quantitative phase of the research as proxy indicators of the population accessing the behaviour management programmes. Given the high research recruitment rates, we feel these can be taken as indicators of the demographics of the populations the programmes are working with.

First, we report the number of parents who attended each programme alone or with someone else, see Table 3.7.

Table 3.7 Attendance at a programme alone or with someone else

How parent attended		Programme A <i>Daytime groups only</i> n (%)	Programme B <i>One evening group</i> n (%)	Programme C <i>Two evening groups</i> n (%)	Programme D <i>Daytime groups only</i> n (%)	All Programmes n (%)
Alone	<i>Married</i> ¹	20 (48.8)	10 (50.0)	16 (45.8)	37 (56.9)	83 (51.6)
	<i>Single</i> ²	6 (14.6)	4 (20.0)	3 (8.6)	16 (24.6)	29 (18.0)
	<i>Missing</i>	2 (4.9)	-		4 (6.2)	6 (3.7)
With child's other parent	<i>Married</i> ¹	7 (17.1)	1 (5.0)	12 (34.4)	2 (3.1)	22 (13.7)
	<i>Single</i> ²	2 (4.9)	-	1 (2.9)	-	3 (1.9)
With other family member	<i>Married</i> ¹	1 (2.4)	3 (15.0)	2 (5.8)	-	6 (3.7)
	<i>Single</i> ²	-	2 (10.0)	-	1 (1.5)	3 (1.9)
With child's support worker	<i>Married</i> ¹	2 (4.9)	-	-	-	2 (1.2)
	<i>Single</i> ²	-	-	-	-	-
With visual impairment support	<i>Married</i> ¹	-	-	-	-	-
	<i>Single</i> ²	-	-	1 (2.9)	-	1 (0.6)
With interpreter	<i>Married</i> ¹	-	-	-	3 (4.6)	3 (1.9)
	<i>Single</i> ²	-	-	-	1 (1.5)	1 (0.6)
With child's other parent and child's support worker	<i>Married</i> ¹	1 (2.4)	-	-	-	1 (0.6)
	<i>Single</i> ²	-	-	-	-	-
With child's other parents and interpreter	<i>Married</i> ¹	-	-	-	1 (1.5)	1 (0.6)
	<i>Single</i> ²	-	-	-	-	-
TOTAL		41 (100)	20 (100)	35 (100)	65 (100)	161 (100)

¹ Includes parents who are living as married.

² Includes parents who are separated, divorced or widowed.

Across all programmes, most parents (72.3%) attended alone. Amongst those who were married or living as married, over half (53.5%) attended alone. With regard to whether more parents attended evening groups as 'couples', less than a quarter (23.6%) of parents attended programmes which ran evening as well as daytime groups with their partner. This suggests that the provision of evening groups does not attract more parents attending as couples. We know from our interviews with parents (see Chapter 6) that lack of evening child-care was a primary reason for this. It was highly unusual for separated parents to attend a programme with the child's other parent.

Across all the programmes, a few parents chose to attend with another family member (6%). However, as the interviews with parents show (see Chapter 6), being able to attend with someone did give some parents the confidence to attend. Thus, although take-up of this option may not be high, it is valued by a minority. Fewer still parents (n=3) attended one of the programmes with someone else involved in the care of their child such as the child's teaching assistant at school or other support worker. Finally, one parent attended a programme with a visual impairment support worker and five parents attended programmes with an interpreter.

Second in relation to parent demographics, we report the gender, family structure and educational qualification of the parents who participated in the research.

Table 3.8 Parents' gender

Programme	Female n (%)	Male n (%)	Total n (%)
Programme A	35 (85.4)	6 (14.6)	41 (100)
Programme B	17 (85.0)	3 (15.0)	20 (100)
Programme C	26 (74.3)	9 (25.8) ¹	35 (100)
Programme D	60 (92.3) ²	5 (7.7)	70 (100)

¹ Includes 1 stepfather and 1 grandfather.

² Includes 1 stepmother, 2 foster/adoptive mothers and 2 grandmothers.

All the programmes were predominantly attended by mothers. Interestingly, of the seven groups studied from Programme C, all included fathers as well as mothers. Only two of these were evening groups, indicating that groups held during the working day were not always a barrier to attendance for men.

Table 3.9 Family structure

Programme	Lone parent n (%)	Living with partner or other adult n (%)	Missing data n (%)	Total n (%)
Programme A	8 (19.5)	31 (75.6)	2 (4.9)	41 (100)
Programme B	6 (30.0)	14 (70.0)	0	20 (100)
Programme C	5 (14.3)	30 (85.7)	0	35 (100)
Programme D	18 (27.7)	43 (66.2)	4 (6.2)	65 (100)

Family structure varied between the programmes. This reflects the locations in which the programmes were being delivered.

Table 3.10 Parents' educational qualification

Programme	None n (%)	Up to 16 n (%)	Beyond 16 n (%)	Missing data n (%)	Total n
Programme A	2 (4.9)	12 (29.3)	22 (53.7)	5 (12.2)	41 (100)
Programme B	7 (35.0)	6 (30.0)	7 (35.0)	0	20 (100)
Programme C	2 (5.7)	6 (17.1)	27 (77.1)	0	35 (100)
Programme D	12 (18.5)	27 (41.5)	23 (35.4)	3 (4.6)	65 (100)

Similarly, there are differences between the programmes in terms of level of educational qualifications achieved. One programme (B) was being delivered to groups where a third of parents had no education qualifications, compared to one in twenty parents attending programme A and one in 18 parents attending programme C.

It is clear from this data that, taken together, the sample of parents recruited to this study is not homogeneous. In one sense, this is an indicator of the success of this research project to recruit parents to the study who, typically, do not participate in research projects. However, it also adds a layer of complexity to any cross-programme analyses.

Chapter 4

Description of the Sleep Management Interventions

4.1 Introduction

In this chapter, we present a brief overview of the sleep management programmes under investigation in the study.

We provide a description of each programme, and then, drawing on the data collected over the period of investigation, report on how the programmes were accessed, take-up, and parent demographics.

4.2 Description of sleep management programmes

The following tables present an overview of each of the four sleep management programmes that took part in the study. General intervention details are provided in Appendix P. For details of the programme contents, see Appendix C.

Table 4.1 Overview of programme E: Specialist Health Visitor Sleep Support Service

PROGRAMME E: Specialist Health Visitor Sleep Support Service	
Aims	To support parents to address their child's sleep problems.
Mode of delivery	One-to-one mode, with follow-up support delivered face-to-face and/or via the telephone.
Disability	Any.
Age range	0-5 years.
Practitioners	Specialist health visitors (SHVs) based within the Child Development and Family Support Centre.
The intervention	Individualised assessment leading to sleep strategy which is implemented by parents. Parents are supported during the implementation phase.
Structure and approach	<ul style="list-style-type: none"> • A structured process but individualised to each family's situation. Approach developed based on depth experience of consultant community paediatrician and specialist health visitors. • Parents complete a sleep diary (ideally for two weeks) and then receive a home visit. The home visit includes an environmental assessment, history-taking (including a review of the sleep diaries). The outcome of that visit is a sleep strategy which the parents implement. Weekly contact from the SHV supports parents as they implement the strategy. This is provided either by further home visits or telephone calls. • 6 weeks is the typical duration of strategy implementation.
Participants	Parents with children with sleep problems. Both parents in the home are encouraged to take part. If the child goes elsewhere to sleep (e.g. a grandparent's home) the SHV will endeavour to speak to them too.
Follow-up	Sleep problems are checked for at subsequent routine clinic appointments. A subsequent deterioration will result in the family being offered a further brief period of intervention from the SHV.

Table 4.2 Overview of programme F: Neighbourhood Early Years (NEYS) Sleep Service

PROGRAMME F: Neighbourhood Early Years (NEYS) Sleep Service	
Aims	To help families to improve their child's sleep.
Mode of delivery	One-to-one mode.
Disability	Any.
Age range	0-5 years.
Practitioners	SEN/Disability Link workers based in Children's centres who have received training from Senior Learning Disability CAMHS Nurse and Clinical Psychologist to become Sleep Counsellors. The Nurse and Psychologist had received accredited training from "Sleep Scotland" which they then adapted to deliver locally.
The intervention	Individualised assessment leading to a 'sleep plan' which is implemented by parents. Parents are supported during the implementation phase through home visits and/or attendance at Sleep Clinic sessions at local children's centre.
Structure and approach	<ul style="list-style-type: none"> • A structured process but individualised to each family's situation. Developed by senior LD CAMHS nurse and clinical psychologist following Sleep Scotland training. • The first session takes place at the local Children's Centre. This comprises a basic assessment of the child's sleep problems. Parents then complete a two-week sleep diary. This is followed by a home visit from a sleep counsellor and a sleep strategy is devised. Subsequent, fortnightly, sessions with the Sleep Counsellor focus on supporting the family to implement a sleep plan. • Typical duration of intervention is 12-16 weeks.
Participants	Parents.
Follow-up	Follow-up support is not offered as a routine part of the intervention. However, sleep problems are checked for where a family has continued contact with the Children's Centre and Early Years Worker.

Table 4.3 Overview of programme G: Managing Your Child's Behaviour to Promote Better Sleep

PROGRAMME G: Managing Your Child's Behaviour to Promote Better Sleep	
Aims	To help parents manage their children's sleep difficulties.
Mode of delivery	Group.
Disability	Learning disabilities, ASC and/or sensory disabilities.
Age range	3-18 years.
Practitioners	Two learning disability qualified and trained staff from Northumberland Children and Young People's Service facilitate the training at any one time. Other learning disability qualified and trained staff may take the lead on individual topics and provide support to parents and carers where necessary.
The intervention	Four three-hour sessions held over a five-week period (with a two-week break between sessions three and four).
Structure and approach	<ul style="list-style-type: none"> • A manual sets out session structures, contains handouts and other teaching materials. • Didactic teaching, group discussion and learning activities are used.
Handouts and homework,	Parents and carers are asked to complete homework between sessions such as completing sleep diaries and environmental assessments as well as plan and implement bedtime routines. All homework is discussed at the next session.
Participants	Parents. (Both parents are encouraged to attend if practicable.)
Follow-up	A three-month follow-up session is not routinely provided. However, in this investigation this was delivered to one group who felt it would be useful.

Table 4.4 Overview of programme H: Sleep Solutions Workshops

PROGRAMME H: Sleep Solutions Workshops	
Aims	To support families of children with sleep difficulties through raising awareness of good sleep practice and basic strategies to support parents in establishing new routines.
Mode of delivery	One-day workshop.
Disability	“Children with additional needs”.
Age range	2-19 years.
Practitioners	Sleep practitioners trained by Sleep Scotland and Solent Healthcare.
The intervention	<p>A one-day workshop for parents and/or professionals lasting around 5 hours. .</p> <p>The intervention is intended both as a one-off intervention and, in the case of complex sleep problems, as a precursor to a family receiving one-to-one sleep support.</p>
Structure and approach	<ul style="list-style-type: none"> • A manual sets out the structure and content of the workshop and contains handouts and other teaching materials. • Predominantly didactic teaching with some group discussion/group-based learning activities.
Participants	Parents and professionals. Where availability allows, parents may attend with their partner, another family member or someone else who supports the child (such as a support worker from the Children’s Centre).
Follow-up	Parents can access either a local Sleep Service for individual 1-1 intervention or our Telephone Advice Service for further support. Professionals can further train with Sleep Scotland or Solent Healthcare to become qualified Sleep Practitioners.

4.3 Accessing the programmes

There was considerable variation in the routes by which parents were invited to access a sleep management programme, see Table 4.5.

Table 4.5 Routes by which parents were invited to attend a parent-training programme

Programme	Paediatric Clinics within Child Development and Family Support Centre	SEN/Disability Link Workers in Children's Centres	Child and Adolescent Learning Disability Team	Voluntary sector	Health, Education or Social Care professionals	Self-referral
E	√				√	√
F		√			√	
G			√		√	
H				√	√	√

Programme E

All parents who attended paediatric clinics at the Child Development and Family Support Centre completed a checklist, which included questions about their child's sleep. Once a behavioural sleep problem was identified, parents were referred to the Specialist Health Visitor (SHV) for face-to-face or telephone support for a period of up to six weeks. Referrals were also received from other professionals working with the child (e.g. portage workers) or families may have self-referred. The majority of referrals, however, were already known to the SHV.

Programme F

Through their work with families, SEN/Disability Link Workers in the Liverpool Children's Centres identified parents with children with sleep problems, and referred them to their local sleep clinic comprising around six to eight fortnightly sessions.

Programme G

Typically, community nurses within the Child and Adolescent Learning Disability Team referred parents on their caseloads who were experiencing problems with their child's sleep to the group-based parent-training programmes. However, referrals also came to the team through other professionals from education (teaching staff, school nurses), health (paediatricians, CAMHS) and social care (social workers).

Programme H

The way in which the one-day workshops were promoted depended on the commissioning and funding organisation. Those tendered by the local authority or primary care trust as part of a service level agreement were advertised free to both parents and professionals within that region via flyers, leaflets, newsletters, local authority databases, parent support services, health and education services, etc. Those organised directly by SCOPE's local sleep service targeted parents through face-to-face and web-based parenting networks; community venues such as children's centres, schools and health centres; professionals working with the family; or local voluntary organisations. Parents would then self-refer and remain on a waiting list until a place became available at a workshop running in their local

area. However, for these workshops, places were first allocated to ten professionals to be paid for out of *continuing professional development* budgets, which then funded ten free places for parents. Finally, those financed and hosted by another organisation would recruit workshop participants directly themselves.

4.4 Take-up

There was also considerable variation in take-up rates, see Table 4.6.

Table 4.6 Take-up

Programme ('lead organisation')	Total no. parents offered programme over 12 months	No. of parents expressing an interest	No. of parents taking up offer	Take-up rate
Programme E (NHS: Child Health)				
	30	-	18	60%
Programme F (NHS: Community Support Team for Children with Learning Disabilities)				
	63	51	37	59%
Programme G (NHS: Child and Adolescent Learning Disability Team)				
	29	-	25	86%
Programme H (Voluntary sector: SCOPE)				
	<i>Not available</i>			

4.5 Parent demographics

We have used the data collected in the quantitative phase of the research as proxy indicators of the population accessing the sleep-management programmes. We feel that due to the high recruitment rates to the research, this data can be viewed as an indicator of the demographic characteristics of the parents accessing these programmes.

Firstly, we examine whether parents received support on their own or with someone else. See Table 4.7. Across all programmes, the vast majority of parents (82.4%) attended alone, and amongst parents that were married or living as married, half (50.0%) attended alone. Only one parent who was separated/divorced received support with the child's other parent.

Table 4.7 Programme received alone or with someone else

		Programmes				
		E n (%)	F n (%)	G n (%)	H n (%)	All n (%)
Alone	Married ¹	12 (92.3)	5 (41.6)	16 (69.6)	4 (15.4)	37 (50.0)
	Single ²	1 (7.7)	2 (16.6)	1 (4.3)	20 (76.9)	24 (32.4)
With partner/child's other parent	Married ¹		1 (8.3)	6 (26.1)		7 (9.5)
	Single ²				1 (3.8)	1 (1.4)
	Missing		1 (8.3)			1 (1.4)
With other: child's grandparent	Married ₁					
	Single ²					
With other: family friend	Married ¹					
	Single ²					
With other: support worker	Married ¹				1 (3.8)	1 (1.4)
	Single ²					
Missing	Married ¹					
	Single ²		3 (24.9)			3 (4.1)
TOTAL IN PROGRAMME		13 (100.0)	12 (100.0)	23 (100.0)	26 (100.0)	74 (100.0)

¹ Married or living as married.

² Includes separated/divorced.

Secondly, we examine the gender, family structure, and educational qualifications of the parents who participated in the research. It can be seen from Table 4.8 that most parents involved in the programmes were the child's biological parents (94.6%) and were predominantly mothers (87.8%). The variation in family structure between the programmes (see Table 4.9) reflects the locations in which the programmes were being delivered. With regard to educational qualifications, it is interesting to note from Table 4.10 that around one-third of parents who received one-to-one sleep management support, did not have any qualifications. This contrasts with those who attended the group programmes, where less than ten per cent of parents had no qualifications.

Table 4.8 Parents' gender

Programme	Female n (%)	Male n (%)	Total n (%)
E	13 (100)	-	13 (100)
F	10 ¹ (83.3)	2 (16.7)	12 (100)
G	20 ² (86.9)	3 (13.0) ³	23 (100)
H	25 ⁴ (96.1)	1 (3.8)	26 (100)
Total	68 (91.9)	6 (8.1)	74 (100)

¹ Includes one grandmother.² Includes one foster mother.³ Includes one foster father.⁴ Includes one adoptive mother.**Table 4.9 Family structure**

Programme	Single parent n (%)	Living with partner or other adult n (%)	Total n (%)
E	4 (30.8)	9 (69.2)	13 (100)
F	5 (41.7)	7 (58.3)	12 (100)
G	1 (4.3)	22 (95.7)	23 (100)
H	5 (19.2)	21 (80.9)	26 (100)
Total	15 (20.3)	59 (79.7)	74 (100)

Table 4.10 Parents' educational qualification

Programme	None n (%)	Up to 16 n (%)	Beyond 16 n (%)	Total N (%)
E	4 (30.8)	4 (30.8)	5 (38.5)	13 (100)
F	4 (33.3)	5 (41.7)	3 (25.0)	12 (100)
G	2 (8.7)	6 (26.1)	15 (65.2)	23 (100)
H	2 (7.7)	12 (46.2)	12 (46.2)	26 (100)
Total	12 (16.2)	27 (36.5)	35 (47.3)	74 (100)

Chapter 5

Key Issues in Developing and Delivering the Interventions: Practitioners' Experiences

5.1 Introduction

This chapter focuses on practitioners' experiences of developing and delivering the interventions under investigation. Included within the interview sample were the practitioners who had developed the intervention. Interviews with these professionals explored the rationale for the mode and approach taken to the intervention they developed, as well as their experiences of delivering it. Other topics explored in interviews with professionals are reported in Chapter 18.

This chapter concerns both the behaviour and sleep interventions. Differences in views and experiences according both to the focus of the intervention and intervention mode are noted and explored.

5.2 Rationale for the mode and approach

Rationale behind developing the programmes

All the programmes were developed in response to an unmet need for parenting support that the programme authors reported increasingly encountering in their everyday professional lives.

It was mostly because we were getting so many young people through with autism and Asperger's Syndrome, and I suppose what we did was concentrate on the diagnosis first of all, and as the years went by, we began to think about interventions. And at that time there weren't very many interventions available.

[A, 1]

I've been working as a consultant now for thirteen years and (...) as I was talking to families and going through histories and asking what their main issues and priorities were, sleep just came up as a recurring theme as just being so crucial for family life. And so the more I was hearing that (...) [I] became aware that actually there, there was very little at that time going on to support families with sleep problems

[E, 1]

The mode of delivery

Behaviour management programmes

For three interventions, the authors⁶ reported that the decision to develop a group-based intervention had been a positive decision, as opposed to one driven by resource constraints. A number of reasons were given for that choice.

⁶ That is, author(s) of the programme. These are the individuals who developed and piloted the programmes, and produced a programme manual and associated resources.

First, one of the key objectives of the programme was to facilitate mutual support between parents, hence the group-mode was the only possibility.

We're aware parents don't get to meet other parents because they don't have the 'school gate contact' ... it was a way of us getting parents together and it's been very helpful for that.

[D, 1]

Second were reasons of therapeutic effectiveness. The authors cited their clinical experiences of using groups for other interventions and/or research evidence on the effectiveness of groups for parent-training interventions (for example, NICE (2006)) as the reasons for choosing this approach.

Third, a group-based intervention was also seen as increasing the portfolio of services and support they could offer parents. In addition, there was the acknowledgement that, in a resource-constrained environment with high levels of expressed need, developing a group-based intervention was a very attractive option.

... And just the sheer volume of referrals that we get, so actually it was a very efficient way of us dealing with those referrals.

[D, 1]

... just the feeling that a lot of these families didn't necessarily need really intensive one-to-one work, but needed something ... and that we couldn't see them all individually anyway.

[A, 4]

The (considerable) added-value gained from the group-mode - in terms of its therapeutic value - which all the interviewees had observed as they developed and piloted the intervention meant that they continued to deliver the intervention in that way.

Whilst the fourth intervention had originally chosen the group approach solely in response to high numbers of referrals for behaviour support, they rapidly observed the considerable benefits of delivering the intervention to groups as opposed through one-to-one sessions.

What we hadn't anticipated was how much better the intervention was for having the parents help each other talk to about their own stories. It was so much better than we could ever have anticipated and added something more than could be achieved in a one-to-one basis.

[A, 1]

Sleep management programmes

The sleep management programmes included in this study took three forms: individually-delivered support, a group-based intervention and a one-day workshop.

Interestingly, it does not appear that the options regarding the mode of delivery were explored by those developing the one-to-one programmes. Both programmes were adapted or developed from existing one-to-one sleep management approaches and/or were an extension of current ways of working with families. The decision to adopt a group-mode for the group-based intervention had solely been driven by resource constraints. However, the benefits of the group mode were acknowledged and observed:

I mean, we're well aware of research into the effectiveness of group work etcetera, and I have to say that the feedback from parents around being in a group has been very, very positive. It doesn't suit everyone, but those that have experienced [the intervention] have had a very, very positive experience. They use each other's experiences and solutions to help, kind of, find strategies for themselves to work through.

[G, 1]

Similarly, a one-day workshop approach was seen as a cost-effective way of providing information and advice about sleep to parents and/or providing interim support until one-to-one support was available. However, the value of bringing parents together, in terms of the support that provides to parents, was also explicitly acknowledged by the authors of the workshop-based intervention.

Ethos

Across the four behaviour interventions, an explicit decision had been taken to adopt an approach characterised by the family-partnership model (Davis and Day, 2010).

I was heavily influenced by Hilton Davis's work on parent partnerships, with the emphasis on listening to parents' stories [and] hearing what they say; instead of coming along and saying "Here you are, I've got the magic wand and the solution". I think that Hilton Davis's approach of building up relationships with families; first of all listening to them very carefully, helping them to reflect what might be going on, was so much more powerful.

[A, 1]

I think what is important about [...] is the understanding that it gives. It's not a set of techniques where you try one thing and if it doesn't work you try another thing. It's about trying to help parents understand what are the difficulties in autism, so that if one strategy doesn't work then they can work out their own solution to the next one.

[C, 1]

A tension can emerge, however, when parents come to a programme expecting 'to be told what to do', and not expecting that they will need to engage in the process of improving their child's behaviour. In addition, some of the authors specifically cautioned about the danger of assuming such an approach does not require high levels of clinical expertise.

Sometimes it can give the impression that you're not doing very much, you know, 'cos you're listening so carefully and using your expertise then to be able to feedback some of your thoughts.

[A, 1]

Qualitative differences were noted in the ways that professionals described the ethos of the sleep-management interventions, both compared to the behaviour management interventions and between the different sleep interventions themselves. Thus, whilst the approach taken to the group-based and workshop sleep management programmes were explicitly grounded in the family-partnership model, this approach did not explicitly emerge from the accounts of professionals who developed the one-to-one interventions.

There is an interesting difference between the sleep interventions in terms of the extent to which parents are supported in implementing their new knowledge, skills and strategies for managing their child's sleep. Clearly for the one-day workshop no on-going support is possible (excepting those parents already on the waiting list for one-to-one support). The

group-mode programme is delivered over a five week period which allows some degree of support and feedback to parents but is a very limited time period, (and shorter than any of behaviour management programmes we investigated). In contrast, two of the sleep interventions are designed around supporting the parent to implement a sleep strategy until the sleep problem is satisfactorily resolved. Certainly, the professionals we interviewed believed that some families will require on-going, individual support in order to change the way they manage their child's sleep. It will be interesting to discover what light this study can shed on whether a group-delivered intervention is a viable option for at least some parents and, in addition, whether that one-to-one support can be delivered through telephone calls as opposed to face-to-face meetings.

The need for autism-specific and/or disability specific parent-training programmes

In terms of the behaviour interventions, many of the professionals interviewed had experience of delivering generic parenting-training programmes (for example, Webster-Stratton). None had found them satisfactory when working with parents of disabled children, even when some changes or adaptations were introduced. This had been one of the motivations behind developing a parenting-programme specifically for parents of children with an autistic spectrum condition and/or disabled children more generally.

The need for autism-specific parent-training programmes was particularly emphasised because 'mainstream' parenting programmes do not accommodate differences in the way that children with ASC experience and perceive the world, and the way that ASC impacts on behaviour. For example, this professional recalled a parent recounting the advice she had been given at a mainstream parent-training programme to ignore undesired behaviours:

A pivotal moment was when I saw a mum who'd said she'd ignored her child with Asperger's for over two hours as he watched the washing machine ... and it hadn't made any difference. She'd done a ... Programme, and that's what she'd been left thinking that she had to do.

[D, 1]

However, at the same time, concern was expressed that the focus on supporting parents with a child with an autistic spectrum condition may mean other parents' needs remain unmet.

I feel it's a bonus that [name of programme] it open to other people [parents of disabled children but no ASC] who can use the strategies effectively as well. ... It can be used by parents who have got other sorts of problems. But still more parents of children with autism come along even though that doesn't reflect the population at all.

[D, 2]

The reasons behind the need for ASC or disability specific sleep interventions were more diverse. Certainly, the need to account for sensory issues when conducting assessments of the bedroom environment were particularly stressed for those children with autistic spectrum conditions. Similarly, it was noted that sleep management strategies may need to comprise smaller 'steps' or goals. In addition, however, professionals delivering these interventions identified additional issues, such as parental stress, attachment and relationship issues, and parents holding low expectations in terms of their child's sleep, which may also need to be addressed. They also highlighted the critical importance of helping parents find an effective way to communicate with the child about, for example, changes to bedtime routine.

The training elements of the programme

Three behaviour management programmes were relatively similar in the objective of the training or teaching element of the programme namely, to increase parents' understanding of behaviour management and their behaviour management strategies. The two autism-specific programmes equally stressed increasing parents' understanding of autistic spectrum conditions and then, on the basis of that knowledge, to develop their understanding and skills regarding the management of their child's behaviour.

Very early on it became clear with discussion with parents' groups and in piloting the programme that what parents wanted was a better understanding of their child's condition, and idea of strategies for managing behaviour
[C, 1]

I feel strongly that it is important for parents to understand autistic spectrum disorder and theories before we move into interventions with them.

[A, 1]

The attention paid to ASC in disability-generic programmes varies according to the make-up of individual groups. The fourth programme, whilst also firmly located in behavioural principles of behaviour management, was less didactic and systematic in its training approach focusing instead on nurturing parents' feelings of confidence as parents and responding to current behaviour management difficulties. The fact that parents were able to attend this programme as often as they desired provides an explanation for the rationale behind this approach.

The desire to promote a sense of working in partnership with families but, at the same time, explicitly increase parents' understanding of their child's condition and the theories underlying behaviour management was a key challenge. Psychological theories of behaviour and behaviour management, and developmental and clinical theories of autism spectrum conditions, are complex topics drawing on unfamiliar constructs and terminologies. The programme authors had worked creatively to overcome this challenge. Visual and experiential learning is used extensively across all the programmes. In addition, the programme authors have developed visual aids, analogies and simple templates to support parents' understanding of theories of behavioural analysis and management strategies.

We've actually tried very explicitly to explain about positive and negative reinforcers and things like that because we wanted parents to be able to think through what was going on when there was an outburst ... to be able to think it through in a way as if I were sat there with them. ... We wanted to make it accessible to families and so we try to give them the tools to help them understand and manage different behaviours. So we talk a lot about becoming a behaviour detective.
[D, 1]

The reason I like ... is because, for me as a clinical psychologist, it draws on functional analysis and gives me a structured way of going through it with exercises to really help parents think about what it feels like [to have an ASC]. That kind of experiential learning, rather than intellectual information giving, is really powerful at times.
[A, 4]

I find it a very, very effective tool ... this is such a tremendous way to work with parents. I wish other courses could actually use this way of delivering information.

[A, 2]

Three of the programmes also incorporated more formal 'teaching' elements. The fourth programme did not formalise learning within the group (in terms of behavioural theory, for instance) in such an explicit way. This reflected the slightly different purpose of this programme, in terms of a greater emphasis on supporting and developing parents' confidence with their relationship with their child.

As noted previously, the sleep interventions represented in this study were much more diverse in their delivery and, for the individually delivered programmes, the notion of training is not appropriate (or certainly carries a different meaning). Similarly, a one-day workshop necessarily has to be more didactic than a programme delivered over four three-hour sessions if all the relevant material is to be covered. There was a sense, however, that the professionals delivering the sleep interventions were very focused on achieving (realistic) improvements in children's sleep. This contrasted with the broader objectives of the behaviour-management programmes which typically gave equal emphasis to parent-centred outcomes such as confidence, knowledge and understanding.

5.3 Views on factors affecting take-up of an intervention

Within this study a variety of different modes of delivering parent-training interventions have been investigated and we have also looked at sleep-management and behaviour management interventions. The interviews with professionals delivering these interventions explored their views on the factors which affected parents' decision to accept the offer of support regarding their child's sleep and behaviour.

Concerns about take-up (or initial engagement) were greater amongst practitioners delivering the group-based behaviour and sleep interventions.

We've had very low drop out. You find if people are going to drop out they just won't come in the first place. If people have come they'll stay with us till the end.

[D, 1]

In contrast, initial take-up for the one-to-one sleep interventions was very high, but a proportion of families then dropped out once the assessment visit had been carried out and it became clear what pursuing the intervention entailed. However, as one practitioner noted, even partial involvement in an intervention can have positive effects:

It is reasonably common that what we would like to offer [to a family] doesn't get seen the whole way through. But I do think that even in those situations, quite a number of those families will have taken something away from that.

[E, 1]

In this section we deal with four overarching factors which practitioners regarded as affecting parents' decision to accept an intervention: readiness, previous experiences of interventions, a pre-existing relationship, and information. The subsequent section focuses specifically on issues associated with group-based interventions.

It is important to note, at the outset, that whilst able to articulate the factors which they believed affected take-up and initial engagement, a number of practitioners could recall

instances when they had been surprised by a parent's refusal or acceptance of an intervention.

But you cannot always predict which families are going to run with it, or not, so it is important to give all families the information and opportunity to decide for themselves
[F, 1]

Readiness

The notion of readiness was a recurrent theme in professionals' accounts. All believed that, unless a parent, or couple, wanted to do something about their child's sleep or behaviour then it was very unlikely they would accept the offer of support.

I guess it's whereabouts they are and what they want ... what they're thinking about the difficulties they've got. So they could come next week and they [have become] customers for change and just want to go for it.
[G, 2]

There's no point in trying to force parents to come, you want them to come with a readiness to be supported and helped. [There are] parents who are actually in denial still, thinking, "It's not for me. I'm not ready for this yet. I'm not ready to face the consequences of having to change my behaviour and accept my role in altering the way we function as a family".

[B, 2]

In any type of work like this it is about seeing families when they are ready to be seen.
[F, 1]

Factors identified by practitioners as affecting readiness were:

- the extent of co-existing demands and situations
- parents' accepting or realising that their child's sleep or behaviour was a problem
- parents' acceptance of their child's diagnosis
- an acceptance of the need to change their own behaviour
- having the capacity to commit making those changes.

The complexity of the child's needs, illness and medical crises, and, for some families, highly chaotic lives, could all make pressing demands on parents' attention and personal resources. In addition, one-off events, such as moving house, a new baby or a particularly difficult time at work were further barriers to readiness. Perversely, sleep deprivation was noted as affecting capacity to engage in a sleep-management intervention.

I think if they are coming on a sleep course it's because they're sleep deprived, and sometimes just the thought of getting to a training event is just too much, to be quite honest.
[H, 2]

The sleep programme is a bit of a commitment, really. We say it will take six to eight sessions. I think families come and think, "Oh, I don't know if we can do all of this."

[F, 1]

A number of professionals observed that initial interest in an intervention could soon fade once parents realised there was no 'quick win' and, importantly, they would be required to change the way they parented. In terms of sleep, more complex issues may also be at play. Parents' own needs may make them reluctant to stop sharing their bed with their child.

But when you explain to them that there isn't necessarily a magic wand, that it's going to require some changes on their part ... some families will [say] "OK, this is not the right time for us to be taking this on".

[E, 1]

I think they start realising that it's not going to be easy. "I'm going to have to either have a few sleepless nights or, you know, get my partner on board ... and he's not going to do it with me , and I'm going to have to do it all on my own". I think maybe they're just on the edge of coping ... and then we come in with suggestions and I think some parents just think, "I can't. I've not got the capacity to do any more than I'm doing".

[F, focus group]

And sometimes they're actually, either consciously or subconsciously, encouraging the child to be in the bed.

[E, 1]

Sometimes, level of engagement in a 'pre-intervention task' provided an indicator of a parent's readiness to engage with the intervention. One of the behaviour interventions required parents to be filmed at home interacting with their child. Completing sleep diaries were pre-requisites to receiving the two one-to-one sleep interventions.

I am quite picky about the sleep diaries, because I find if families are reluctant to do any sort of sleep diary, who absolutely won't put anything down at all, I find they are often the families where we struggle to move forward. But the families who actually come with a bit of detail about what's happened every night for the past couple of weeks, they've already thought about it so much ... they're already focusing on it, they're ready to move on.

[E, 1]

Something that I've found that really tells you whether parents are committed or not is whether they agree to the videoing or not at the beginning. The ones who keep putting this off are the one that don't turn up or maybe just come the once.

[B, 1]

Solutions to the barrier of 'un-readiness' suggested by professionals included regularly repeating the offer of parenting support. An on-going relationship with the parent may also allow the professional to work through some of the issues acting as barrier to readiness. Professionals working in settings where they had routine contact with parents (for example, schools, child development centres, children's centres) noted this had enabled them to overcome parental resistance to engaging with a sleep or behaviour management intervention. Finally, some also noted that providing reassurance that parents would be supported throughout this process of change - both in the short and longer term - could help to move parents towards feeling ready to engage with such interventions. Again, it was professionals working in settings where they had routine contact with families where this was more feasible (and, to parents, more believable).

It works best where you can gain their trust and confidence over a period of time, and you can reassure them that you will be there for the journey with them and are not going to drop out of their lives. Because I guess they've experienced that in the past where they've been set up to fail and some will lose confidence.

Whereas for us, we can honestly say we'll be with you for six/seven years. We'll be right alongside you for the journey, we won't go away, we won't let you down.

[B, 2]

Previous experiences of parenting interventions

A number of practitioners recalled parents who had refused the parenting support being offered them because they believed they had already received a similar intervention.

Typically, this had not resulted in any positive changes. This made them sceptical of, or unwilling to embark on, the intervention being offered.

Sometimes they might say, "Oh, I've tried that before, it didn't work", and won't do it.

[E, 1]

One parent did not think the course would be that useful as she had attended an information day where topics such a mind-blindness and 'getting the gist' were covered. She had not found this very helpful.

[A, 5]

It may be that they've had a negative experience from somebody and maybe feel a little bit sensitive, and feel they are going to be criticised.

[G, 3]

A pre-existing relationship

Practitioners believed that parents were more likely to accept support if there was a pre-existing, trusting relationship between themselves and a parent. Clearly, the extent to which this was possible was dependent on the setting or service delivering the intervention. For example, families will have a long-term relationship with a specialist health visitor at a child development centre. In contrast, for other interventions they will not have met the practitioner(s) before the first appointment or group session.

Information and pre-intervention visits

Practitioners consistently noted the importance of clear information about the nature, and possible outcomes of the intervention. It played a vital role both in engaging parents and ensuring parents did not hold unrealistic expectations.

You get those families who think, "I'll just come along once and it'll be sorted", which is quite worrying.

[B, 1]

A number of different approaches were used across the interventions represented in this study including fliers and leaflets, videos (n=1 intervention), and face-to-face information provision and reassurance (n=2 behaviour, n=2 sleep).

They meet someone who can reassure them and discuss any concerns, sort of hook them in a bit.

[B, 1]

5.4 Barriers to joining group-based interventions

The interviews with professionals delivering group-based parent-training programmes (behaviour (n=4) and sleep (n=1) were analysed to identify the factors they believed acted as barriers or supported take-up to a group-based intervention.

A wide range of factors were identified, see Figure 5.1

Figure 5.1 Factors affecting take-up to a group-based intervention

Joining a group
<ul style="list-style-type: none">• Individual differences• Social anxiety• Pre-existing relationship with programme facilitators• Fear of revelation and criticism• Problems perceived as unique
The regularity, and extent, of commitment required
Venue and location
<ul style="list-style-type: none">• Familiar• Positive connotations• Accessible by public transport• 'Central'
Childcare

Joining a group

Practitioners were keenly aware that group-based interventions did not suit all parents, that some parents are 'wary' of groups. They also observed that, particularly for the ASC programmes where parents may also be on the spectrum, that high levels of social anxiety would preclude a parent joining a group. Parents with learning disabilities and mental health problems were also identified as being particularly unlikely to join a group for this reason.

We have parents who have learning difficulties and learning disabilities who just don't feel confident to attend such a group. And we have parents who just don't like being in a group, simple as that!

[G, 1]

A pre-existing relationship with a group facilitator was viewed as a key factor to overcoming reluctance to join a group.

Two other issues emerged in relation to the group mode being a barrier to take-up. First, practitioners were aware that some parents avoided groups because they were reluctant to reveal quite personal details about their lives; this was particularly the case for the group-based sleep intervention.

Some people are put off by the group mode. [They] are frightened to discuss such personal problems as what happens in their home, at night, in front of a large group of strangers.

[H, 1]

Second, practitioners reported encountering parents who believed their problems were unique, and therefore could not see the benefit of attending a group.

She was very reluctant to come because she thought, "Well, my child's so different ... it's so complicated. There's not another child like that". That's one of the challenges, I think, of working with our parents.

[G, 2]

The regularity and extent of commitment required

A group-based intervention is, necessarily, conducted over a number of weeks and is constrained to a fixed time. This requires a significant commitment from parents. Some are intrinsically put off by this:

There are certain parents that do not feel they can commit to the regularity that the group demands.

[A, 5]

Practitioners also acknowledged that day-time groups tended to exclude parents who worked because of the commitment and potential costs. A reluctance (or inability) to lose pay or annual leave, unsupportive employers or shift patterns prevented parents attending the group-based interventions. Only two of the group-based interventions offered the programme through evening sessions.

Venue

Not unexpectedly, practitioners flagged up that familiar, community-based venues can help overcome reluctance to join a group. Practitioners delivering the group-based sleep intervention had chosen not to use schools in order to reassure parents about confidentiality from school staff.

The issue of accessibility, in terms of journey time and public transport routes, was raised by practitioners delivering interventions in both rural and urban settings. They noted that travel time could easily add a further two hours to the time commitment parents had to make to attend a group. Choosing the right location was a particularly difficult when an intervention was only offered occasionally, as opposed to regularly repeating the intervention in different parts of a region or authority.

So that's a big commitment for parents. You've got them dropping children off at school and whatever, and then getting somewhere. It kind of takes out a whole morning. I mean, it's a two hour slot but it takes out the whole morning, if not more.

[A, 3]

Childcare

Lack of access to childcare or childcare provision was acknowledged to be a significant barrier to parents being able to take-up group-based parenting support. Practitioners noted that parents of children with autistic spectrum conditions particularly struggle to find suitable childcare or babysitters.

Cultural issues

Practitioners' experiences of trying to engage different ethnic groups in group-based parenting interventions varied. Some did not raise this as an issue, despite delivering an intervention in a highly multi-cultural setting. Others reported difficulties and believed that group-based delivery could be a barrier to take-up among some minority groups:

They've told us they don't like talking in public about the shame of having a child with a disability. I think the model doesn't suit them very well. [B, 1]

5.5 Factors affecting on-going engagement with the intervention

Some of the issues practitioners encountered regarding take-up of interventions continued to have an impact in terms of parents' on-going engagement with an intervention. These included factors such as unrealistic expectations, the level, and on-going nature, of commitment required, childcare needs and travelling to venues for appointments or group sessions.

Obviously we have families that never finish. Now whether that's because they don't like the hard work that they have to do, you haven't got the magic wand that comes out of the bag for them, whether it's they're just not in right place ...
[F, focus group]

Additional factors which specifically affected on-going engagement (in a positive and/or negative way) were also identified, namely:

- unanticipated events and situations
- the management of missed sessions
- the experience of positive outcomes
- the group (group-based interventions)
- the ethos (group-based interventions).

Unanticipated events or situations

All practitioners could give examples of where parental ill health (physical or mental) had resulted in a parent not completing an intervention. Bereavement, domestic problems, house moves, and a deterioration in the child's health were other reasons cited as the cause of non-completion of an intervention.

Only one has dropped out of the last group and she has been going through an eviction process and having housing difficulties. [And] last year there was one who dropped out – she had two children with autism and was really struggling emotionally. We wanted to work with her individually but she just found it too much.

[A, 5]

The management of missed sessions or appointments

There was a wide range of reasons why parents did not attend a single, or a couple of sessions or appointments. Indeed, it seemed that practitioners expected that some interruption in the delivery of the intervention was almost inevitable. Child, sibling, and parental ill health, urgent, short-term, demands on parents' time and attention arising from work, childcare or domestic responsibilities were common reasons for this occurrence. With individually delivered interventions, missed appointments were rescheduled and practitioners were proactive in contacting parents to ensure contact was maintained and the intervention could continue.

Managing missed sessions in the group-based interventions was more challenging. If one or more sessions were missed by a parent, all practitioners reported proactively making contact by letter, enclosing relevant handouts. This was sometimes followed up with a telephone call. However, there was no consistent practice between or within interventions about how the parent 'caught up' with the group. It appeared to depend on the content or topic (for example, the more didactic sessions were more fully represented on handouts than others) and practitioners' judgements regarding the parents' needs, abilities and level of engagement. In some instances a one-to-one session was offered, either during the intervening period or immediately before the following session. There was evidence from practitioners accounts that, where parents were already known to the service, a greater effort was made to retain them. This might partly be to do with feeling confident about judging the appropriate level of proactive contact to make. In addition, chance encounters with these parents were more likely and provided an opportunity to encourage them to resume attendance.

The experience of positive outcomes

Motivation to continue with an intervention was seen as being linked to parents' experiences of positive outcomes such as, feeling more informed, more confident and/or observing changes or improvements in the child's sleep or behaviour served to maintain parents' motivation. Indeed some of the interventions utilised a system of reviewing progress (at each appointment or group session) for this purpose.

The ethos of group-based interventions

Practitioners believed that parents responded very positively to the empowering, family-partnership approach adopted by all the group-based interventions. They believed this served to increase parents' motivation and ensure their active engagement with, and commitment to, the intervention and other members of the group.

*Not standing up there as the fount of all knowledge and just lecture them.
[Instead] they start to work out some of their own solutions together. I think
that's probably one of the driving factors why we retain so many.
[C, 1]*

The group

Practitioners observed that, once initial anxieties were overcome, membership of the group and the support parents derived from it, became key factors in ensuring on-going engagement with the intervention.

*One reason [for very high retention rate] is, we would like to think, the quality of
the programme. But the other element, and it's never to be underestimated, is
the supportive environment that allows parents to support each other.
[C, 1]*

However, whilst the majority of parents find attending a parent-training group a very positive experience, practitioners were alert to the fact that, sometimes, this experience can be less than positive and this may result in them leaving the group. A negative experience was attributed to the presence of 'difficult', non-empathetic parents in the group, failing to overcome the initial discomfort of being in a group or simply never quite identifying or forming a relationship with anyone else in the group.

I got a sense that she felt quite disconnected from other parents in the group ... that the rest of the group seemed to gel really well but she never did, and then she stopped coming. I think that how well you get on with other people in group has quite a big impact.

[A, 3]

I think some of the parents in the autism group sometimes have some issues themselves around [recognising in themselves] autistic features. I think they find it very difficult.

[A, 1]

5.6 Managing cultural and language issues

It was clear that, in delivering the interventions, practitioners experienced far more difficulties in terms of managing when English was not a parent's first language compared to responding to or managing cultural issues. Group-based programmes or interventions presented the greatest challenges for overcoming both cultural and language diversity.

Language rather than culture is the barrier. All parents have their own beliefs about parenting.

[A, 4]

Concerns were expressed about parents from minority groups not accessing parenting support. One practitioner noted that there was an under-diagnosis of autism within South East Asian families in his area which, he believed, was caused by parents being reluctant to report their concerns. Another practitioner drew attention to the impact of cultural difference on group dynamics. Here, however, the difficulty concerned facilitation of the group, as opposed to the parents' experience of the group:

Because they are an Arabic family, the dad speaks to my male colleague and it's as if I don't exist. I have no status ... and I can't speak to the mum except through the dad.

[C, 3]

Whilst there were isolated instances, all the practitioners interviewed acknowledged the need for cultural sensitivity. However, accommodating a diversity of English linguistic ability was a much more dominant theme in practitioners' accounts of their experiences of delivering group-based interventions. Two separate situations emerged: parents with English as a second language but not using interpreters; using interpreters

Parents with English as a second language

Most of the practitioners interviewed had experience of delivering a programme to a group which included parents whose first language was not English, but who did not have an interpreter. They noticed that these parents could find the pace of the sessions too fast and that they may not fully participate in discussions. Practitioners also found that some of the concepts covered in the programme could be unfamiliar and difficult to 'translate' into familiar and meaningful concepts.

We've had some where English isn't their first language so might be struggling with some of the concepts. Sometimes we have to break stuff down a little bit more, and be aware of the language we use ... some of those things we might take for granted where English is a first language, we might use some of those metaphors.

[A, 3]

Providing extra time with these parents, before or after sessions was a strategy which practitioners often used to ensure these parents were following and grasping the content of the programme.

Finally, a couple of the practitioners noted that, where required, they tried to construct the membership of a group so that it included two parents who used the same minority language. This often enabled some *ad hoc* interpretation to take place, something which was less disruptive and seemed to support greater participation and sense of belonging compared to using an interpreting service. Obviously, this was not a possibility where a parent's English was more limited.

I've got a situation at the moment with two Arabic parents who both said they didn't need an interpreter. What's incredibly helpful is they translate for each other. This has helped them chip in. So, there's a sentence one of them wants to say, and if they feel they're not getting their message across they'll say to the other one ... and then the two of them try to portray it. And that's been helpful. So certainly I think, just generally, that if it's possible to have another person there who speaks your first language, then that seems to facilitate engagement. They can also chat to each other during breaks.

[D, 1]

Using interpreting services

The practitioners delivering one of the group-based interventions routinely used an interpreter. In contrast, the remainder of the practitioners interviewed stated they would not use an interpreter when delivering a group-based intervention. They believed an interpreter would make facilitating the group too difficult, that it would slow down the pace of the group too much and that the presence of an interpreter would be distracting for parents. They also felt that parents using an interpreter would find integration into a group very difficult. These practitioners reported that one-to-one support would be offered instead. A suggested alternative, though not actually implemented, was to run a group for parents who all use the same minority language. In this situation, using an interpreter would, it was felt, be workable. However, translation of the programme materials was not a possibility.

We had the same one [interpreter] each week. She was fantastic, and I think that mum did feel part of the group, even though she didn't speak any English at all.

[D, 2]

In reviewing their learning of working with interpreters, the practitioners using interpreters to deliver an intervention made the following points.

- they had found it was not possible to work with more than one interpreter: the level of noise and distraction became too high
- they had increased the amount of small group work as this enabled greater participation in discussions by parents using an interpreter
- they endeavour to use the same interpreter across the whole programme
- interpreters are briefed as to their role; for example, not answering questions on behalf of the parent; the level of interpreting support required by a parent

- it works best if the parent(s) and interpreter are seated as far from the facilitator(s) as is possible within the group.

5.7 Practitioners' personal reflections

All the practitioners interviewed had no doubts that the intervention or programme they were involved in delivering made a difference to, at least, some families' lives by achieving one or more of the following outcomes: improving parenting skills, aiding their understanding of their child's condition, improving children's sleep and/or behaviours, and increasing parents' sense of support and confidence as parents.

It was one of the first [programmes] that I thought helped people to think about how the world feels if you've got ASC. ... Seeing them meet each other and talk to each other. And I think you get a sense that it's really beneficial for them to get an opportunity to do that.

[A, 4]

It's lovely if the children's behaviour does change as well, but sometimes I do think it might, that the children haven't changed very much and it's actually the parents who have changed – it's their management of their stress levels and their ability to cope

[B, 1]

When I got started on this, I just thought straightaway, "... yeah, I'm actually meeting somebody's needs". It was very very marked.

[C, 1]

Running the groups is one of the best bit of my job. Because there's something really exciting about seeing the change with a whole group of parents.

[D, 1]

... getting the feedback that says ... "Do you know, my child's slept for the first time for ... you know, ... in their beds for the last four nights. And just simple little things like that can make a huge difference.

[G, 1]

I've seen people come in with dark, dark eyes, as I see it, looking like: "No hope. What you're going to tell me today that no bugger else has tried to tell me?" And then to go out with this spark in their eyes, like: "I can try something!".

[H, 1]

Some families it's a great success and it's like a weight's been lifted off.

[F, focus group]

Not unexpectedly, therefore, all the practitioners interviewed were exceptionally positive about delivering these interventions. Those involved in delivering group-based interventions relished interacting more informally with parents than, they felt, was possible in one-to-one work. They also reported finding it helpful and interesting to hear parents sharing their experiences with each other.

5.8 Summary

This chapter reports the views of professionals who 'authored' the interventions under investigation as well as the views and experiences of professionals who are simply involved in delivering it. This has allowed us to explore the rationale behind the mode and approach of the interventions which have been the focus of this study and, also, to describe experiences of delivering these interventions.

Interestingly, whereas the group mode was consistently viewed as an appropriate mode for delivering a behaviour management intervention, this was not the case for sleep interventions where both individual and group interventions were being delivered and, indeed, the group mode was only chosen because of resource constraints. To a greater or lesser extent, the behaviour interventions explicitly sought to achieve additional outcomes in terms of improvements in parents' sense of support, hence the choice of group mode.

Mode of delivery also appeared to affect the nature of the therapeutic relationship. Group delivered interventions consistently adopted a 'shared expertise' approach and there was a sense of working in partnership with parents to develop solutions to the difficulties they were facing. This ethos did not emerge from the accounts of professionals delivering one-to-one interventions. Indeed, practitioners working in both these modes were keenly aware of the difference it made to the nature of their relationship with parents.

It was very clear from these practitioners' accounts that they believed generic parenting programmes are likely to be inadequate or inappropriate for parents of children with autistic spectrum conditions (ASC) and/or learning difficulties. For example, an understanding of ASC was seen to be fundamental to parents learning how to best manage the child's behaviour. More generally, it was believed that generic interventions cannot sufficiently be adjusted to accommodate differences in communication and learning difficulties which a disabled child may have.

There were very mixed experiences of intervention take-up and retention. The group mode was perceived as acting as a barrier to take-up, but then to supporting on-going engagement and retention. The dominant theme in professionals' discussions of take-up of behaviour or sleep support was the notion of 'readiness'. Unless parents were 'ready' to engage with the intervention, and the demands it would make on them, then professionals' efforts were likely to be wasted.

Readiness was affected both by external events and circumstances and parents' acceptance of their child's diagnosis and their need for help. Lastly, and given that all the interventions in this study were parent-led, it was not surprising to learn that the final factor perceived as contributing to parental readiness was having the capacity to commit to changes in parenting styles and strategies. There was a sense that this notion of readiness was more frequently referred to in the accounts of practitioners delivering sleep interventions, perhaps reflecting the very high, short-term, demands these interventions can make, particularly given parents are likely to be sleep deprived at the outset. Offering an intervention on a number of occasions, and preferably by someone known to and trusted by the parent, were seen as strategies by which 'un-readiness' could be overcome.

The interviews with parents explored their views of attending group-based programmes (see Chapter 6). The barriers and/or facilitators to attending groups which parents identified were very similar to those which professionals observed. In addition, practitioners believed that the presence of mental health or learning difficulties could be barriers to attending a group. The transitory nature of some barriers – such as ill-health, work demands, difficult family

circumstances – reiterates the need to repeatedly offer interventions such as these to parents.

Diverse views were held regarding the use of interpreters in group-delivered interventions. One intervention (D) used them routinely, others had never tried to use interpreters or had stopped doing so. The experiences of Intervention D certainly suggest it is possible. They report valuable lessons learnt regarding the use of interpreters and clearly their current ease with using interpreters is based on cumulative experience. Interestingly, language, as opposed to cultural differences, was seen as presenting the more significant barrier to including and integrating families from minority groups into group delivered interventions.

Chapter 6

Factors Affecting Take-Up and Engagement of the Behaviour Management Programmes: Parents' Accounts

6.1 Introduction

In this chapter, we report the findings from the individual and focus group interviews with parents on what motivated them to participate in the group-based parent-training programmes on behaviour management, and to continue attending the programmes. We examine the factors identified by parents that influenced their decision to take part in the programme and the factors that supported their ongoing attendance and engagement with the programme. In addition, the experiences of parents from minority groups who attended the programmes are reported.

6.2 Factors influencing take-up

A wide range of factors supported or hindered parents deciding to take-up the offer of attendance at a parent-training programme. These can be loosely clustered into:

- the referral process;
- practical issues of access;
- the duration of the programme and sessions;
- the 'newness' of the experience;
- perceptions of the facilitators
- concerns about joining a parent-training programme;
- motivations
- readiness.

Aspects of the referral process

The identity of the referrer and the information provided both appeared to play an important role in parents' deciding to take-up the offer of attending a programme.

Referral or encouragement from a trusted practitioner

Many parents had been referred to, or encouraged to attend, the parent training programme by a practitioner who knew them and their child. This in itself suggested to parents that the programme would be relevant to their family's particular needs and personal goals, and motivated them to attend.

I think, to be honest, I had enough, sort of, trust and respect for [the facilitator] to think this is going to be worth coming to.
[15⁷ (Mother), Programme A, focus group]

The information valued by parents when deciding whether to attend

The amount of information provided to parents in advance of the first session varied between programmes. Typically, parents who received quite detailed information found it valuable in terms of helping them to decide whether or not to attend.

⁷ Each participant was assigned an identification number. This identification system is used throughout all the chapters reporting qualitative data analysis.

39 (mother): *The other thing that I think was quite good [was] there was quite a lot of detail about what the course was going to involve and what was going to be discussed during each session and that was quite useful.*

46 (mother): *I think as well that would actually impact on whether you thought it was worth actually coming.*

[Programme C, focus group]

Parents agreed that a lack of information about what taking part in the programme would involve could be 'off-putting'. Indeed, one parent went as far as first sending her own mother along to find out more and report back to her.

I didn't actually attend the very first one, I sent my mum along first (laughs) ... and she kind of brought all the information back to me and then she sort of said "Well I've done it, why don't you do it?" So it was like "OK then."

[28 (Mother), Programme B]

The sorts of information parents valued included: what they could expect to learn and gain from the programme, the content or focus of each session, how the group was run (specifically, what they would be expected to do if they took part) and who facilitated or led the programme. Photographs of a group in progress and the facilitators were important sources of information in themselves.

I think from, just from seeing the, the first letter we got, it had sort of, it had a photograph of [the facilitators] ... [it] just looked like they [the group] were sitting chatting and having a coffee. And I think just getting that initial letter with a coffee cup on and things like that, it just made it like not formal. You, you sort of got that idea that it wasn't going to be too formal and you were going along like, rather like, like for a chat and a coffee type of thing. So that, that like made yah think it wasn't going to be too scary. (laughs)

[31 (Mother), Programme B]

Practical issues of access

Timing of sessions

A practical consideration clearly important to families thinking about attending a parent-training programme was the timing of the meetings. This was particularly evident in terms of issues of childcare and paid employment. Most programmes were delivered during the day, but two of the programmes were being delivered through day and evening groups.

All the daytime groups fitted within the school day and were run during term time. This obviously suited parents with school-aged children who were not in (full-time) paid-employment. Not surprisingly, it was fathers who were more likely to be excluded from daytime groups. However, some parents reported having flexible employers who had allowed them time off to attend the group. Others had taken annual leave to accompany their partner to at least some of the sessions. Self-employed parents, whilst more likely to be able to organise their work in such a way so that they could attend the programme, felt that a possible loss of earnings or earning potential could be a barrier to take-up. Parents who worked shifts reported that plenty of advance notice of the dates and times assisted with them planning or requesting changes to their shifts.

Preferences for the precise timings of the daytime groups differed between parents in paid employment and those who were at home with their children. Working parents suggested that the groups should be held at the beginning or end of the working day as this would be the least disruptive. However, these timings would not suit parents of children with childcare responsibilities. For example, parents who attended a programme being delivered in their

children's school expressed a preference for meetings to start at the beginning of the school day so as not to 'take up' all their day.

The main advantages of evening meetings were that they may be more accessible for parents reliant on family for childcare and for parents in paid employment. Evening meetings may also be more suitable when parents wish to attend together. However, it is worth noting that one parent who attended a programme which ran in the evening described finding it difficult to maintain her full concentration and interest for the duration of a session after a full day at work.

Meeting childcare needs

For parents with pre-school children or those attending evening groups, the need to find, and sometimes pay for, suitable childcare could be a significant barrier to parents deciding to attend, and continue attending, a parent-training programme. For some, the nature of their child's condition restricted access to informal child-care.

The other issue is if it's an evening one, ... if it's an autistic child, child on the autistic spectrum, you can't just get a normal babysitter in as such.

[45 (Mother), Programme C, focus group]

One of the programmes provided crèche facilities for parents with pre-school children. (However, parents noted that this provision was not available for children aged under one year.) Another programme allowed parents to bring their younger children along to sessions. Parents reported that without these facilities, they would not have been able to attend the group.

A lack of childcare – provided either by the programme or through informal networks – also meant it was often impossible for parents or partners to attend group meetings jointly.

Costs

When clearly a necessity one of the parent-training programmes provided support with transport costs. One parent reported she would have been unable to attend this programme if her taxi fares had not been covered.

Location

Some parents travelled considerable distances by car or undertook complex and inconvenient public transport journeys in order to attend a programme. A willingness to undertake these journeys could be seen as reflection of their need for support.

It was clear from parents' accounts that running the programme in areas considered 'unsafe' (especially when groups took place in the evening) or where there were insufficient parking spaces could be barriers to parents' joining or continuing to attend a programme.

The duration of programme and sessions

The programmes ranged from six to twelve weekly sessions, with each session lasting between two to three hours. It was clear from some parents' accounts that committing time to attend a programme had been carefully weighed up and parents had to be sure it was worth that investment of time:

... Hours and minutes are precious when you've got young kids, even normal kids, so, you know, that has to be weighed up.

[38 (Father), Programme C, focus group]

Whilst parents sometimes described the longer programmes as a 'massive commitment'⁸, this lengthy duration was, for some parents, particularly appealing.

And I felt, when I saw how long the course was, I was actually quite pleased because it showed me that this was something pretty serious and this wasn't going to be some glib superficial overview. We were actually going into this properly and that pleased me and I think it was quite a commitment.

[15 (Mother), Programme A, focus group]

The 'new-ness' of the experience

An existing relationship with the programme facilitators

Many parents already knew the programme facilitators because they or their child was using another service provided by those individuals (e.g. school, CAMHS community learning disability team; autism assessment service). Parents therefore felt they already had some sort of personal relationship and trusted them.

A familiarity with the individuals delivering the programmes appeared to be a key factor in parents' decision to take part in the group. It also helped 'to break the ice' at the first session.

I was quite confident just going, cos I knew [facilitator 1] as well and I knew [facilitator 2] with him [child] going to that school. So it wasn't like I was on me own or not like I didn't know anybody

[26 (Mother), Programme B]

In contrast, parents who did not know the programme facilitators beforehand recalled feeling apprehensive about what the facilitators would be like, either as individuals and/or whether they would be good at working with parents. If parents had not encountered a particular profession (for example, clinical psychology) before this could also cause uncertainty or anxiety in terms of the practitioner's role, contribution to the programme, and areas of expertise.

The familiarity of the location

Delivering the programme in a familiar location, such as in local schools and children's centres, appeared to support take-up.

I think if you know people and you know the venue and you know people in the venue you, you know, you don't feel as if you're sort of walking into the, a strange building by yourself

[28 (Mother), Programme B]

Being able to attend with someone else

Across all the parent-training programmes, parents were welcome to attend sessions with their partners or others involved in the care of the child or with others in a supporting role.

Sometimes the main objective of attending with someone else was because of a shared desire for support with the child's behaviour. In these instances, it was partners, grandparents or the child's teaching assistant/support worker at school who co-attended. However, on occasion the main or dual purpose of bringing someone along to the sessions was as a source of support for the parent. Partners, grandparents, aunts or older siblings fulfilled this role. It is important to note that, as well as supporting attendance *per se*,

⁸ [17 (Mother) Programme A].

parents also said going with someone else gave them the confidence to take part in the session once there.

[Attending with husband helped] 'cause when I go somewhere with him I'm a little bit more confident. I'm not very confident on my own.
[41 (Mother), Programme C]

[Taking mother along helped] because I have a bit of agoraphobia, in that, in the way that I don't like to go out alone, so it really helped me with being able to go. I don't think I'd have been able to do it otherwise. I'm not saying other people wouldn't have been able to do it, but I personally wouldn't have been able to do it.

[16 (Mother), Programme A]

Perceptions of the programme facilitators

Facilitators perceived as experts

Parents viewed the facilitators as experts in the fields of childhood disability, autism and behaviour management. For some parents, the opportunity to access this expertise and specialist support was the main reason behind the decision to attend a parent-training programme.

I knew that if we're getting that sort of professional [input], that was really appealing.

[20 (Father), Programme A, focus group]

Facilitators existing knowledge of the children

A programme being run by facilitators with a prior knowledge of the children represented in the group was seen by parents to increase the likely effectiveness of the programme.

Oh definitely, yeah, cos [the facilitator] don't want to be coming into a, into a room full of parents and not know each child, you know, otherwise they'd be giving us tips for someone else (laughs).

[26 (Mother), Programme B]

Concerns about joining a parent-training programme

Parents recalled the sorts of concerns they had about attending a programme. The nature and extent of these concerns varied between parents.

The group format

Many parents recalled that being worried about joining a group and having to speak up in a group setting. In particular, parents' anticipated they would have to disclose personal or 'private' information; some were also concerned that they would find themselves getting upset in the group.

I was concerned that I wouldn't get too upset at these meetings because sometimes talking about these issues really digs deep into your heart, doesn't it? And I could cry quite easily at some of them and I was a bit nervous that I would get upset, but I found that in fact, as we spoke – I mean, one or two people did get upset from time to time, but it was okay because we had enough rapport between us for that to be okay.

[15 (Mother), Programme A, focus group]

A number of mothers believed the group format may particularly act as a barrier to fathers accessing such programmes. Indeed, some mothers said their partners were put off attending groups because of this concern.

I have to say, I mean, my husband only came to one or two because he's not really a group person. He came along when we had a one-to-one session with the Psychiatrist as part of the, you know, programme because that was going to be the small one, and that's what suited him much better. But he just couldn't ... he wasn't up to the rest of it. It wasn't his thing.

[15 (Mother), Programme A, focus group]

Well first of all me husband didn't want to go to the groups cos he thought "Oh no, I'm not going to sit and talk about my private life in front of everybody".

[31 (Mother), Programme B]

Fear of negative judgements

A few parents reported they had been worried that their parenting skills would be judged in some way, or they would not be as good a parent as others attending.

I was a bit apprehensive that it might be, I should say, too goody-goody, you know. But we're all parents at the end of the day, and there are times when, no matter what you put into place, you just lose the plot and screech and, you know (laughs) things like that. And you're, you're worried about that sort of side of it, you know, you just imagine it'd be too much.

[49 (Mother), Programme D, focus group]

I think when I first, when I first went I thought ah God, am I going to be the, the only one with problems, but then when yah get there and realise that there's other people in exactly the same position you realise that you're OK (laughs) you know.

[31 (Mother), Programme B]

[At the outset] I was a very closed person, I thought it was a failure to have to ask for help, that as the parent I should deal with everything.

[28 (Mother), Programme B]

Indeed, one parent feared that acknowledging their parenting problems might instigate some sort of official involvement in their lives.

Yeah, I was because I thought am I going to go into this room and say to a, like a psychologist and a head teacher that I can't cope with my child. (laughs) So I thought oh God, what, what'll happen? Will, will they get Social Services involved and, and stuff like that. So it was a little bit scary.

[31 (Mother), Programme B]

Motivations to take-up a parent-training programme

Parents reported one or more reasons why they were both motivated to take-up the offer of parenting support. The most frequently reported reasons were:

- to learn how to better manage their child's behaviour
- an opportunity to learn more about their child's condition
- to meet with other parents in similar situations.

Generally, parents' motivations or goals were consistent with the aims of the programmes they attended.

Learning strategies to help manage their child's difficult behaviours

Unsurprisingly, one of the main reason that motivated parents to attend a parent-training programme was for help to manage their child's difficult behaviours. The types of behaviours parents wanted to work on were wide-ranging including: managing feeding, hygiene/toileting, dressing, bedtime; managing/pre-empting anger and agitation; improving behaviours with siblings and peers; improving communication and social skills; and reducing disruptive, non-compliant or destructive behaviours.

Learning about their child's condition

The autism-specific programmes were particularly seen as meeting parents' desires to learn and understand more about their child's condition, and this was a key motivation to attending a programme.

I think we – like I say, we'd relatively recently had a diagnosis and the fact that somebody was running a course that was going to tell us all about Asperger's Syndrome, everything about it and how we're going to deal with it, it was just like, this is just what we need and we were really excited about coming to something like this 'cause we thought, you know, the fact that there's help, if you like, and this education, if you like, is available to us, we'd be silly to not come.

[39 (Mother), Programme C, focus group]

Interestingly, some of the fathers who were interviewed seemed to particularly view the programme as a source of information about their child's condition.

You see your Consultant every three months, so there were nowhere to get information from; we didn't know where to get information from. When sort of things like this – and again, at Consultant, we said, "Look, we need help on this, what, you know, we know we've got this child in this box, what do we do?"

[45 (Father), Programme C, focus group]

Perhaps men are just look for something different in it. I don't know about you, [name of another father], but I thought it was more about learning, rather than it being a, sort of, I don't know, self-help group [laughs] where you're going more for therapeutic, exactly, so I think different requirements.

[14 (Father), Programme A, focus group]

An opportunity to meet other parents

The opportunity to meet and share experiences with other parents was another important factor in encouraging take-up. Parents regarded the group as a potential source of social or emotional support and as an opportunity to learn from other parents.

... you can feel very, very isolated as a parent of a child on the autistic spectrum ... it's a real comfort to know, you know, there's other people just like you.

[46 (Mother), Programme C, focus group]

... so this was the first chance I've ever had to meet with anybody else ... so I hoped that that would kind of be an opportunity to talk to others and see how they were managing ...

[25 (Mother), Programme A, focus group]

Other motivations

Other motivations reported by parents for going along to a parent-training programme included becoming 'better' and 'more confident' parents; improved communication with their children; a happier family life; and more information about other sources or support for their child and family. Additionally parents cited reasons related to their own emotional and psychological well-being, such as wanting to feel 'better able to cope', 'less stressed', 'more positive' and 'in control'.

Readiness to engage

In addition to the factors which motivated parents to take-up the offer of attending a parent-training programme, several parents also reported a sense of 'readiness' to engage in a programme which may require them to change their parenting approach. This notion of 'readiness' encapsulated two elements: a recognition by parents that they were struggling with their child's behaviours, and an acceptance that they needed 'expert' help to address these problems.

I think, as a person, I was ready, I needed some help so that I was ready to go and ready to like ask for help. So it was quite easy for me.

[31 (Mother), Programme B]

So, I mean, I'd a couple of years of diagnosis before I went on it and, you know, really I should have gone on it the first time really because I think I would have felt a lot better about things, definitely [but ...] if you're not in the right place, you're not in the right place.

[12 (Mother), Programme A, focus group]

[The psychologist] give yah advice to go there but I think in yourself you, you know it's there and you've just got to be ready and think right, I'm ready to go to this group, do you know what I mean?

[26 (Mother), Programme B]

6.3 Factors supporting on-going attendance and engagement

So far the factors which influenced parents' decision to take-up the programmes have been described. Some of those factors (particularly motivations to attend, childcare, attending with someone else) also played a role in parents continued attendance and engagement with the programme. In this section the focus is on on-going engagement or 'intervention retention', and the factors which, based on parents' accounts, supported on-going attendance and engagement. Before turning to this, data on retention rates across the four programmes is discussed.

Retention rates

Table 6.1 reports retention rates for each programme. Drop-out was defined as ceasing to attend a programme as opposed to missing one or two sessions due to extenuating circumstances. The research team identified drop outs from programme and drop-out status was confirmed by the programme facilitators.

Table 6.1 Mean rate of retention by parent-training programme and research site

Programme	Duration (weeks)	Parents/carers who started programme (n)	Parents/carers who completed programme (n)	Retention rate (%)
Programme A	11	49	44	90
Site 1		23	22	96
Site 2		9	8	88
Site 3		17	14	82
Programme B	6	42	36	86
Site 1		36 ^a	30	83
Site 2		6	6	100
Programme C	6	46	43	93
Site 1		15	13	87
Site 2 ^b		46	43	93
Programme D	10	75	63	84

^a Four of these parents had already attended Programme B on a previous occasion.

^b Only 4 groups included in figures since the data was incomplete for the 5th group.

Overall retention rates across the programmes ranged between 84 per cent and 93 per cent. It also varied within programmes, typically to a lesser extent, between the different sites delivering it.

It is important that these differences in retention rates are viewed in the context of the population from which the parents were recruited. Programmes B and D were being delivered to parents from 'harder-to-reach' groups as indicated by lone-parent status and qualifications at school leaving age compared to Programmes A and C (see Chapter 3). In addition, one of the sites delivering Programme B (the programme with the highest drop-out rate) had a policy of encouraging parents to attend one of its groups on more than one occasion in order to 'top up' their skills. This may partly explain why more parents did not complete this programme as parents felt more able to take a 'pick and mix' approach to attendance. It is interesting that the length of the programme does not appear to be associated with retention.

Reasons for failing to complete the programme

The reasons for non-completion of a programme fell into two domains: extenuating circumstances and, more unusually, 'difficulties' with the programme. Extenuating circumstances included: family bereavement; getting a job; and ill health. 'Difficulties' with the programme included a parent feeling isolated within the group because their child had more complex difficulties than others, and, in terms of autism-specific interventions, the content of the programme 'forcing' a parent to confront or face the possibility that they may also have an autistic spectrum condition.

Overview of factors supporting retention to the programme

An additional and different set of factors emerged from parents' accounts, which supported their on-going attendance and engagement with the programme. These were:

- the group
- the programme approach
- the facilitators
- managing missed sessions.

Each of these factors will be described in turn. First, though, it is important to draw attention to the fact that parents did not spontaneously mention that changes or improvements to parenting and/or child's behaviour acted as a motivator to continue attending the programme. This is somewhat unexpected given that we know most parents reported positive outcomes at the end of attending a programme (see Chapters 7 to 10). It may simply be that these changes or improvements were viewed by parents as the ultimate outcomes of the programme, as opposed to playing a role in their on-going engagement.

The group

Despite the initial concerns about joining a group reported earlier, soon 'the group' became a key factor supporting on-going engagement with the programme. The relationships being forged with other group members, sharing experiences, and the offering of mutual support were enormously attractive.

The so-called professionals, they might know, they might have read the textbook, but they don't understand. They don't understand the situation ... until you've been in that situation, you don't know. But to have people around who does know and does understand, that makes a [difference].

[45 (Father), Programme C, focus group]

Well sometimes I get really nervous being in groups, especially with people I don't know, but I did feel comfortable within that group [because of] the openness of some of the parents.

[1 (Mother) Programme A]

Importantly, among the parents from black and minority ethnic (BME) groups interviewed, this was also their experience.

Because sometimes you don't want to tell people how your children ... [are] but when you are together (...) you have confidence.

[51 (Mother, Black African), Programme D, focus group]

I wasn't ashamed to talk about my child, which I sometimes feel when I go among parents with ordinary children with no disability.

[43 (Mother, Black African), Programme C]

Indeed, for some parents the opportunity to share with and learn from other parents was ascribed as the main reason for attending and the positive outcomes they had experienced.

We probably would have taken that time more just as a group for a chitchat because we found a lot of it was very useful. In the free time, like in the coffee break, it was like you couldn't get to speak to people quick enough to discuss your problems with your children. 'Cause it was very helpful to speak to other parents and that time was precious and I would rather have had that time doing that ... just having a general chatting session.

[23, (Mother), Programme A, focus group]

The approach and skills of the facilitators, the use of 'ground rules' and the 'friendliness' and 'openness' of other parents were reported as reasons why parents felt enabled to share with and participate in the group.

Well we had rules at the start, didn't we? We sort of like, we made our own rules at the start that, you know, we would agree to differ and we would, obviously what was said in the room stayed in the room, you know. So you, because you're making the rules yourselves, you feel more confident about what you're saying, you know, you're happy to talk about, I mean obviously like the first session, everyone's a bit, but after that, and you sort of really get into it...

[49 (Mother), Programme D, focus group]

At the same time it is important to note parents observed that not all parents contributed, or got involved in, the group as much as others. They wondered if these parents had found being part of the group such a positive and helpful experience.

There were a few who were quite quiet all the way through and I hope that they learnt as much and got as much of what they wanted out of it as those of us who were more vocal and more, sort of, more united ... and more supported as a couple in what we were doing with our children.

[13 (Mother), Programme A, focus group]

In addition, it was also clear from parents' accounts that the groups were not equally supportive and cohesive. Dominating or irritating personalities were cited as reasons why groups did not properly "gel" or had not become as supportive as they could have potentially been.

Very few negative experiences of the group were reported. The most frequent complaints were feeling that some sessions were rushed and that there was insufficient time to cover the programme material as well as respond to issues raised by parents in group discussions. This proved to be a particularly difficult experience when there was insufficient time to deal with another group member who was upset. Parents also expressed frustration when facilitators did not move the group on when a parent went 'off topic'.

That just means they [facilitators] need better time management. They need to be better at telling us to shut up (laughter), 'cause we do talk quite a lot!

[38 (Father), Programme C, focus group]

The composition of group

Given the importance of the group in maintaining engagement in the programme, the way the group composition affected parents' experiences of their group was explored in detail.

Some parents valued homogenous groups in respect of the age, disability and severity of condition of the children represented. These parents believed this provided the greatest opportunity to meet, share with and learn from other parents whose experiences chimed with their own. Indeed, a few parents reported feeling uncomfortable in a group where their

child's abilities were considerably greater or less than those of the majority. For example, one parent also described how attending her group had made her feel "*disillusioned, demoralised and not at all positive*" [8 (Mother) Programme A]. She felt the other children represented in the group were more 'academic' and, as a result, all the other parents had discovered their child was particularly good at something.

Others, however, had enjoyed being part of a more heterogeneous group, with a range of ages and disabilities represented. These parents believed this had enhanced their learning by providing a wider range of experiences to draw upon and discuss. In particular, many parents of younger children valued the opportunity to learn from the experiences of those with older children.

... everyone had a child of a different age range as well so it was great cos you could confide in each other and give each other, you know, advice on what you've learnt.

[50 (Mother), Programme D]

Equally, being the parent of one of the older children represented in the group could be a positive, affirming their own earlier experiences.

Around two-thirds of the groups comprised of both mothers and fathers, and this was never raised as a problem by interviewees. However, the mothers who had attended a women-only group, felt that having fathers present would have hampered group intimacy.

Size of the group

The groups attended by parents varied in size from four to 21 participants. Both parents who had attended smaller groups and those who had attended larger groups spoke positively about 'their group'. The main benefits of a smaller group emerging from parents' accounts were that they afforded greater informality and opportunities to share and discuss. The advantages parents perceived of larger groups were that they provided greater collective experience to draw upon.

The programme approach

All the parent-training programmes took a collaborative, as opposed to didactic approach. Whilst each had some more formal teaching elements (for example, on the principles of behavioural approaches to managing difficult behaviour, understanding ASC), emphasis was also placed (to a greater or lesser extent) on the group discussing and generating options and strategies. Parents responded very positively to this approach and it clearly supported their on-going engagement with the programme.

As reported earlier, some parents were nervous about being judged and being told they were doing things wrong. Their actual experiences were, however, in marked contrast. The great majority of parents said they felt empowered by the approach taken by the programme. The value placed on their own knowledge and experiences particularly supported their sense of empowerment. They appreciated being recognised as the experts on their own children, and having their views taken seriously.

... [the facilitator] said that was because "only you, as a parent, really knows your child".

[27 (Mother), Programme B]

I think the fact that it was a small informal group, so by the very nature that it was, it tended to be interactive and it felt more like a two-way process, not just being in a lecture room and, you know, all of us there sort of chipped in with our own experiences and, shared experiences and, and we, well I certainly felt that they were, they were valued by the, the people taking the course.

[17 (Mother), Programme A]

This collaborative approach led parents to perceive themselves as having an equal relationship with the facilitators who were commonly viewed as 'just part of the group', an impression reinforced by the facilitators sharing their own experience as parents and, more simply, joining parents at the coffee breaks.

Obviously she, she brought many a thing to the group experience-wise, but it's just the case of, you know, they're not just, she's not a clinical psychologist, she's a mum, she's a parent, and that's what she brought for the group, you know, she give you that confidence. Cos you tend to find a lot of people just say "Oh well my son does that" or "Thingy does that, it's normal, it's their age" you know, and you know it's not.

[50 (Mother), Programme D]

However, it is important to note that a few parents were frustrated by this collaborative approach. They had expected, and wanted, to be told by the facilitators what was the 'right' or 'wrong' way to parent their child.

The characteristics of the facilitators

The third key factor supporting adherence/on-going engagement with the programme were the facilitators. A number of facilitator characteristics emerged as supporting on-going parental engagement.

Approachable facilitators

The facilitators were consistently reported as playing a key role in making parents feel comfortable and at ease in the group which, in turn, meant they were likely to continue attending the programme, especially in the early days when ease and relationships between parents in the group had not yet formed. Parents recalled the facilitators' excellent 'people skills' and appreciated they way they were friendly and approachable.

But we always got a lovely welcome, didn't we, from, you know ... they'd always be someone like [name of facilitator] or the others with big smiles saying "Oh hello, come in!", you know; and that was lovely, you know ... so you think, "Oh, well I'm in the right place".

[15 (Mother), Programme A, focus group]

They were, like really approachable that, they were just so, you would sort of go in to the room and maybe [name of facilitator] would have his shoes off and (laughter) it sounds weird but if you go in and somebody's sitting with their shoes off and they're really comfortable it makes you feel comfortable.

[31 (Mother), Programme B]

Facilitators' group work skills

Parents were also conscious of facilitators' skills in managing groups and leading discussions. They noticed that the facilitators were skilled at listening and ensuring all parents contributed and participated to the extent they were comfortable with, and provided encouragement and reassurance when needed.

They kind of sit back but they are aware, and if, obviously if you're getting a bit upset with things like that they will step in and maybe change the subject or move on to another person. It's, well just like together like it's brilliant, they're just brilliant support. They can kind of, I think because they've been obviously in their jobs for years, they can tell and they know.

[28 (Mother), Programme B]

The perceived commitment of the facilitators

Across all the programmes, parents perceived the facilitators as having a genuine concern for them, and a real desire to help them, often commenting on how facilitators were prepared to come in early and stay late to talk to parents individually. As well as helping to build on and maintain relationships with the facilitators, it helped parents to feel valued and more positive about the programme.

[The facilitators] were lovely, they were all really nice ... they were easy to talk to and they seemed really nice people, so – and they didn't seem – you didn't feel like you were a bother to anybody.

[16 (Mother), Intervention A]

The facilitators also appeared to really enjoy running the programme, which added to parents' sense of being in the 'right place' and again supported their ongoing engagement.

Well they love doing it, don't they? I mean, it's, you know, they really enjoy it.

[12 (Mother), Programme A, focus group]

Managing missed sessions

Inevitably, some parents were not able to attend all the sessions of their parent-training programme due to illness, holidays or other commitments.

The strategies programmes used to manage missed sessions varied. All the programmes passed on copies of any handouts from sessions that had been missed. Some also provided a one-to-one 'catch up' with one of the group facilitators either at home, over the phone, or at the beginning or end of the following session. Parents reported that this support to catch up was an important factor in helping them continue to attend and complete a programme. However, not all parents received this support or were satisfied with the support they did receive.

Yeah, well, they were meant to go through it – [name of facilitator] was meant to go through it with me, but, like I say, we never – they've got – she was just, sort of, saying they've got a long waiting list and that they needed to see other people, so I felt a bit – I felt like I shouldn't be using their time when other people needed them.

[16 (Mother), Intervention A]

... we just got photocopied material, which I don't think was ideal.

[46 (Mother), Intervention C, focus group]

6.4 The experiences of minority groups attending the programmes

This final section focuses specifically on reporting the experiences of parents who were in a minority in their groups, specifically parents from minority ethnic groups and fathers.

BME parents

Parents receiving the programmes and participating in the research were predominantly white British. However, one of the programmes (D) was delivered to a more ethnically mixed group. The BME parents from these programmes said they had valued the diversity within the group they had attended and the wide range of experiences that were shared. They commented that ethnically mixed groups were 'less isolating' than being in a group solely for parents from the same ethnic group.

... [a] mixed group is fine because then you can listen to other people's views and how they manage [child's autism]. Because sometime Asian people, we have sort of the same, similar things like that [views]. We can then find out different views in a mixed group.

[48 (Mother) (Pakistani)]⁹

The view was also expressed that it was the child's disability which was the common thread that bound the parents together. Sharing the same problems in respect of their child's disability and behaviour, transcended any racial and ethnic differences.

Using interpreters

An interpreting service was provided at this programme. Parents who used interpreters reported that they had been able to keep up with what the facilitators were saying, take part in group discussions and ask questions if there was anything that was unclear or anything else they wanted to know. In some cases, interpreters also translated the session handouts for parents.

These parents noted that successful communication depended upon the facilitators' skills in working with the interpreters, particularly in allowing enough time for interpretation of both the facilitators speech and parents' responses and contribution. In order to provide continuity to the parent and interpreter, and to the facilitator and wider group, parents felt it was important that the same interpreter attended all the sessions.

However, not all parents with limited English chose to have an interpreter at the sessions. Some preferred to manage on their own as they felt they would not learn as much if an interpreter was there to 'do the job' for them. Others did not want to hinder the group dynamic by introducing an interpreter and, therefore, interrupting the flow of discussion. (Interestingly, one of the researchers noted that one parent who used an interpreter in the research interview chose not to use an interpreter for the parenting programme itself. The reasons behind this decision were not explored with this parent, but it suggests that not all parents who needed language support in the parenting groups, sought out and/or received this support.)

It is not possible, however, to determine how accurately parents with limited English, regardless of whether or not they used an interpreter, were able to follow all the groups' discourse. There was some initial concern amongst BME parents not using interpreters that

⁹ Programme identity withheld to protect anonymity.

they would not understand what was being said, and also some acceptance that they would understand the gist of what was being said if not the detail.

Fathers

As reported earlier, the programmes were predominantly attended by mothers. However, the fathers did not perceive being in the minority as a problem, even when they were the only male in the group. Again, it appeared that shared situations and experiences cut across gender differences.

Fathers did acknowledge that a support group could be an uncomfortable environment for men. Indeed, this was initially the experience of some of the fathers interviewed.

I think women find it easier to talk about things generally about their children because I think it's - I don't want to be stereotypical here - but, you know, obviously you [mothers] bring the children up and you go to the playgroups together and things like that; whereas blokes are supposed to go out and work and do those things. I know it's changed, but I think it was difficult for ... not difficult, it was a bit harder for us to come in, or for me, to come in and, sort of, you know, sort of, be comfortable with it. But after the first session you got used to it and it was fine.

[10 (Father), Programme A, focus group]

6.5 Summary

This chapter has reported findings from a very rich qualitative dataset on the factors which influenced parents' decisions to attend a parent-training programme, and those which supported their on-going attendance and engagement with the programme. Whilst it was not possible in this study to include parents who had turned down the invitation to attend a parent-training programme, we would suggest it is possible to draw some conclusions about what might be 'getting in the way' of a parent attending a parent-training programme.

First, it is clear that a number of factors are at play when parents are deciding to take-up the offer of a place on a parent-training programme. Parents have a range of concerns and information needs which, unless addressed, can act as barriers to take-up. The support and encouragement of a trusted practitioner can be an important factor in this process. We would also highlight the way that a lack of access to child-care can prevent parents even giving proper consideration to attending a programme.

Second, the group format typically generates high levels of unease and anxiety and can be very off-putting for parents. Paradoxically, once parents have joined the programme, it is 'the group' which is one of the main factors which means they continue to attend. Portraying the benefits of 'the group' as well as allaying concerns would seem to be important areas on which to focus in the information provided to parents.

The notion of parents feeling 'ready' to tackle their child's behaviour emerged from parents accounts. 'Readiness' features strongly in practitioners' views about factors influencing take-up, and is more fully explored in Chapter 5.

The high rate of retention to the programmes suggests that, once parents decide to attend, then the experience of the programme is effective in supporting on-going engagement. At this stage, the group format appears to play a very important role in retention. Specifically, parents develop relationships with and a commitment to each other, and they also find other parents are a source of practical and emotional support. However, it is important not to

ignore the experiences of a small minority of parents for whom the experience of being in a group was not at all positive and, in a sense, could be portrayed as harmful.

Parents typically responded to and endorsed the family partnership¹⁰ approach which each of the parent-training programmes adopted. However, once again, it is important to note that a small number of parents found this approach unsatisfactory as they had been hoping for a more prescriptive approach.

However, whilst a minority of parents did not find attending the programme a positive or enjoyable experiences, in terms of the parents we interviewed, it was not cultural or ethnicity variables which identified this minority. Overall, BME parents who had attended a programme spoke very positively of their experiences. Even the use of interpreters had not, for the parents we interviewed, inhibited their inclusion and participation in the group. Indeed it would seem that the shared experience of having a disabled child has the potential to cut powerfully across cultural, ethnic and gender differences.

¹⁰ The Family Partnership Model (Davis *et al.*, 2002; Day, C. & Davis, H., 2009) advocates a collaborative approach to working with families in which professionals seek to combine parents' and professionals' expertise in order to develop and build parental self-efficacy and identify effective and realistic problem management strategies.

Chapter 7

Intervention A: A Group-Based Parent-Training Programme for Parents of Children with Autistic Spectrum Conditions

In this chapter we report findings on the effectiveness of a group-delivered parent-training intervention for parents of children who have autistic spectrum conditions.

Main findings

- There is evidence that at least some parents of children with ASC will benefit from attending this programme both in terms of their sense of satisfaction as a parent and their child's behaviour.
- At 24 week (6 month) follow-up, progress towards achieving parent-set goals for child behaviour was observed for 96% of goals.
- There is evidence to suggest that parents of children with Asperger's syndrome or Higher Functioning Autism are more likely to experience greater improvements in parent and child outcomes compared to parents of children with ASC and learning difficulties.
- Improvements on some parent and child outcome indicators were maintained at 6 month follow-up.
- The mean cost of delivering the intervention was £5,750. The cost per person per session ranged from £36.6 and £155.10

7.1 Overview of the intervention

ASCEND (Autism Spectrum Conditions – Enhancing Nurture and Development)	
Aims	To increase understanding of children with ASC, to empower parents to address specific behaviours and to support their child's behavioural development.
Target population	Parents of children newly or recently diagnosed with Autism Spectrum Conditions (ASCs). Separate groups for Autism and Asperger's with appropriate adaptations. Grandparents and professionals may also attend.
Age range	Pre-school to 19 years.
Structure & approach	11, weekly 2 ½-hour sessions. (Max. group size=20 (representing 8-10 children)) Manual sets out session structures and content, also contains handouts and other teaching materials. Five sessions concerned with increasing parents' understanding of autism; five sessions concerned with behavioural theory principles and behaviour management; final session is recap and consolidation. Training approach includes: recap of themes introduced in previous week; introduction of new topic with demonstrations and case examples; group exercises to reinforce key messages of week's theme; group discussion.

7.2 Overview of the investigation

Design	Controlled trial. Comparator (or 'no intervention') group drawn from programme waiting list. Groups well matched on socio-demographic and baseline scores. Outcome measures administered: pre-intervention; post-intervention; 12 weeks follow-up; 24 weeks follow-up (IG only). Rating of achievement towards parent-set goals: baseline (week 7 of programme; post intervention; 12 & 24 week follow-up).	
Outcomes	<ul style="list-style-type: none"> Parent-set child behaviour goal(s). Standardised measure of Parenting Sense of Competence (PSOC; Johnston and Mash, 1989) <ul style="list-style-type: none"> PSOC-Satisfaction subscale (satisfaction with the parenting role) PSOC-Efficacy subscale (feeling of efficacy as a parent) Two standardised measures of child behaviour: <ul style="list-style-type: none"> Eyberg Child Behaviour Index (ECBI; Eyberg and Pincus, 1999): <ul style="list-style-type: none"> ECBI-Intensity (IS): frequency of disruptive behaviours ECBI-Problem (PS): no. disruptive behaviours problematic to parent Challenging Child Behaviour Scale (CCBS; Bourke-Taylor et al, 2010) 	
Sample	Intervention Group	Waiting List Control Group
Children	n=36	n=21
Age of child (Mean (SD))	8 yrs (3.53)	9.95 yrs (3.74)
Male (%)	33 (91.7)	18 (85.7)
ASC and LD	21 (58.3%)	8 (38.1%)
Specialist education	14 (38.5)	3 (14.3)
Parents	n=41	n=21
Mother (%)	35 (85.4)	19 (90.5)
Two parent household (%)	31 (79.5)d	18 (85.7)
Higher Education (%)	24 (66.7) d	10 (47.6)
White British (%)	27 (69.2) d	21 (100)
English First Language	34 (87.2) d	21 (100)
Response rates: 77% (post intervention); 74% (12 wk f-up); 51% (24 wk f-up, IG only).		
Intervention integrity	90%.	

7.3 The evidence of effectiveness

Parent-set child behaviour goals

During session seven of the programme, when parents work with clinicians to develop strategies to work on one of the challenging behaviour problems they are facing, parents set up to three behaviour related goals for their child.¹¹ These would often be behaviours that are related to the child's autistic spectrum condition, for example, 'stop kissing a wall in kitchen'. Post intervention, over 70 per cent of goals they set had improved¹² (see Table 7.1).¹³ Only one goal had deteriorated from when it was set. Twelve weeks after the programme had finished, improvement had increased to 87 per cent; by 24 weeks post-intervention 96 per cent of goals had improved from when they were set. Only one goal was rated as having not changed. A sizeable proportion of the goals set continued to improve post-intervention with over half (56%) of goals showing further improvement from post-intervention to 12 week follow-up and 44 per cent showing improvement from post-intervention to 24 week follow-up.¹⁴

Table 7.1 Direction of change for parents who set behaviour goals for their child

Change in goal attainment rating	Time Period		
	Baseline ¹ to post-intervention (n=43 goals)	Baseline to 12 weeks f/up (n=30 goals)	Baseline to 24 weeks f/up (n=22 goals)
Improved	31 (72.1%)	26 (86.7%)	21 (95.5%)
No change	11 (25.6%)	4 (13.3%)	1 (4.5%)
Deteriorated	1 (2.3%)	0 (0%)	0 (0%)

¹ Baseline is week 7 of the programme when the goals were set.

Mean scores doubled from baseline to post-intervention and continued to steadily increase 12 and 24 weeks after the programme had finished (See Table 7.2 and Figure 7.2). These changes were highly statistically significant ($F(3)=86.6$, $p<.001$).¹⁵ Further tests explored between which time points the significant change occurred. These showed that there was significant change (in a positive direction shown by the mean scores) between when the scores were collected and each subsequent time point. This demonstrates that positive change was maintained post intervention. Whilst the scores continued to increase post intervention, these changes were not significant.¹⁶

¹¹ A 10-point rating scale was used to indicate the extent to which a goal has been achieved: 1=very far from this goal; 10=I have achieved my goal.

¹² Improvement/Deterioration is based on whether the goal scores have moved 1+ scores in a positive or negative direction.

¹³ Where two parents had set goals for the same child, goals were taken from the 'main carer' (typically the mother).

¹⁴ Descriptive data in this chapter makes use of all the data we have available. Statistical tests however will only use data where there is a complete set, e.g. data available from a person at each time point.

¹⁵ The parent's ID code was entered as a between-subjects factor into the ANOVA as some parents had given more than one goal.

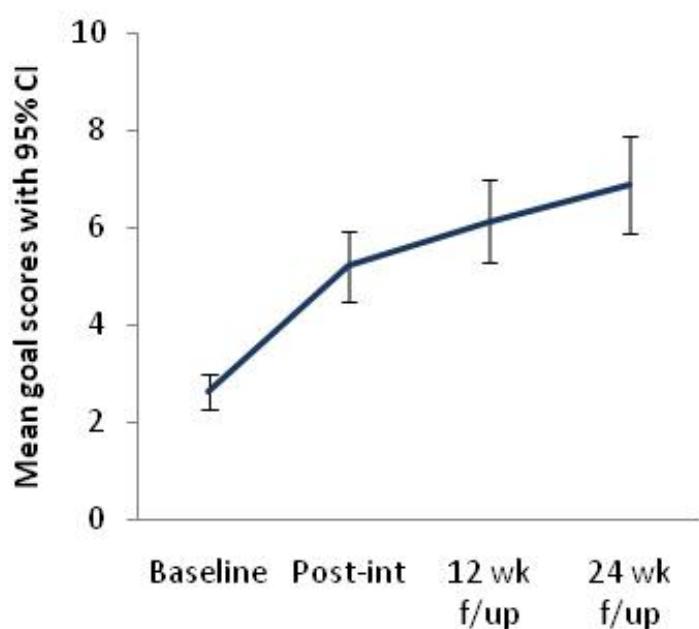
¹⁶ A Bonferroni adjustment was used to account for the multiple comparisons between the different time points.

Table 7.2 Mean goal attainment rating over time

	Baseline			Post-intervention			12 week follow-up			24 week follow-up		
	N	M	SD	N	M	SD	N	M	SD	N	M	SD
Goals	59	2.61	1.43	47	5.21	2.48	36	6.14	2.49	26	6.88	2.46

N = number of goal scores available; M= mean goal attainment rating; SD=standard deviation.

Figure 7.3 Changes in mean goal attainment: Baseline to 24 week follow-up



Parents' sense of competence

Differences in outcomes for the intervention and waiting list groups

Attending the parent-training programme was associated with a steady increase¹⁷ in feelings of parental satisfaction, represented by the mean scores for the satisfaction subscale,¹⁸ whilst scores also improved for the efficacy subscale¹⁹, with a slight deterioration 12 weeks post-intervention. For parents who had not yet attended the parent-training group, there appeared to be little change in feelings of satisfaction or efficacy, with slight movement in

¹⁷ An increased score represents improvement on the PSOC.

¹⁸ The Satisfaction subscale (9 items) of the Parenting Sense of Competence Scale (PSOC) is an affective dimension, measuring the extent to which parents are satisfied with their role as a parent, capturing parental frustration, anxiety and motivation. Scores can range from 9-54.

¹⁹ The Efficacy subscale (7 items) of the PSOC measures the extent to which parents feel they are managing the role of being a parent. It captures parents' perceptions of their competence, problem-solving ability and capability in the parenting role. Scores can range from 7-42.

scores over time (See Table 7.3 and Figure 7.3). Differences between the groups were not statistically significant.

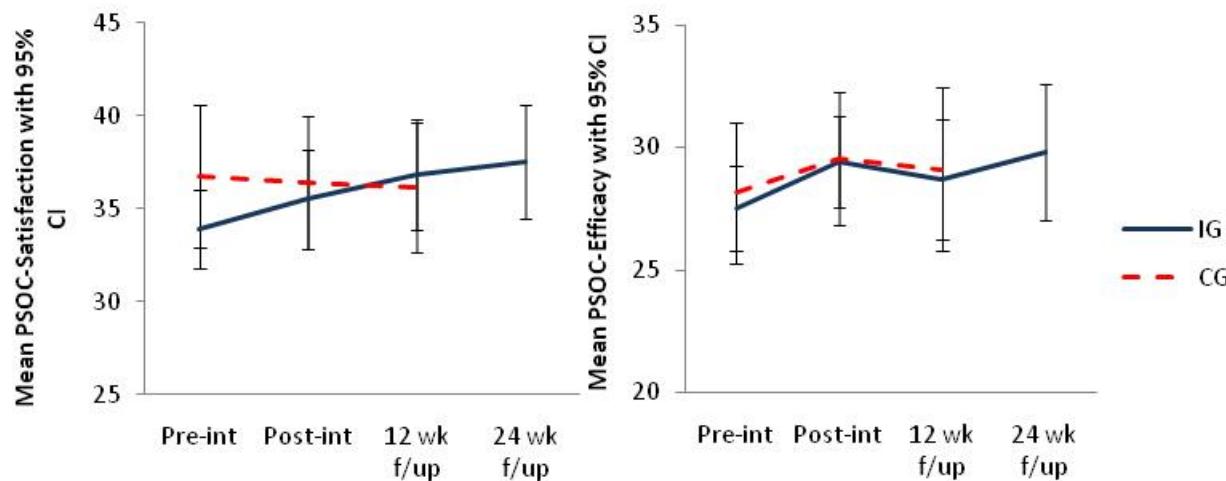
The addition of whether the child had a learning disability to the analytical model was statistically significant for the Satisfaction Subscale. Exploration of the mean scores for parents who had a child with and without a learning disability revealed that parents who had children with a learning disability in addition to an ASC generally gave lower ratings of parental satisfaction and also efficacy.²⁰

²⁰ Results of ANCOVA for whether child having a LD impacted parental sense of competence. Post-intervention: (PSOC-Satisfaction) $F(1)= 7.948$, $p<.01$, (PSOC-Efficacy): $F(1)=.321$, $p=.574$. 12 week follow-up: (PSOC-Satisfaction) $F(1)=6.634$, $p<.05$, (PSOC-Efficacy) $F(1)=1.378$, $p=.248$.

Table 7.3 Parenting Sense of Competence Outcomes

		Pre-intervention			Post-intervention			ANCOVA Pre-Post	12 wk f/up			ANCOVA Pre-12 wk f/up	24 wk f/up		
		N	M	SD	N	M	SD		N	M	SD		N	M	SD
PSOC-Satisfaction	IG	38	33.92	6.37	34	35.50	7.77	$F(1)=1.036$, $p=.314$	18	36.82	7.61	$F(1)=.963$, $p=.332$	22	37.50	6.95
	CG	21	36.76	8.41	17	36.41	6.96		18	36.11	7.02		-	-	-
PSOC-Efficacy	IG	37	27.51	5.21	33	29.42	5.22	$F(1)=1.219$, $p=.276$	28	28.71	6.31	$F(1)=.789$, $p=.380$	22	29.82	6.25
	CG	21	28.14	6.37	17	29.53	5.27		18	29.11	6.73		-	-	-

Figure 7.4 Mean Parenting Sense of Competence Scores: Pre-intervention to 24 week follow-up



The size and direction of change in parents' sense of competence

Effect statistics²¹ explored the size (and direction) of changes in parents' sense of competence across the study period, see Table 7.4 and Figure 7.4. Because of the potential impact that the child's diagnosis could be having on the effectiveness of the parent-training group, those parents who received the intervention are split into whether their child did or did not have a learning disability.

Looking first at the Satisfaction subscale it is immediately visible that parents with a child with a learning disability are not appearing to show the same effect post-intervention as those who did not. Immediately post-intervention, there is no difference between those parents who have a child with a learning disability and those who have not attended the parent group in terms of parental satisfaction, both reporting a small *negative* effect. Those parents who have children with a diagnosis of Asperger's or High Functioning Autism report positive effects which increase at each subsequent data collection point.

In terms of parental efficacy, immediately post-intervention there is a positive effect size for all parents who attended a parent training-group. However, this is short-lived for those with children with a learning disability. At 12 and 24 week follow-up there is a negative effect size for these parents suggesting that they are now feeling less confident than when they began the parenting group.

Table 7.4 Effect size for changes in scores from Pre-Intervention on Parenting Sense of Competence (PSOC)

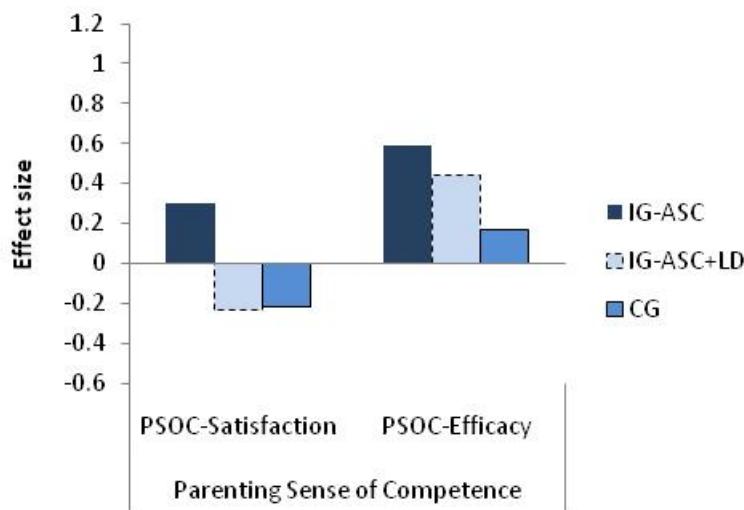
		Effect size from pre-intervention (d^2)		
		Post-intervention	Post-intervention	Post-intervention
PSOC-Satisfaction	IG-ASC	.30	.52	.63
	IG-LD	-.23	.08	.32
	CG	-.22 ¹	.01	-
PSOC-Efficacy	IG-ASC	.59 ²	.45	.37
	IG-LD	.44	-.33	-.20
	CG	.17	.26	-

¹ A negative effect size indicates a deterioration in scores between the two time points.

² Effect sizes have been reversed so that a positive effect size reflects an improvement in scores.

²¹ The effect size statistic quantifies the difference between two sets of data or between two groups. 0.2 is defined as a 'small' effect size, 0.5 as a medium effect size, and 0.8 as a 'large' effect size. In this study effect sizes were calculated within each sample (e.g. those who had attended a parent group) the effect size between two time points being calculated. Effect size is calculated by dividing the difference between the means by the pooled standard deviation (Cohen's $d = (MT1 - MTx)/SD$).

Figure 7.5 Effect sizes for changes in scores on Parenting Sense of Competence (PSOC) post-intervention



The proportion of parents who improved on the measure of Parenting Sense of Competence

Scores on the Satisfaction and Efficacy sub-scales were then examined in order to determine whether an individual's change in scores (from pre-intervention) could be regarded as 'true' changes as opposed to spurious changes caused by inadequacies in the measure. The statistic used is known as the Reliable Change Index (RCI).²² This is an important indicator of the clinical, as opposed to statistical, significance of any observed changes associated with an intervention.

Table 7.5 sets out the proportion of parents whose scores on the measure of Parenting Sense of Competence improved, did not change, or deteriorated (as classified by the RCI). Comparisons are made between those parents who attended the programme and the no-intervention comparator group. As with the previous section, parents who attended a parent training group are split into those whose child had a learning disability and those who did not.

²² A reliable change was defined as those where a score of >1.96 on the Reliable Change Index was achieved (Hawley, 1995; Jacobson and Truax, 1991). The reliable change index (RCI) for each case was calculated by dividing the difference between the Time 1 and 2 scores by the standard error of measurement (SEmeas) [RCI = $Mt1 - Mt2/Sdiff$]. Sdiff will be obtained by calculating the square route of double the standard error squared ($Sdiff = \sqrt{2(SE)^2}$). A chi-squared test will examine whether reliable change is significant across the treatment groups.

Table 7.5 The reliable change on Parenting Sense of Competence: intervention group versus control group

	Parents' sense of competence					
	Parents' sense of satisfaction			Parents' sense of efficacy		
	IG-ASC	IG-LD	CG	IG	IG-LD	CG
Post intervention						
Reliably improved	6 (42.9%)	3 (17.6%)	2 (11.8%)	6 (42.9%)	4 (25%)	4 (23.5%)
No change	7 (50%)	11 (64.7%)	12 (70.6%)	7 (50%)	11 (68.8%)	12 (70.6%)
Reliable deterioration	1 (7.1%)	3 (17.6%)	3 (17.6%)	1 (7.1%)	1 (6.3%)	1 (5.9%)
Chi-square Pre-post	<i>Fisher's Exact Test</i> =4.416, <i>p</i> =.348.			<i>Fisher's Exact Test</i> =2.169, <i>p</i> =.809		
12 week follow-up						
Reliably improved	5 (41.7%)	2 (15.4%)	3 (16.7%)	4 (33.3%)	0	6 (33.3%)
No change	6 (50%)	8 (61.5%)	12 (66.7%)	6 (50%)	9 (75%)	9 (50.0%)
Reliable deterioration	1 (8.3%)	3 (23.1%)	3 (16.7%)	2 (16.7%)	3 (25%)	3 (16.7%)
Chi-square Pre-12 wk f/up	<i>Fisher's Exact Test</i> =3.312, <i>p</i> =.550			<i>Fisher's Exact Test</i> =5.960, <i>p</i> =.206		
24 week follow-up²³						
Reliably improved	6 (54.5%)	4 (44.4%)	-	5 (45.5%)	0	-
No change	4 (36.4%)	3 (33.3%)	-	5 (45.5%)	5 (62.5%)	-
Reliable deterioration	1 (9.1%)	2 (22.2%)	-	1 (9.1%)	3 (37.5%)	-

A greater proportion of parents who attended the group and who did not have a child with a learning disability reported reliable improvement across both the satisfaction and efficacy subscales and at each follow-up time point. Considerably fewer parents with children with a learning disability reported reliable improvement. These proportions were typically similar to those parents who had not yet attended a parent training group.

Furthermore, several parents who attended the parent-group who had a child with a learning disability reported reliable deterioration. The potential that this intervention may have a negative impact on some parents' sense of efficacy should be investigated further.

²³ 24 week post intervention comparisons not possible as data not collected from waiting list control group at this time point.

Parent-report child behaviour

Differences in outcomes for the intervention and waiting list groups

Attending the parent-training programme was associated with improved²⁴ post-intervention mean scores across all three standardised measures of behaviour. Mean scores for those who had not yet attended the programme also improved, but not to such a great extent as seen in the intervention group, especially for the ECBI-Intensity²⁵ and Problem²⁶ Subscales. When compared to those who had not yet received the intervention, the change was statistically significant for the ECBI-Intensity scale (See Table 7.6). The addition of whether the child had a learning disability to the model analysing change did not add statistical significance to the model for any of these measures. However, mean scores for parents with children with a learning disability as well as an ASC who received the intervention were compared to those who attended who did not and interesting results were found. Pre-intervention, those parents with a child with a LD reported much more severe behaviour difficulties for their child than those who did not (ECBI-IS and ECBI-PS). Post-intervention, there are much larger improvements for the parents with children who do not have a learning disability, in particular for the ECBI-Intensity scale.²⁷

Overall, improvements in the ECBI-Intensity and ECBI-Problem scales appeared to be maintained post intervention, whilst steady improvement was less visible in the Challenging Child Behaviour Scale²⁸ (see Table 7.6 and Figures 7.5 and 7.6).

²⁴ A lower score represents improvements for all child-behaviour (ECBI, CCBS) measures.

²⁵ The ECBI-Intensity scale measures the frequency of disruptive behaviours by summing the frequency of each disruptive behaviour.

²⁶ The ECBI-Problem scale is a count of disruptive behaviours that the parent rates as problematic.

²⁷ Pre-intervention scores ECBI-IS: ASC only – M=128.75, SD=36.55; ASC+LD – M=144.75, SD=46.64. ECBI-PS: ASC-only – M=11.88, SD=8.34, ASC+LD – M=20.25, SD=9.32. Post-intervention scores: ECBI-IS: ASC-only – M=117, SD=23.18, ASC+LD – M=142.75, SD = 41.04. ECBI-PS: ASC-only – M=9.00, SD=8.14, ASC+LD- M=19.5, SD=7.51.

²⁸ The Challenging Child Behaviour Scale measures parents' reports of the frequency of challenging or difficult to manage behaviours in the home.

Table 7.6 Child behaviour outcomes

		Pre-intervention			Post-intervention			ANCOVA Pre-post	12 wk f/up			ANCOVA pre-12 wk f/up	24 wk f/up			Repeated measures ANOVA
	Group	N	M	SD	N	M	SD		N	M	SD		N	M	SD	
ECBI - Intensity	IG	30	140.57	33.22	26	128.19	29.26	$F(1)=4.753,$ $p<.05$	25	130.80	32.90		20	130.10	32.19	$F(3)=2.369,$ $p=.127^G$
	CG	17	132.53	35.27	17	131.12	37.67		--	--	--		--	--	--	
ECBI - Problem	IG	31	18.19	9.17	24	15.38	8.14	$F(1)=.519,$ $p=.476$	25	13.32	8.55		19	12.63	8.40	$F(3)=.937,$ $p=.396^G$
	CG	20	15.25	6.97	17	13.82	10.01		--	--	--		--	--	--	
CCBS	IG	32	34.84	7.07	28	33.25	5.89	$F(1)=.061$ $df(1),$ $p=.806$	25	35.00	6.79	$F(1)=2.160,$ $p=.150$	20	33.25	7.16	
	CG	20	34.15	8.02	16	33.06	7.20		17	31.47	8.32		--	--	--	

¹ Greenhouse Geisser adjustment.

Figure 7.6 Mean ECBI scores: pre-intervention – 24 week follow-up

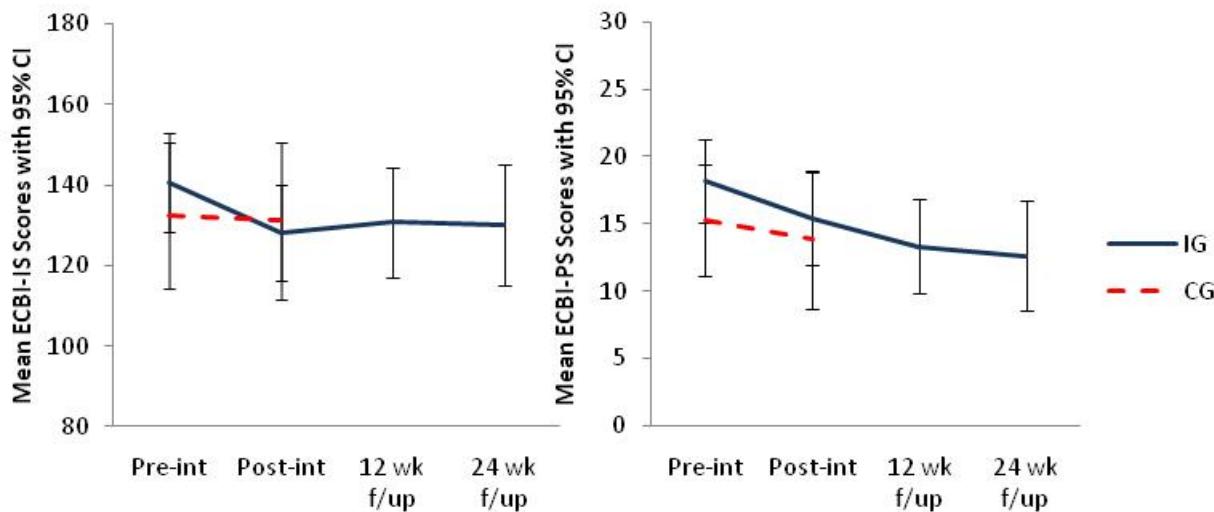
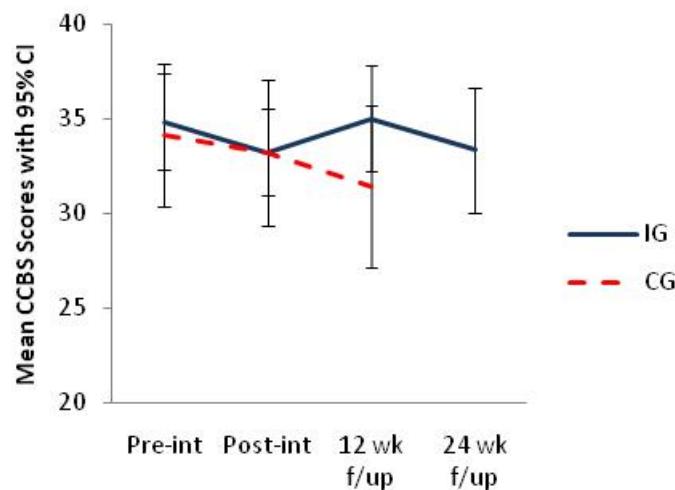


Figure 7.7 Mean Challenging Child Behaviour Scale scores: pre-intervention – 24 week follow-up



The scale of improvement in parent-report child behaviour

Overall, the size of improvement in scores on parent-report measures of child behaviour was greater for parents who had received the intervention and whose child did not have a learning disability. By 24 week follow-up, this group was showing medium effect sizes across each of the measures of child behaviour. In comparison, those parents who had attended a group with a child with a learning disability demonstrated small effect sizes, with the exception of the ECBI-Problem Scale at 12 week follow-up where a small-medium effect was found. Post-intervention effect sizes are greater for all parents who had received the intervention than those who had not on the ECBI scales.

Because effect sizes for parents who had not attended the parent training group are not available at follow-up for the ECBI or at 24 week follow-up for the CCBS effect sizes need to be interpreted with caution (see Table 7.7 and Figure 7.7).

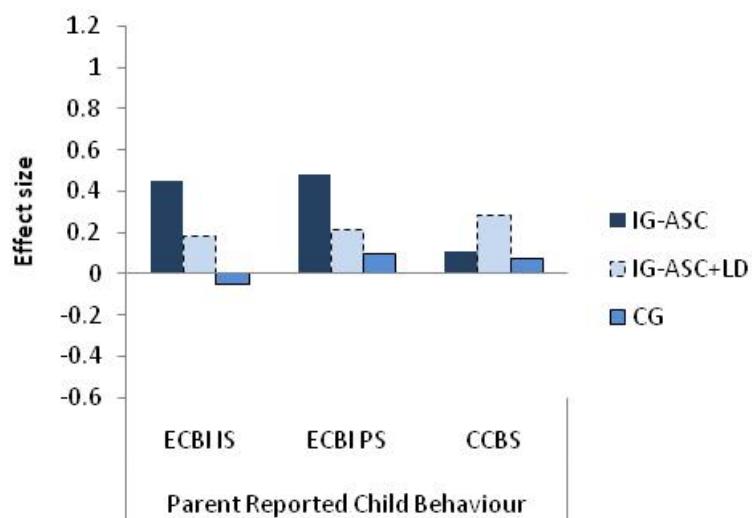
Table 7.7 Effect sizes for changes in scores on child behaviour outcome measures

Outcome indicator	Group	Effect size from pre-intervention (d^2)		
		Post-intervention	12 week follow-up	24 week follow-up (IG only)
ECBI Intensity Scale	IG-ASC only	.45	.28	.41
	IG-ASC+LD	.18	.11	.21
	CG	-.05 ²	-	-
ECBI Problem Scale	IG-ASC only	.48	.29	.56
	IG-ASC+LD	.21	.41	.22
	CG	.10	-	-
Child's Challenging Behaviour Scale (CCBS)	IG-ASC only	.11	.41	.54
	IG-ASC+LD	.28	.11	.32
	CG	.07	.41	-

¹ Effect size is categorised in the following way: 0.2='small' effect size; 0.5='medium' effect size; 0.8='large' effect size.

² A negative effect size indicates a deterioration in mean scores between the two time points.

Figure 7.8 Effect sizes for changes in scores on the Eyberg Child Behaviour Inventory and the Challenging Child Behaviour Scale post-intervention



Movement around clinical cut-off points

Clinical cut-off points are available for both the ECBI scales.²⁹ Pre-intervention, over half of all parents scored their child above the clinical cut-off point on the ECBI-Intensity Scale. This figure subsequently fell for those who had attended the parent-training group to a low of 30.8 per cent (n=8) post-intervention, but then increased again to 44 per cent (n=11) and 45 per cent (n=9) at 12 and 24 week follow-up. The drop post-intervention was approaching statistical significance. The proportion of parents who had not yet attended the parent training group scoring above the clinical cut-off also dropped post-intervention, but to a lesser extent (see Table 7.8 and Figure 7.8).

The number of parents who had attended the group scoring in the clinical range on the ECBI-Problem scale steadily reduced by more than half from 71 per cent at pre-intervention to 32 per cent at 24 week follow-up.

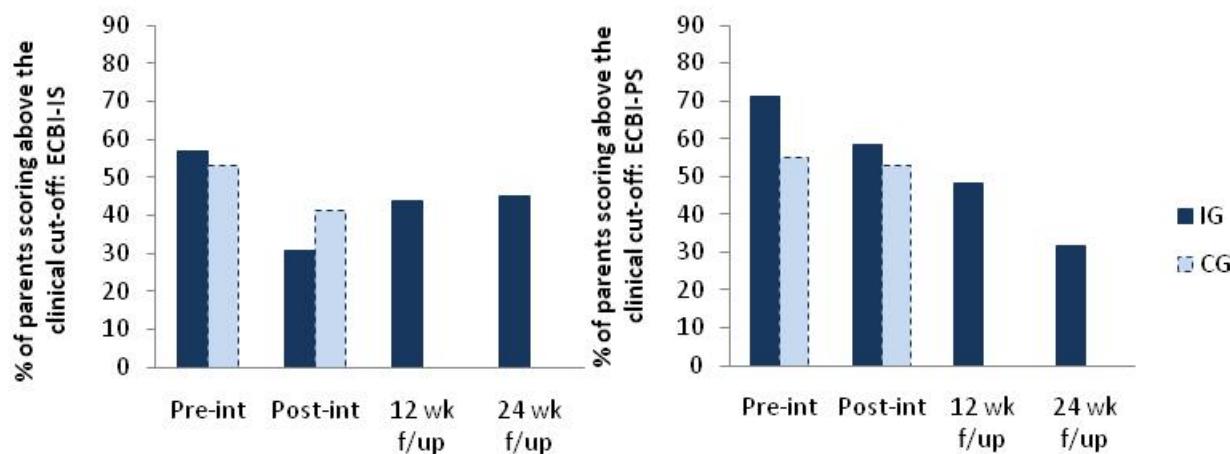
Table 7.8 Movement about clinical cut-off points by group: pre-intervention – 24 weeks follow-up

		Pre-intervention		Post-intervention		McNemar's χ^2 pre-post	12 week f/up		McNemar's χ^2 pre-12 wk f/up	24 week f/up	
		N	N (% above cut-off)	N	N (% above cut-off)		N	N (% above cut-off)		N	N (% above cut-off)
ECBI - Intensity	IG	30	17 (56.7%)	26	8 (30.8%)	$p=.063^b$	25	11 (44.0%)	$p=.500^b$	20	9 (45%)
	CG	17	9 (52.9%)	17	7 (41.2%)	$p=1.000^b$	-	-	-	-	-
ECBI- Problem	IG	31	22 (71.0%)	24	14 (58.3%)	$p=.687^b$	25	12 (48%)	$p=.727$	19	6 (31.6%)
	CG	20	11 (55.0%)	17	9 (52.9%)	$p=1.000$	-	-	-	-	-

b- Binomial distribution used.

²⁹ Clinical cut-off scores are recommended by the author of the manual (Eyberg and Pincus, 1999) to classify children as having behaviour problems are 131 (ECBI-IS) and 15 (ECBI-PS).

Figure 7.9 Proportion of parents scoring above the clinical cut-off on the ECBI scale: pre-intervention – 24 week follow-up



The proportion of parents reporting changes in their child's behaviour

As with the Parenting Sense of Competence outcomes, Reliable Change statistics were used to test whether observed improvements in child behaviour for the intervention group were clinically significant, see Table 7.9.

Looking first at the ECBI scales, there is a difference in the proportions of parents showing improvement. Immediately post-intervention, those parents who attended the group and whose child does not have a learning disability had the greatest proportion showing reliable improvement, with those who had a child with a learning disability faring as well as those who had not yet attended the parenting group. At follow-up there is only data for the parents who received the intervention. Interestingly, at 12 week follow-up three parents (30%) whose child had a diagnosis of Asperger's or High Functioning Autism showed reliable deterioration on the ECBI-Problem Scale.

By 24 week follow-up the typical pattern had returned with a greater proportion of the parents with a child with Asperger's or High Functioning Autism showing reliable improvement.

Interestingly, the differences were not so marked for the CCBS. Whilst a greater proportion of parents who had attended the parenting group (regardless of child's diagnosis) demonstrated reliable improvement immediately post-intervention, this distinction between parents who had and had not attended the parenting group had disappeared by 12 week follow-up.

Table 7.9 The proportion of parents reporting changes in the frequency of challenging or difficult to manage behaviours in the home: Reliable Change Statistics

	ECBI-Intensity Scale			ECBI-Problem Scale			Children's Challenging Behaviour Scale		
	IG-ASC only	IG-ASC+LD	CG	IG-ASC only	IG-ASC+LD	CG	IG-ASC only	IG-ASC+LD	CG
Post-intervention									
Reliably improved	4 (36.4%)	1 (8.3%)	0 (0%)	4 (40%)	3 (23.1%)	3 (18.8%)	2 (20%)	4 (26.7%)	1 (6.3%)
No change	7 (63.6%)	10 (83.3%)	13 (92.9%)	5 (50%)	10 (76.9%)	11 (68.8%)	7 (70%)	10 (66.7%)	14 (87.5%)
Reliable deterioration	0	1 (8.3%)	1 (7.1%)	1 (10%)	0	2 (12.5%)	1 (10%)	1 (6.7%)	1 (6.3%)
Chi-square Pre-post	<i>Fisher's Exact Test = 6.826, p=.058</i>			<i>Fisher's Exact Test = 3.347, p=.557</i>			<i>Fisher's Exact Test = 3.117, p=.593</i>		
12 week follow-up									
Reliably improved	2 (20.0%)	2 (18.2%)	-	3 (30%)	4 (40%)		2 (20%)	3 (23.1%)	5 (29.4%)
No change	8 (80%)	8 (72.7%)	-	4 (40%)	6 (60%)		8 (80%)	9 (69.2%)	12 (70.6%)
Reliable deterioration	0	1 (9.1%)	-	3 (30%)	0		0	1 (7.7%)	0 (0%)
Chi-square Pre-12 wk f/up							<i>Fisher's Exact Test = 2.345, p=.817</i>		
24 week follow-up									
	4 (44.4%)	1 (14.3%)	-	4 (44.4%)	1 (14.3%)	-	4 (44.4%)	4 (40%)	-
	5 (55.6%)	6 (85.7%)	-	4 (44.4%)	6 (85.7%)	-	5 (55.6%)	4 (40%)	-
	0	0	-	1 (11.1%)	0	-	0	2 (20%)	-

7.4 Costs

In this section we present data on the costs of delivering the intervention; evidence about the impact of the child's behaviour problems on parents; and their and their children's use of services which relate to the presence of child behaviour problems. We also present data on changes in use of these services over the intervention and follow-up period.

Pre-intervention data (pertaining to the 12 weeks leading up to the start of the intervention) on the children's service use was available from 41 parents in the intervention sample and 21 in the comparator group.³⁰ At the 12 weeks post-intervention time point, the sample had reduced considerably for the intervention group (28 parents) but less so for the comparator group (18 parents). The sample size for the parent impact and service use data is slightly less.

It is important to remember that, for these particular interventions, increases in overall service use may be expected. By attending the intervention parents may hear from other parents about services (statutory and voluntary sector) of which they were not previously aware. Signposting to other sources of voluntary sector or statutory support was also something practitioners delivering the intervention may undertake. Practitioners delivering this intervention also expected, on occasion, to need to refer a parent for additional one-to-one work from the CAMHS LD team.

A longer follow-up period (or prospective study) would be required in order to establish whether these early intervention/preventive programmes prevented later use of higher cost tertiary or specialist education, health and/or social care services for the child and other family members.

Intervention costs

Three CAMHS LD team in different NHS trusts delivering the intervention participated in this study. There was a considerable range in the number of facilitators and attendees. One course, for example, was facilitated by two consultant-level CAMHS professionals and two other CAMHS team members; between 14 and 17 people attended each session. More commonly there were just two or three non-consultant facilitators and between five and nine people attending. No interpreters were present at the sessions attended by the study participants and occasionally individual facilitators were absent.

Staff time accounted for the main part of the cost, and this included time setting-up the group, planning the sessions and travelling, as well as delivering the intervention and debriefing. The *cost of delivering the intervention* ranged from £3410 to £8325 per programme (mean=£5570).

The cost per session varied depending on the number, profession and their Agenda for Change salary band. The most expensive course session cost was £800 and the least expensive was £255. The variation in the number of participants means that the *cost per person per session* ranged from between £36.6 and £155.10.

The *cost per person for the intervention* varied, therefore, depending on the number of facilitators (between one and four) and parents at each session and the number of sessions each parent attended (between one and twelve; the follow-up session tended to be least well attended). Thus the mean costs for parents attending this course was £614.90, but the range was between £200.80 and £2542.80 for a parent who attended eleven of the twelve

³⁰ Referred to collectively as the 'cost sample'.

sessions of a course with only five participants that was led by a consultant-level CAMHS professionals and co-facilitated by at least two other CAMHS team members.

Parents' service use and impact of behaviour problems on employment and daily life

Prior to the intervention, 32 (53%) of the 60 parents in the 'cost sample' reported that their child's behaviour had affected their health; 24 of whom were in the intervention group (36%). By the 12 week follow-up time point, just under half the sample (22, 49%) reported their health had been affected, 14 of whom were in the intervention group (52%). However, they used very few services as a result at either time point (see Appendix Q, Tables Q.1 and Q.2).

Relatively few days were lost from work due to the impact of the child's behaviour problems. Thirty-four (55%) of the 62 parents in the pre-intervention 'cost sample' were in paid employment, although this was spread unevenly between the intervention and comparator groups: 46 per cent and 71 per cent respectively. Across the 'cost sample', six parents took a total of 42 days off work because of their child's behaviour problems; 30 of these days were reported by just one parent. Sixteen parents reported that there were days in the past three months in which the child's problems had prevented them undertaking their normal activities, ten of whom said this was for between five and 25 days.

At the 12 week follow-up time point, similar proportions of parents were in employment and reported days lost from work, or days affected by their child's behaviour. Twenty-seven parents in the 'cost sample' were in employment (IG=52%; CG=72%), with two parents in the comparator group taking days off work because of their child's behaviour (16 and 20 days) and four in the intervention group (between one and eight days). Thirteen parents said their child's behaviour had affected their usual activities for between two and 20 days in the previous three months.

Service use for the children and associated costs

As Table 7.10 shows most children were in mainstream schools at the pre-intervention time point, although a much higher proportion of children in the intervention group (31% vs. 14%) were using specialist education resources.

At pre-intervention and 12 week follow-up, eight of the intervention group (20%) and three (14%) of the comparator group had had days off school because of their behaviour problems. On average fewer days were taken off prior to the 12 week follow-up time point than prior to the pre-intervention time point (4.1 vs. 5.7 average days; three and seven children from the intervention and comparator groups respectively for each period). A higher proportion in the intervention group had a Statement of Special Educational Needs at the 12 week follow-up time point (72% vs. 57%), but a lower proportion of this group had been excluded compared to the comparator group (17% vs. 40%).

Table 7.10 Type of school attended

Type of school	Pre-intervention time point; n attending (%)		12 week follow-up time point; n attending (%)	
	Intervention n=41	Comparator n=21	Intervention n=27	Comparator n=18
Nursery/pre-school	4 (10%)	1 (5%)	2 (7%)	0
Mainstream primary	13 (32%)	10 (48%)	11 (41%)	9 (50%)
Mainstream secondary	8 (20%)	6 (29%)	5 (19%)	5 (28%)
Special needs unit in mainstream school	3 (7%)	0	1 (4%)	0
Special needs school	10 (24%)	3 (14%)	8 (30%)	3 (17%)
Other	3 (7%)	1 (5%)	0	1 (6%)

The pattern of service use for children during the three months prior to the pre-intervention time point and for the 3 months after completing the main part of the intervention was a mix of some relatively commonly used services and others used by very few children. Details can be found in Appendix Q (Table Q.1).

With the exception of social care services (short-breaks, social workers, family support workers and the like) a higher proportion of the intervention group were using almost all services. The most commonly used services at both time points were outpatient services and GP contacts for reasons other than behaviour, speech and language therapy, and repeat prescriptions. These were all used by around a third to a half of all children in the intervention group and between ten per cent and 25 per cent for the comparator group children. Both the intervention and comparator group children made reasonably high use of CAMH services; about half the children at the pre-intervention time point, and just under a third at the 12 week follow-up time point. Social care services tend to be less commonly used although 20 per cent of the intervention families at pre-intervention had seen a social worker in the previous three months, as had 24 per cent of the comparator group. Other health and social care services (nurses, key workers, family support workers, etc.) were used by only a few families.

Given the generally sparse use of any individual services, Table 7.11 presents the support costs information using broad service groups, organised by provider (see Table Q.2, Appendix Q). The table shows the mean costs and range for service category by group, and for the total costs of public sector support and services because of the child's behaviour. Following on from the higher rates of service use for the intervention group, we see they have generally higher observed costs at the pre-intervention time point (first two data columns) for each of the service groupings and for total costs, with the exception of costs for mental health services. Simple t-tests suggest that only mean costs for hospital services and for community health services are significantly higher for the intervention group ($p=0.019$ and $p=0.028$ respectively); total cost for all services is significant at 10% ($p=0.07$).³¹ The higher mean hospital costs are driven by costly inpatient admissions, used by two children in the intervention group.

³¹ Note that bootstrapped confidence intervals (1000 repetitions) are as follows: hospital services = -1.683 - 334.181; community health services = 26.520 - 158.207; total services = -109.948 - 711.365. These confirm that mean costs are significantly different for community health services as the confidence intervals do not include zero.

Table 7.11 Service costs over 3 months prior data collection time points

Service/support	Pre-intervention time point		12 week follow-up time point	
	Intervention n=41 Mean £ (range)	Comparator, n=21 Mean £ (range)	Intervention n=28 Mean £ (range)	Comparator n=18 Mean £ (range)
Hospital services	£194.40 (£0 - £2541)	£22.80 (£0 - £163)	£95.00 (£0 - £978)	£50.90 (£0 - £326)
Mental health services	£65.90 (£0 - £360)	£85.00 (£0 - £307)	£91.60 (£0 - £652)	£36.50 (£0 - £288)
Community health	£97.40 (£0 - £900)	£29.80 (£0 - £148)	£82.10 (£0 - £900)	£37.20 (£0 - £256)
Primary care	£78.60 (£0 - £547)	£37.30 (£0 - £188)	£70.60 (£0 - £453)	£41.60 (£0 - £176)
Social care	£318.90 (£0 - £3129)	£222.40 (£0 - £2205)	£286.70 (£0 - £2536)	£267.80 (£0 - £2618)
Total cost of child's service use	£755.20 (£0 - £4139)	£397.30 (£0 - £2426)	£626.00 (£0 - £3397)	£434.00 (£0 - £2875)
Services for behaviour	£69.00 (£0 - £360)	£95.90 (£0 - £312)	£98.60 (£0 - £652)	£58.10 (£0 - £575)
Main carer's service use	£31.20 (£0 - £440)	£39.10 (£0 - £264)	£65.20 (£0 - £955)	£36.20 (£0 - £444)

The penultimate row of Table 7.11 shows the total costs for all behaviour-related services. This includes the costs for outpatient appointments for behaviour problems, family therapist, CAMHS contacts, and contact with GPs, health visitors and community nurses for behaviour-related problems. These absorb similar proportions of the total costs: nine per cent for the intervention group and ten per cent for the control group. At the pre-intervention time point, observed costs are higher for the comparator group but a t-test suggests they are not significantly different. At the 12 week follow-up time point, the intervention group costs are higher but again there is no statistically significant difference.

At the 12 week follow-up time point, the picture of higher observed costs for the intervention group is repeated across all the cost categories. Mean costs for the intervention group appear to have reduced in comparison to the pre-intervention data, except for the mental health services category. For the comparator group there is an increase in mean costs across the two data collection time points, again with the exception of mental health services. None of the between group cost differences reached statistical significance.

The final row of Table 7.11 shows the total costs of the services used by parents because of their child's behaviour problems. Although these costs were generally quite low, the mean cost is higher for the intervention group at the 12 week follow-up time point than at the pre-intervention time point, but the converse is true for the control group. A t-test suggests they are not significantly different between groups.

7.5 Summary of the findings

- Progress in attaining goals for improved child behaviour and standardised measures of parents' sense of competence and parent-report child behaviour were used to assess the effectiveness of the intervention. Outcomes were compared to a waiting list control (or no intervention group) at post-intervention and 12 and 24 week follow-up.
- Significant progress towards attaining parent-set goals for child behaviour was recorded at 12 week and 24 week follow-up.
- Programme attendance was associated with improvements in parents' sense of satisfaction, although differences between those who had and had not attended the

group did not reach statistical significance. Improvements in the waiting list control group on the efficacy subscale meant that improvements in feelings of efficacy in the intervention group could not be attributed to attendance of the programme.

- Exploration of outcomes for parents whose child did or did not have a learning disability in addition to being on the autistic spectrum revealed some interesting findings, with parents who had a child without a learning disability typically having more confidence at the outset and gaining more confidence following attendance at the group.
- Programme attendance was associated with a reported improvement in the frequency (ECBI-IS) and severity (ECBI-PS) of challenging behaviours. These improvements were maintained at 12 and 24 week follow-up. The ECBI-Intensity scale was the only scale to be found statistically improved post-intervention, when compared to parents who had not yet attended the group.
- Evidence from this study to suggest behaviours that mothers of disabled children find challenging (CCBS) became easier to manage was more equivocal.
- When outcomes for parents whose child does and does not have a learning disability are compared the intervention is associated with better outcomes for those parents whose child does not have a learning disability. These parents have typically lower ratings of problem behaviours at the outset.
- The data suggest higher needs among the intervention group at the pre-intervention time point compared to the comparator group. Higher proportions of parents from the intervention group reported that their health was affected by their child's behaviour, fewer parents were in work and fewer of their children attended mainstream schools. Higher proportions of children from the intervention group used specialised education resources, and hospital and community health services.
- These higher service utilisation rates led to higher observed public sector costs for the intervention group in the three months prior to the pre-intervention data collection time point, although the small sample and the wide range of costs meant statistical findings should be treated with some caution.
- The number of facilitator, profession and their Agenda for Change salary band of varied between sessions and between research sites. This, together with the variation in the number of participants, means that the *cost per person per session* ranged from between £36.6 and £155.10.
- The cost of delivering the intervention ranged from £3410 to £8325 per programme (mean=£5570).
- Intervention costs per person were calculated as the sum of the unit costs for each session each parent attended and were between £200 and £2,542.80 around a mean of £615 per person.

Conclusions

- There is evidence that some parents of children with ASC, in particular those with a diagnosis of Asperger's or High Functioning Autism may benefit from attending this programme, both in terms of their sense of satisfaction as a parent, and in their child's behaviour.
- While observed costs to the public sector at the 12 week follow-up time point remain higher for the intervention group, there is some evidence of a reduction in mean costs. However, a larger sample would be required to verify this. Total costs at this time point were not significantly different between the groups.

Chapter 8

Intervention B: A Group-Based Parent-Training Programme for Parents of Children with Disabilities

In this chapter we report findings on the effectiveness of a group-delivered parent-training intervention for parents of disabled children.

Main findings

- Small sample sizes and differences between the intervention and control groups on key variables restrict the conclusions which can be drawn.
- Significant progress towards attaining parent-set goals for child behaviour was recorded post-intervention. There were also some improvements in parents' sense of efficacy and a reduction in the number of problem child behaviours. However, improvements were not maintained in the longer term.
- Some parents may require on-going parenting support. Repeat attendance of this intervention is common.
- The mean cost of delivering the intervention was £3,635. The cost per person per session ranged between £46 and £354.

8.1 Overview of the intervention

CONFIDENT PARENTING	
Aims	To empower parents to confidently manage their child.
Target population	Parents of primary-school aged children with disabilities including ASC, learning and complex disabilities. Other family members and family friends can attend.
Age range	3 – 11 years.
Structure & approach	6, weekly 2 hour sessions. (Max group size=12 (representing max. of 8 children.) A facilitator's handbook sets out the approach and the core elements to be covered: parental feelings; parenting skills and strategies; communication; developing the child's skills; working together with other family members. However, the specific focus of each session is driven by the needs and experiences of the group. Training approach includes the use of video footage of parent/child and teacher/child interaction to provide feedback, modelling and generate discussion.

8.2 Overview of the investigation

Design	Controlled trial. Comparator (or 'no intervention') group poorly matched on parental education qualifications and child behaviour. Outcome measures administered: pre-intervention; post-intervention; 12 weeks follow-up; 24 weeks follow-up (IG only). Response rate very poor at 24 week follow-up and data not used. Rating of achievement towards parent-set goals: baseline (some variation in which session of the programme goals were set); post intervention; 12 & 24 week follow-up.	
Outcomes	<ul style="list-style-type: none"> Parent-set child behaviour goal(s). Standardised measure of Parenting Sense of Competence (PSOC; Johnston and Mash, 1989) <ul style="list-style-type: none"> PSOC-Satisfaction subscale (satisfaction with the parenting role) PSOC-Efficacy subscale (feeling of efficacy as a parent) Two standardised measures of child behaviour: <ul style="list-style-type: none"> Eyberg Child Behaviour Index (ECBI; Eyberg and Pincus, 1999): <ul style="list-style-type: none"> ECBI-Intensity (IS): frequency of disruptive behaviours ECBI-Problem (PS): no. disruptive behaviours problematic to parent Challenging Child Behaviour Scale (CCBS; Bourke-Taylor et al, 2010) 	
Sample	Intervention Group	Waiting List Control Group
Children	n=20	n=20
Age of child (Mean (SD))	6.85 yrs (1.69)	7.45 yrs (2.35)
Male (%)	13 (65%)	14 (70%)
Has learning disabilities	16 (80%)	14 (70%)
Specialist education	16 (80%)	19 (95%)
Parents	n=20	n=20
Mother (%)	17 (85%)	18 (90%)
Two parent household (%)	14 (70%)	15 (75%)
Higher Education (%)	7 (35%)	17 (85%)
White British (%)	17 (85%)	17 (85%)
English First Language	20 (100%)	20 (100%)
Response rates:	90% (post intervention); 80% (12 wk f-up).	

8.3 The evidence of effectiveness

Parent-set goals

In the first parent training group we investigated parents were asked to set their goals midway through the programme. Goals were set based on what the parents hoped to get out of the intervention, for example: 'to gain confidence and be assured we are doing the right things'.³² Post-intervention, there had been improvement³³ for nearly three-quarters of the goals set. Twelve weeks after the programme had finished, the number of parents reporting improvement had dropped slightly, however there were now no parents reporting a deterioration from when they set the goal.

Table 8.1 Direction of change from baseline for goals set midway through the programme

Changes in goal attainment rating	Post-intervention (n=11 goals)	12 week follow-up (n=11 goals)
Improved	8 (73%)	7 (64%)
No change	1 (9%)	4 (36%)
Deteriorated	2 (18%)	0 (0%)

The increase in mean goal attainment from when the goals were first set was statistically significant.³⁴ Table 8.2 and Figure 8.2 show that mean scores improved following the parent training group.

Table 8.2 Mean scores and ANCOVA for the goal scores

Baseline			Post-intervention			12 week follow-up			Repeated Measures One Way ANCOVA
N	M	SD	N	M	SD	N	M	SD	
11	5.09	2.07	11	6.91	2.07	11	6.64	1.69	$F(1.052)=17.479$, $df=1.052$, $p<.01^1$

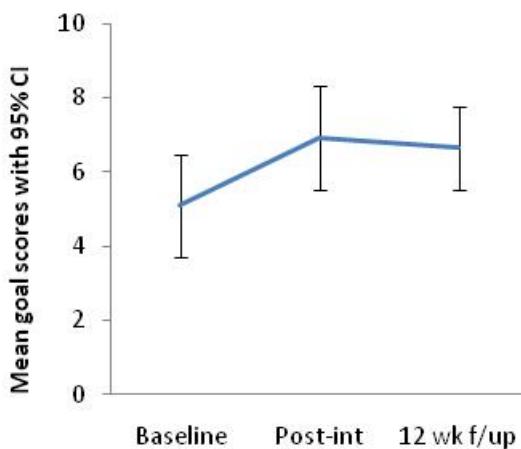
¹ Greenhouse-Geisser adjustment for sphericity.

³² A 10-point rating scale was used to indicate the extent to which a goal has been achieved: 1=very far from this goal; 10=I have achieved my goal.

³³ Improvement/Deterioration is based on whether the goal scores have moved 1+ scores in a positive or negative direction.

³⁴ The parent's ID code was entered as a between-subjects factor into the ANOVA as some parents had given more than one goal.

Figure 8.3 Change in mean goal scores over time



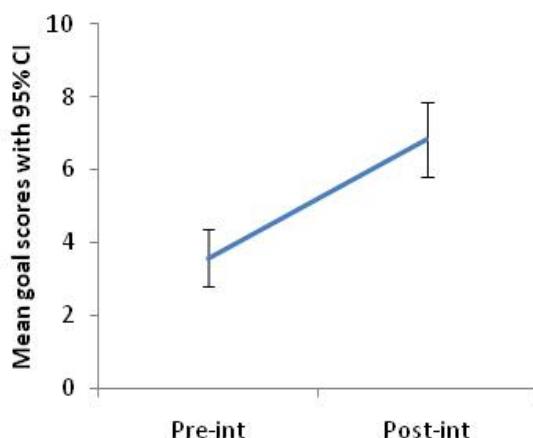
Later groups were asked to set goals at the start of the programme. This data is available at pre and post-intervention. Immediately following the intervention all parents for whom goals data was available (n=12 goals) reported progress in attaining the goal they set when they started the programme.

The increase in mean goal attainment from when the goals were set was statistically significant (see Table 8.3 and Figure 8.3).

Table 8.3 Mean scores and ANCOVA for the goal scores

Pre-intervention			Post-intervention			Repeated Measures One Way ANCOVA
N	M	SD	N	M	SD	
12	3.58	1.24	12	6.83	1.59	$F(1)=111.690$, $p<.001$

Figure 8.4 Change in mean goal scores over time



Parents' sense of competence

Differences in outcomes for the intervention and waiting list groups

Attendance at the parent training programme was associated with slight improvements³⁵ at post-intervention for both feelings of satisfaction (PSOC-Satisfaction³⁶) and efficacy (PSOC-Efficacy³⁷), however, when compared to those who had not attended the group they were not significant. Gains made by parents who had attended the parent-training group were typically lost by follow-up, (see Table 8.4 and Figure 8.4a). Whilst the analysis comparing scores at 12 week follow-up was approaching significance for the PSOC-Satisfaction subscale – exploration of the mean scores used showed that this was actually due to the deterioration in scores by parents who had attended the parent-training group.

Table 8.4 Parenting Sense of Competence outcomes

		Pre-intervention			Post-intervention			ANCOVA Pre-post	12 week follow-up			ANCOVA Pre-12 week follow-up
		N	M	SD	N	M	SD		N	M	SD	
PSOC-Satisfaction	IG	20	30.65	6.09	16	32.31	5.95	$F(1).319, p=.424^{38}$	13	30.46	4.74	$F(1)=3.861, p=.060^{39}$
	CG	19	35.00	8.69	20	35.65	6.34		18	35.06	8.19	
PSOC-Efficacy	IG	20	28.30	6.20	16	30.00	5.61	$F(1)=.907, p=.348$	13	28.62	6.29	$F(2)=.000, p=.996$
	CG	19	29.32	5.92	20	29.95	5.10		18	29.5	5.40	

³⁵ An increased score represents improvement on the PSOC.

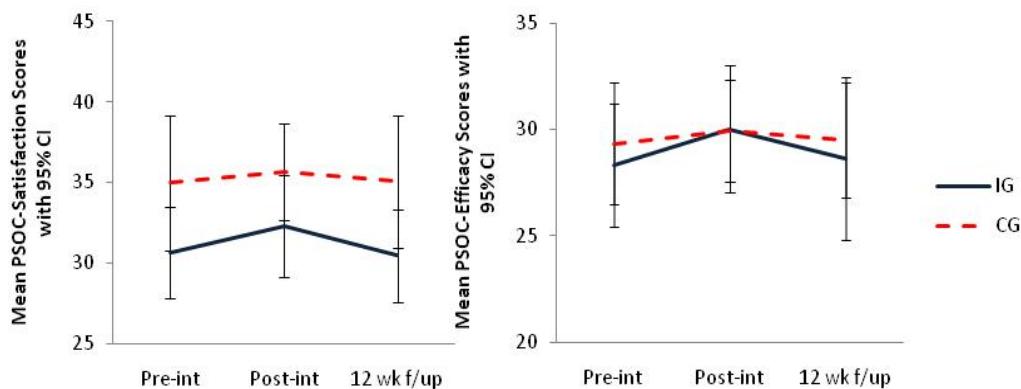
³⁶ The Satisfaction subscale (9 items) of the Parenting Sense of Competence Scale (PSOC) is an affective dimension, measuring the extent to which parents are satisfied with their role as a parent, capturing parental frustration, anxiety and motivation. Scores can range from 9-54.

³⁷ The Efficacy subscale (7 items) of the PSOC measures the extent to which parents feel they are managing the role of being a parent. It captures parents' perceptions of their competence, problem-solving ability and capability in the parenting role. Scores can range from 7-42.

³⁸ The inclusion of qualification level as a co-variate did not add significantly to the model for any of the measures (PSOC-Satisfaction: $F(1)=.104, p=.749$; PSOC-Efficacy: $F(1)=, p=.$

³⁹ The inclusion of qualification level as a co-variate did not add significantly to the model for any of the measures (PSOC-Satisfaction: $F(1)=.319, p=.576$; PSOC-Efficacy: $F(1)=.047, p=.831$.

Figure 8.5a Mean Parenting Sense of Competence Scores: pre-intervention to 12 week follow-up



The size and direction of change in parents' sense of competence

Effect statistics⁴⁰ explored the size (and direction) of changes in parents' sense of competence across the study period, see Table 8.5 and Figure 8.4b.

Post-intervention, the size of changes in mean scores on both the Parenting Sense of Competence subscales were greater for the intervention group than the waiting list control group. A medium effect size ($d^2=.44$) was found for those parents who had attended a parent-training group post-intervention on the PSOC-Efficacy subscale, whilst a small effect was found for feelings of satisfaction ($d^2=.20$). However, at follow-up, not only had positive effects been lost for parents who had attended the parent-training group, but effect sizes were negative suggesting that for some parents their scores had deteriorated from baseline. (Mean scores and standard deviations can be found in Table 8.3. Changes in mean scores are visually displayed in Figure 8.3.).

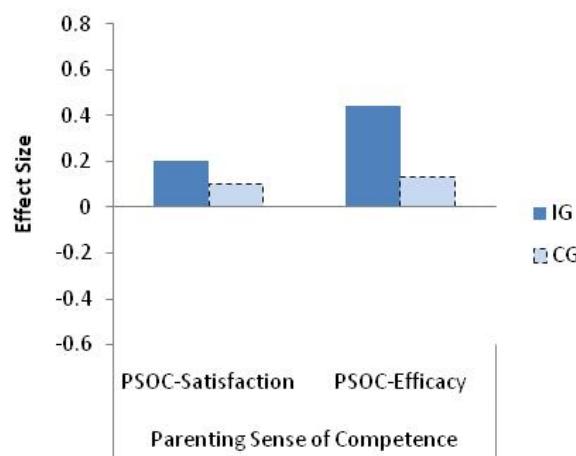
Table 8.5 Effect size for changes in scores from Pre-Intervention on Parenting Sense of Competence (PSOC)

Outcome Indicator	Group	Effect size from pre-intervention (d^2)	
		Post-intervention	12 week follow-up
PSOC-Satisfaction	IG	.20	-.33
	CG	.10	.04
PSOC-Efficacy	IG	.44	-.05
	CG	.13	.20

(Effect sizes in *italics* show where the effect is in a **negative** direction, i.e. scores at follow-up are worse than at baseline) Effect sizes have been reversed so that a positive effect size reflects a positive change.

⁴⁰ The effect size statistic quantifies the difference between two sets of data or between two groups. 0.2 is defined as a 'small' effect size, 0.5 as a medium effect size, and 0.8 as a 'large' effect size. In this study effect sizes were calculated within each sample (e.g. those who had attended a parent group) the effect size between two time points being calculated. Effect size is calculated by dividing the difference between the means by the pooled standard deviation (Cohen's $d = (MT1 - MT2)/SD$).

Figure 8.5b Effect sizes for changes in scores on Parenting Sense of Competence (PSOC) post-intervention



The proportion of parents who improved on the measure of Parenting Sense of Competence

Scores on the Satisfaction and Efficacy subscales were then examined in order to determine whether changes in scores (from pre-intervention) could be regarded as 'true' changes as opposed to spurious changes caused by inadequacies in the measure. The statistic used is known as the Reliable Change Index (RCI).⁴¹ This is an important indicator of the clinical, as opposed to statistical, significance of any observed changes associated with an intervention.

Table 8.6 sets out the proportion of parents whose scores on the measure of Parenting Sense of Competence improved, did not change, or deteriorated (as classified by the RCI). Comparisons are made between those parents who attended the programme and the no-intervention comparator group.

Regarding parental feelings of satisfaction with the parenting role, little difference can be seen between those who have and have not attended the parent-training group post-intervention. Twelve weeks later, it is actually some of the parents who have received the intervention who are faring worse than those who have not, three show reliable deterioration compared to none of those in the control group.

The picture is more positive for feelings of efficacy. Over twice as many parents who have attended a parent-training group show reliable improvement post-intervention, compared to those who have not been offered the intervention. However, these improvements are not maintained in the longer term (see Table 8.6).

⁴¹ A reliable change was defined as those where a score of >1.96 on the Reliable Change Index was achieved (Hawley, 1995; Jacobson and Truax, 1991). The reliable change index (RCI) for each case was calculated by dividing the difference between the Time 1 and 2 scores by the standard error of measurement (SEmeas) [RCI = $Mt1 - Mt2/Sdiff$]. Sdiff will be obtained by calculating the square route of double the standard error squared ($Sdiff = \sqrt{2(SE)^2}$). A chi-squared test will examine whether reliable change is significant across the treatment groups.

Table 8.6 The reliable change on Parenting Sense of Competence: intervention group versus control group

	Parenting Sense of Competence			
	Satisfaction		Efficacy	
	IG	CG	IG	CG
Post intervention				
Reliably improved	2 (12.5%)	3 (15.8%)	8 (50.0%)	3 (23.1%)
No reliable change	13 (81.3%)	15 (78.9%)	5 (31.3%)	7 (53.8%)
Reliable deterioration	1 (6.3%)	1 (5.3%)	3 (18.8%)	3 (23.1%)
Chi-square Pre-Post	<i>Fisher's Exact Test</i> =.413, <i>p</i> =1.000		<i>Fisher's Exact Test</i> =3.522, <i>p</i> =1.67	
12 weeks follow-up⁴²				
Reliably improved	2 (15.4%)	3 (17.6%)	3 (23.1%)	5 (29.4%)
No reliable change	8 (61.5%)	14 (82.4%)	7 (53.8%)	9 (52.9%)
Reliable deterioration	3 (23.1%)	0	3 (23.1%)	3 (17.6%)
Chi-square Pre-12 week f/up	<i>Fisher's Exact Test</i> =3.981, <i>p</i> =.159		<i>Fisher's Exact Test</i> =.360, <i>p</i> =1.000	

Parent-report child behaviour

Differences in outcomes for the intervention and waiting list groups

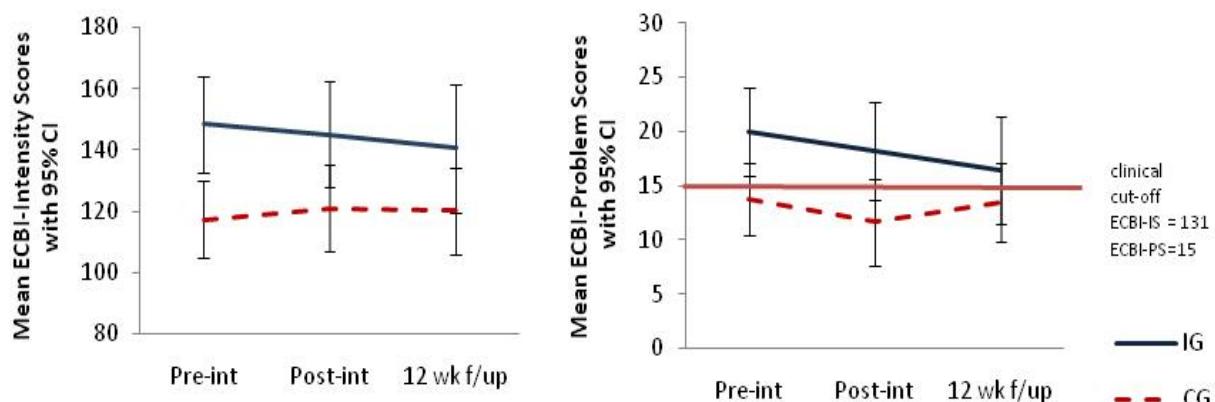
Attending the parent-training programme was associated with slightly improved scores on each of the standardised measures of child behaviour, see Table 8.7. However, these improvements were not significant when compared against the CG. Further improvements in scores were found 12 weeks after completion of the programme. These were not statistically significant for the ECBI scales, however they were approaching significance for the CCBS (see Table 8.7 and Figure 8.5a and 8.5b).

⁴² Twenty-four week post intervention comparisons not possible as data not collected from waiting list control group at this time point.

Table 8.7 Child behaviour outcomes

		Pre-intervention			Post-intervention			ANCOVA Pre-post	12 week follow-up			ANCOVA pre-12 week follow-up
		N	M	SD	N	M	SD		N	M	SD	
ECBI Intensity	IG	19	148.37	32.21	15	145.13	30.93	$F(1)=.105$, $p=.748$	13	140.54	34.50	$F(1)=.729$, $p=.402$
	CG	18	117.39	25.01	18	121.06	28.59		18	120.22	28.56	
ECBI Problem	IG	19	20.00	8.49	15	18.20	8.03	$F(1)=.009$, $p=.924$	13	16.38	8.17	$F(1)=.736$, $p=.399$
	CG	20	13.75	7.26	18	11.61	7.92		18	13.44	7.29	
CCBS	IG	15	36.73	8.01	13	35.62	6.02	$F(1)=.428$, $p=.519^{43}$	11	34.0	7.14	$F(1)=3.323$, $p=.082^{44}$
	CG	19	30.95	7.05	18	31.39	6.70		17	33.24	5.44	

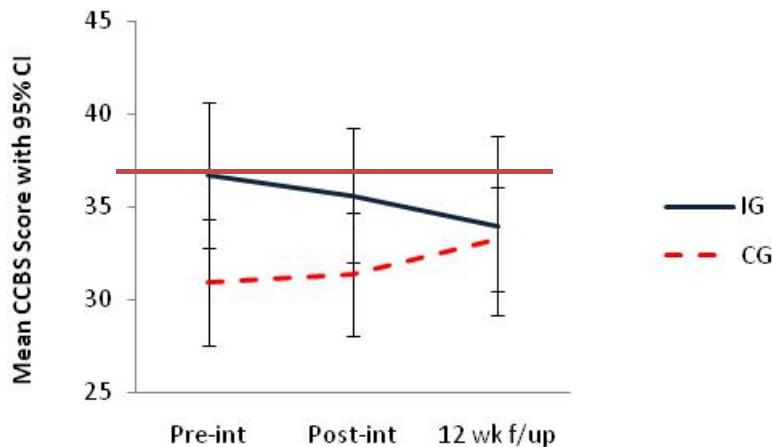
Figure 8.6a Mean ECBI scores: pre-intervention - 12 week follow-up



⁴³ The inclusion of qualification level as a co-variate did not add significantly to the model for any of the measures (ECBI IS: $F=.070$, $df(1)$, $p=.793$; ECBI Pb: $F=2.453$, $df(1)$, $p=.128$; CCBS: $F=.882$, $df(1)$, $p=.357$).

⁴⁴ The inclusion of qualification level as a co-variate did not add significantly to the model for any of the measures (ECBI IS: $F(1)=1.310$, $p=.264$; ECBI Pb: $F(1)=1.145$, $p=.294$; CCBS: $F(1)=1.005$, $p=.327$).

Figure 8.6b Mean CCBS scores: pre-intervention - 12 week follow-up



The scale of improvement in parent-report child behaviour

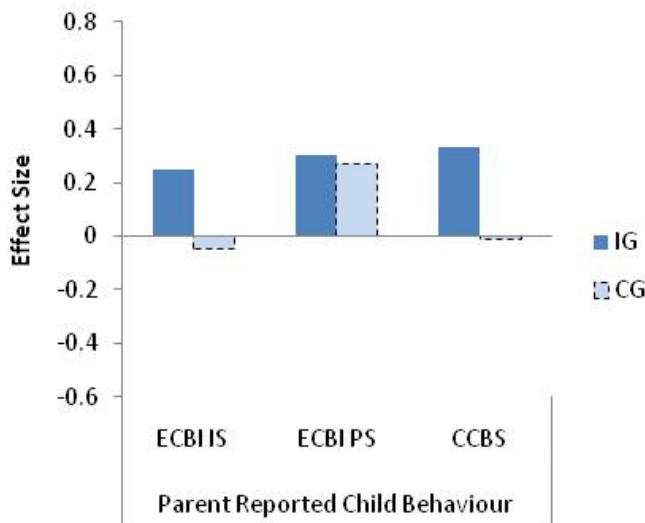
The size of improvement in scores on parent-report measures of child behaviour was consistently greater for the intervention group compared to the no treatment control at each measurement point. Effect sizes were largest post-intervention, becoming smaller at follow-up, see Table 8.8 and Figure 8.6.

Table 8.8 Effect sizes for changes in scores on child behaviour outcome measures

		T2	T3
ECBI IS	INT	.25	.10
	CG	-.05	.04
ECBI PS	INT	.30	.25
	CG	.27	.03
CCBS	INT	.33	.21
	CG	-.01	-.30

(Effect sizes in *italics* indicates the change was in a **negative** direction, i.e. scores deteriorated.)

Figure 8.7 Effect sizes for changes in scores on the Eyberg Child Behaviour Inventory and the Challenging Child Behaviour Scale post-intervention



Movement around clinical cut-off points

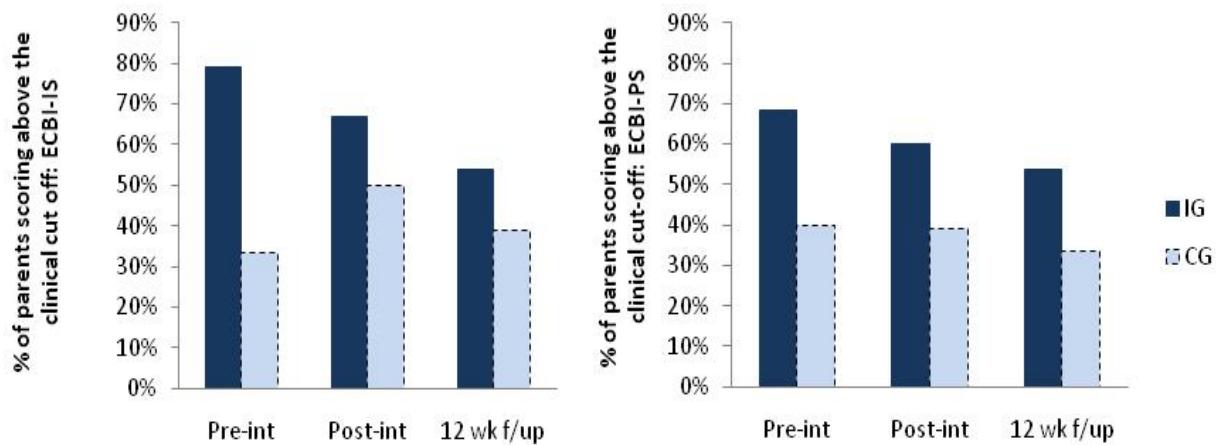
Clinical cut-off points are available for both the ECBI scales.⁴⁵ Pre-intervention, nearly 80 per cent of the children whose parents were attending the programme were scoring above the clinical cut-off point on the ECBI-Intensity scale and around 60 per cent were scoring above the clinical cut-off point on the ECBI-Problem scale. At the end of the parent-training programme a greater proportion of children represented in the intervention group were below the clinical cut-off points on these scales compared to pre-intervention. This is in contrast to those who had not attended a group where a greater proportion of children were rated above the clinical cut-off post-intervention, see Figure 8.7. These changes over time were not statistically significant, see Table 8.9.

Table 8.9 Movement about clinical cut-off points by group and time

		N (%) above clinical cut-off		McNemar's χ^2 pre-post	12 week follow-up	McNemar's χ^2 pre-12 week follow-up
		Pre-intervention	Post-intervention			
ECBI - Intensity	IG	15 (78.9%)	10 (66.7%)	.500	7 (53.8%)	1.000
	CG	6 (33.3%)	9 (50%)	.625	7 (38.9%)	1.000
ECBI-Problem	IG	13 (68.4%)	9 (60%)	1.000	7 (53.8%)	1.000
	CG	8(40%)	7 (48.5%)	1.000	6 (33.3%)	1.000

⁴⁵ Clinical cut-off scores are recommended by the author of the manual (Eyberg and Pincus, 1999) to classify children as having behaviour problems are 131 (ECBI-IS) and 15 (ECBI-PS).

Figure 8.8 Proportion of parents scoring above the clinical cut-off on ECBI scale: pre-intervention - 12 week follow-up



The proportion of parents reporting changes in their child's behaviour

As with the Parenting Sense of Competence outcomes, Reliable Change statistics were used to test whether observed improvements in child behaviour for the intervention group were clinically significant, see Table 8.10.

The largest proportion of parents who had received the intervention were showing improvement immediately post-intervention. In the longer term there was little difference between those who had or had not attended the parent-training group in terms of reliable improvement; however fewer parents who had attended a group showed reliable deterioration.

Table 8.10 The proportion of parents reporting changes in the frequency of challenging or difficult to manage behaviours in the home: Reliable Change Statistics

	ECBI Intensity Scale		ECBI Problem Scale		Child Challenging Behaviour Scale	
	IG	CG	IG	CG	IG	CG
Post-intervention						
Reliably improved	4 (26.7%)	2 (11.8%)	5 (33.3%)	4 (22.2%)	4 (36.4%)	3 (16.7%)
No reliable change	10 (66.7%)	11 (64.7%)	10 (66.7%)	13 (72.2%)	6 (54.5%)	13 (72.2%)
Reliable deterioration	1 (6.7%)	4 (23.5%)	0 (0%)	1 (5.6%)	1 (9.1%)	2 (11.1%)
Chi-square Pre-Post	<i>Fisher's Exact Test</i> =2.250, <i>p</i> =.390		<i>Fisher's Exact Test</i> =1.224, <i>p</i> =.836		<i>Fisher's Exact Test</i> =1.589, <i>p</i> =.618	
12 weeks follow-up						
Reliably improved	3 (25.0%)	3 (18.8%)	2 (16.7%)	3 (16.7%)	0 (0%)	3 (17.6%)
No reliable change	8 (66.7%)	11 (68.8%)	10 (83.3%)	10 (55.6%)	9 (100%)	8 (47.1%)
Reliable deterioration	1 (8.3%)	2 (12.5%)	0 (0%)	5 (27.8%)	0 (0%)	6 (35.3%)
Chi-square Pre-12 week f/up	<i>Fisher's Exact Test</i> =.231, <i>p</i> =1.000		<i>Fisher's Exact Test</i> =4.057, <i>p</i> =.147		<i>Fisher's Exact Test</i> =6.543, <i>p</i> <.05	

8.4 Costs

In this section we present data on the costs of delivering the intervention. The detailed exploration of the service-related costs associated with the presence of child behaviour problems in the family and the possible impact of the intervention on those costs presented for the other behaviour management interventions has not been due to the small sample size.

Intervention costs

We have sufficient data to estimate the costs for four of the five groups run during the study period in one of the two study areas. Groups were run between Autumn 2009 and Autumn 2010. The main facilitators were a head teacher, a consultant clinical psychologist and an assistant psychologist, although a teacher and a trainee psychologist were also present at some of the sessions. Two programmes started with ten participants and two were smaller, starting with three or five participants. Commonly there were three facilitators and between three and eight parents attending. No interpreters were present at the sessions. Staff time accounted for the main part of the cost, and this included time setting-up the group, planning the sessions, as well as delivering the intervention and debriefing.

The cost of delivering the intervention was £2,385 to £4,515 per programme (mean = £3,635). The cost per session varied depending on the number, profession and the Agenda

for Change or education authority salary band for each facilitator. The most expensive session cost £708 and the least expensive was £364. The variation between sessions in both facilitators and number of participants means that the *cost per person per session* ranged widely from between £46 and £354. The most expensive session was facilitated by a head teacher, a consultant and a trainee psychologist but just two parents attended and the least expensive session had eight parents attending and was facilitated by a teacher and two psychologists.

The *cost per person for the intervention* varied, therefore, depending on the number of facilitators (between one and four), the number of parents at each session, and the number of sessions each parent attended. Thus the mean costs for parents attending one of the four groups of the Confident Parenting course was £391, but the range was between £56 (just one session attended) and £940. The high figure was for a parent who attended five of the six sessions facilitated by a head teacher, a consultant-level CAMHS professional and a trainee psychologist - five parents started this programme but attendance reduced to two parents for some sessions.

8.5 Summary of the findings

- Progress in attaining goals for improved child behaviour and standardised measures of parents' sense of competence and parent-report child behaviour were used to assess the effectiveness of the intervention. Outcomes were compared to a no treatment control at post-intervention and 12 week follow-up.
- Significant progress towards attaining parent-set goals for child behaviour was recorded post intervention.
- Programme attendance was associated with slight improvements in parents' sense of competence, and specifically their feelings of efficacy with the parenting role. Improvements were not maintained at follow-up.
- Medium positive effect sizes were found for PSOC-Efficacy Scale for the intervention group post-intervention. However, at follow-up, effect sizes were negative for the intervention group, showing that on the whole, scores had deteriorated from baseline.
- Programme attendance was also associated with slight improvements in parents' reports of the frequency of challenging or difficult to manage behaviours. These improvements were maintained at 12 week, follow-up, but were not large enough to be statistically significant.
- The variation between sessions in both facilitators and number of participants means that the *cost per person per session* ranged widely from between £46 and £354.
- The *cost of delivering the intervention* was £2,385 to £4,515 per programme (mean = £3,635).

Conclusions

- The parents attending these groups are often from hard to reach families with children that display very challenging behaviours. Any improvements that can be made in their confidence and management of their children's behaviour should be seen as a success.
- There is some evidence that some parents may benefit in the shorter term from attending the programme, however improvements do not appear to be maintained in the longer term. Parents may need to re-attend the group to maintain the benefits.
- Parents attending these groups are likely to need continued support and reassurance with their child.
- Further research needs to examine a larger number of parents receiving the intervention and also a better matched comparator group that is facing similar challenges.

Chapter 9

Intervention C: A Group-Based Parent-Training Programme for Parents of Children with Autistic Spectrum Conditions

In this chapter we report findings on the effectiveness of a second group-delivered parent-training intervention for parents of children with Autistic Spectrum Conditions.

Main findings

- There is evidence that at least some parents of children with ASC will benefit from attending this programme, both in terms of their sense of satisfaction as a parent, and in their child's behaviour.
- There is consistent evidence that improvements in parent and child outcomes measured at the end of the programme are maintained at 12 week follow-up.
- The evidence regarding longer-term maintenance of post-programme outcomes is more equivocal. However, significant progress towards attaining parent-set goals for child behaviour was recorded at 12 week and 24 week follow-up.
- The total cost of providing the intervention varied from £1,190-£3,460 per programme (mean = £2,390). The cost per person per session varied from £46 to £354.

9.1 Overview of the intervention

CYGNET	
Aims	To increase understanding of ASCs and behaviour, behavioural theory and behaviour management. To signpost to other relevant ASC resources. Provide an opportunity for parents of children with ASC to meet.
Target population	Parents of children with ASC. Other family members may attend.
Age range	7 – 18 years.
Structure & approach	6, weekly 2.5 hour sessions. (Max group size = 12 parents/carers.) Manual sets out session structures and content. It also contains handouts and other teaching materials. First three sessions concerned with increasing parents' understanding of autism; two sessions concerned with behavioural theory principles and behaviour management; final session focuses on topic identified by parents attending the programme. Training approach includes a formal teaching element, supported by slides/video-clips, small and whole group exercises and discussions.

9.2 Overview of the investigation

Design	Controlled trial: intervention and waiting list control group. Groups well matched at baseline. Outcome measures administered: pre-intervention; post-intervention; 12 weeks follow-up; 24 weeks follow-up (IG only). Rating of achievement towards parent-set goals: baseline (session 5/6); 12 & 24 week follow-up.	
Outcomes	<ul style="list-style-type: none"> Parent-set child behaviour goal(s). Standardised measure of Parenting Sense of Competence (PSOC; Johnston and Mash, 1989) <ul style="list-style-type: none"> PSOC-Satisfaction subscale (satisfaction with the parenting role) PSOC-Efficacy subscale (feeling of efficacy as a parent) Two standardised measures of child behaviour: <ul style="list-style-type: none"> Eyberg Child Behaviour Index (ECBI; Eyberg and Pincus, 1999): <ul style="list-style-type: none"> ECBI-Intensity (IS): frequency of disruptive behaviours ECBI-Problem (PS): no. disruptive behaviours problematic to parent Challenging Child Behaviour Scale (CCBS; Bourke-Taylor et al, 2010) 	
Sample	Intervention Group	Waiting List Control Group
Children	n=29	n=31
Age of child (<i>Mean (SD)</i>)	10.19 yrs (3.73)	9.90 yrs (3.06)
Male (%)	26 (89.7%)	25 (80.7%)
Specialist education	8 (22.9%)	6 (18.2%)
Parents	n=35	n=33
Mother (%)	26 (74.3%)	30 (90.9%)
Two parent household (%)	30 (85.7%)	22 (66.7%)
Higher Education (%)	23 (65.7%)	24 (72.7%)
White British (%)	32 (91.4%)	28 (87.5%)
English First Language	34 (97.1%)	31 (93.9%)
Response rates: 82% (post intervention); 76% (12 wk f-up); 77% (24 wk f-up)		
Intervention integrity	97%	

9.3 The evidence of effectiveness

Parent-set child behaviour goals

After the fifth session of the programme, during which the parents and facilitators discussed behaviour management strategies, parents set up to three behaviour-related goals for their child. For example, '[child] eating at the dinner table with the rest of the family', '[child] to get himself ready for school on four out of five days'. Twelve weeks after the programme had finished, progress had been achieved for 90 per cent of the child behaviour goal(s) set by parents,⁴⁶ see Table 9.1. Twenty-four weeks after the programme, the goal attainment ratings⁴⁷ for just under 90 per cent of the goals were higher than at baseline. For a sizeable proportion of goals (40%), additional progress towards the attaining the goal was made during the period between the 12 and 24 week follow-up time points.

Table 9.1 Direction of change for parents who set behaviour goals for their child

Change in goal attainment rating	Time period		
	Baseline ¹ to 12 weeks follow-up (n=21 goals)	Baseline to 24 weeks follow-up (n=27 goals)	12 to 24 weeks follow-up (n=17 goals)
Improved	19 (90.5%)	24 (88.9%)	7 (41.2%)
No change	2 (9.5%)	1 (3.7%)	7 (41.2%)
Deteriorated	0 (0%)	2 (7.4%)	3 (17.6%)

¹ Baseline is week 5 of the programme when the goals were set.

The increase in mean goal attainment from when the goals were set in Week 5 of the programme and at 12 weeks follow-up was statistically significant ($F(1)=26.01$, $p<.001$)⁴⁸. This increase was maintained at 24 weeks after completion of the programme ($F(1)=30.62$, $p<.001$).⁴⁹ Whilst further improvements were demonstrated between 12 and 24 weeks follow-up, these changes were not statistically significant ($F(1)=.430$, $p=.537$). Table 9.2 shows the mean goal attainment ratings at baseline and then 12 and 24 weeks post-intervention. These data are also displayed in Figure 9.2.

⁴⁶ For these analyses, behaviour goals collected from fathers who had accompanied mothers were excluded so that the same goals for a child were not double counted.

⁴⁷ A 10 point rating scale was used to indicate the extent to which a goal has been achieved: 1=very far from this goal; 10=I have achieved my goal.

⁴⁸ The parent's ID code was entered as a between-subjects factor into the ANOVA as some parents had given more than one goal.

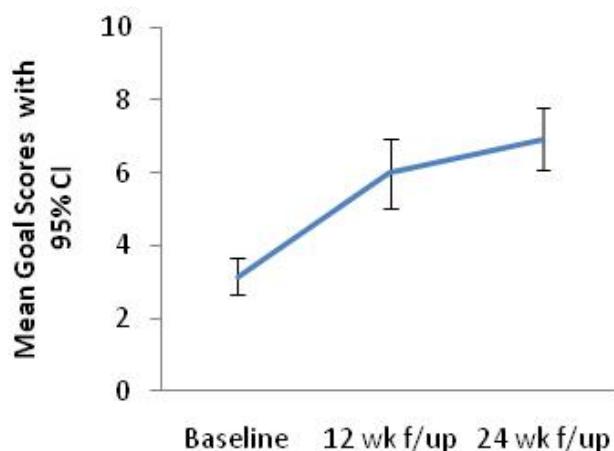
⁴⁹ Bonferroni adjustments were carried out for multiple comparisons.

Table 9.2 Mean goal attainment rating: Baseline – 24 weeks follow-up

Baseline			12 weeks f/up			24 weeks f/up		
N	M	SD	N	M	SD	N	M	SD
40	3.15	1.56	23	6.00	2.22	29	6.93	2.23

N = number of goal scores available; M= mean goal attainment rating; SD=standard deviation

Figure 9.3 Changes in mean goal attainment: Baseline to 24 week follow-up



Parents' sense of competence

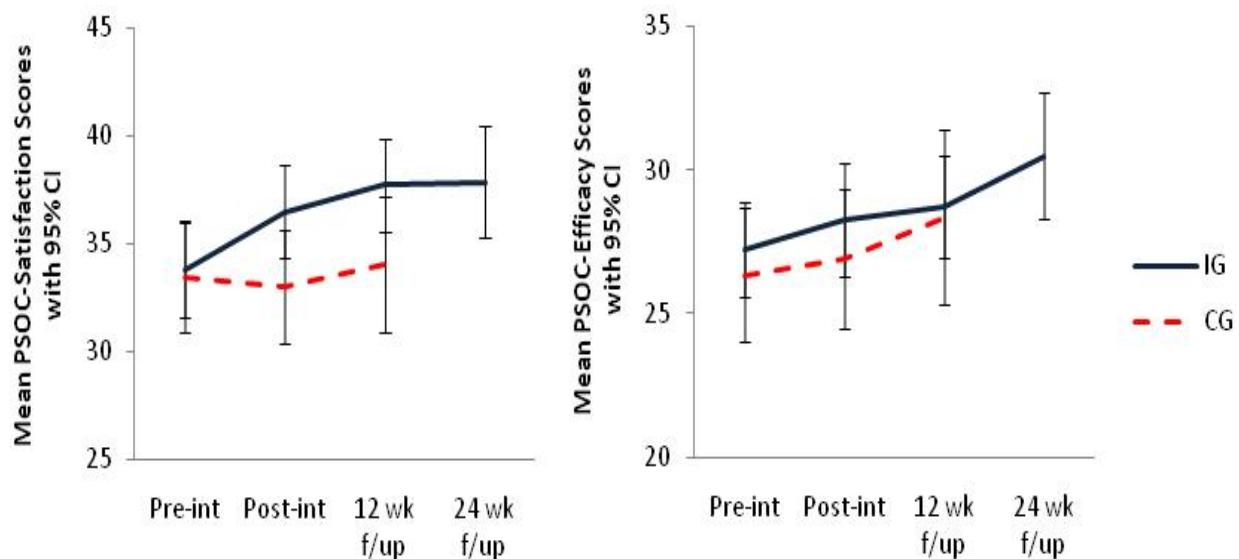
Differences in outcomes for the intervention and waiting list groups

When the scores of parents who attended the group were compared to parents on the waiting list, attending the parent-training programme was associated with statistically significant improvements in parents' satisfaction with their parenting role (PSOC-Satisfaction⁵⁰), see Table 9.3.⁵¹ This association was also apparent 12 weeks after completing the programme, and was approaching statistical significance. There was also evidence that the improvements in parents' satisfaction with their parenting role associated with attending the parent-training programme were maintained 24 weeks after completing the programme, see Figure 9.3. Mean scores increased at each follow-up point for those who attended a parent-training group, whilst scores remained stable for those on the waiting list.

⁵⁰ The Satisfaction subscale (9 items) of the Parenting Sense of Competence Scale (PSOC) is an affective dimension, measuring the extent to which parents are satisfied with their role as a parent, capturing parental frustration, anxiety and motivation. Scores can range from 9-54.

⁵¹ An increased score represents improvement on the PSOC.

Figure 9.4 Mean Parenting Sense of Competence Scores: pre-intervention to 24 week follow-up



Whilst mean PSOC-Efficacy⁵² scores increased at follow-up for parents who attended the parent-training group, these increases were not associated with statistically significant improvements in parents' sense of efficacy when compared to parents on the waiting list, see Table 9.3 and Figure 9.4.

⁵² The Efficacy subscale (7 items) of the PSOC measures the extent to which parents feel they are managing the role of being a parent. It captures parents' perceptions of their competence, problem-solving ability and capability in the parenting role. Scores can range from 7-42.

Table 9.3 Parenting Sense of Competence outcomes

	Group	Pre-intervention			Post-intervention			ANCOVA pre-post	12 week f/up			ANCOVA pre-12 wk f/up	24 week f/up		
		N	M	SD	N	M	SD		N	M	SD		N	M	SD
PSOC- Satisfaction	IG	35	33.83	6.43	29	36.48	5.64	$F(1,55)$ $=8.12,$ $p<.01^b$	29	37.72	5.64	$F(1,49)$ $=4.02,$ $p=.051$	27	37.85	6.51
	CG	33	33.45	7.12	29	33.03	6.87		23	34.09	7.27		--	--	--
PSOC- Efficacy	IG	34	27.21	4.75	29	28.24	5.19	$F(1,55)$ $=0.199,$ $p=.657$	29	28.69	4.68	$F(1,49)$ $=0.68,$ $p=.413$	27	30.48	5.62
	CG	33	26.33	6.55	29	26.90	6.37		23	28.35	6.97		--	--	--

The size and direction of change in parents' sense of competence

Effect statistics⁵³ explored the size (and direction) of changes in parents' sense of competence across the study period, see Table 9.4.

Overall, the size of changes in standardised mean scores between pre-intervention and each follow-on point were greater for the intervention group than the waiting list control group. For the intervention group, the size of improvement was, greatest at 12 and 24 week follow-up for the PSOC-Satisfaction scale and 24 week follow-up for the PSOC-Efficacy scale, where medium effect sizes were found, as opposed to immediately after the end of the programme where effect sizes were small, see Table 9.4 and Figure 9.4. (Mean scores and standard deviations can be found in Table 9.3. Changes in mean scores are visually displayed in Figure 9.3.) Interestingly, a small-medium effect size was also found for change with the control group between pre-intervention and 12 week follow-up for feelings of parental efficacy. This limits the meaningfulness of any change to the intervention group on this subscale as it may not be associated with the programme.

Table 9.4 Effect size for changes in scores from Pre-Intervention on Parenting Sense of Competence (PSOC)

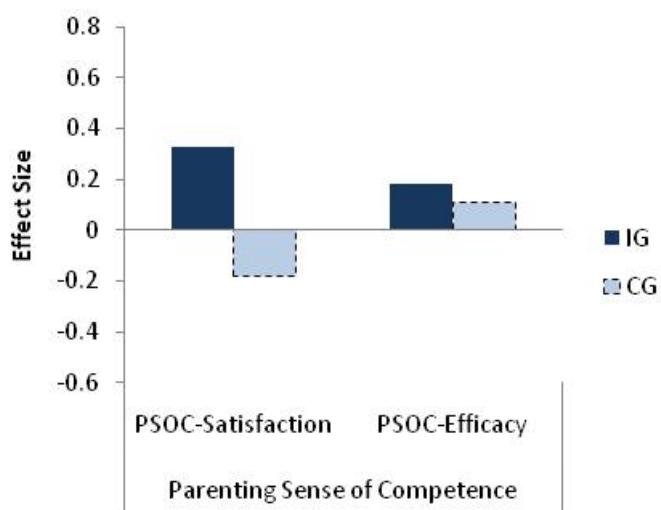
Outcome indicator	Group	Effect size from pre-intervention (d^2)		
		Post-Intervention	12 week follow-up	24 week follow-up (IG only)
PSOC-Satisfaction	IG	.33	.55	.48
	CG	-.18 ²	.20	--
PSOC-Efficacy	IG	.18	.14	.59
	CG	.11	.41	--

¹ Effect size is categorised in the following way: 0.2='small' effect size; 0.5='medium' effect size; 0.8='large' effect size.

² A negative effect size indicates a deterioration in scores between the two time points.

⁵³ The effect size statistic quantifies the difference between two sets of data or between two groups. 0.2 is defined as a 'small' effect size, 0.5 as a medium effect size, and 0.8 as a 'large' effect size. In this study effect sizes were calculated within each sample (e.g. those who had attended a parent group) the effect size between two time – points being calculated. Effect size is calculated by dividing the difference between the means by the pooled standard deviation (Cohen's $d = (MT1 - MTx)/SD$).

Figure 9.5 Effect sizes for changes in scores on Parenting Sense of Competence (PSOC) post-intervention



The proportion of parents who improved on the measure of Parenting Sense of Competence

Scores on the Satisfaction and Efficacy subscales were then examined in order to determine whether changes in scores (from pre-intervention) could be regarded as 'true' changes as opposed to spurious changes caused by inadequacies in the measure. The statistic used is known as the Reliable Change Index (RCI).⁵⁴ This is an important indicator of the clinical, as opposed to statistical, significance of any observed changes associated with an intervention.

Table 9.5 sets out the proportion of parents whose scores on the measure of Parenting Sense of Competence improved, did not change, or deteriorated (as classified by the RCI). Comparisons are made between those parents who attended the programme and the no-intervention comparator group.

At the post-intervention time point, more of the parents who had attended the programme had reliably improved on the measure of parenting satisfaction compared to the no-intervention comparator group (34.5% vs. 6.9%, $p < .05$). However, this difference was not found at 12 weeks post-intervention. This can be attributed to improvements within the comparator group on this outcome indicator, as opposed to deterioration within the intervention group. At 24 weeks follow-up there remained a third of parents showing reliable improvement on the PSOC-Satisfaction subscale. As there is no data at 24 week follow-up for the control parents, these findings need to be interpreted with caution.

⁵⁴ A reliable change was defined as those where a score of >1.96 on the Reliable Change Index was achieved (Hawley, 1995; Jacobson and Truax, 1991). The reliable change index (RCI) for each case was calculated by dividing the difference between the Time 1 and 2 scores by the standard error of measurement (SEmeas) [RCI = $Mt1 - Mt2/Sdiff$]. Sdiff will be obtained by calculating the square route of double the standard error squared (Sdiff = $\sqrt{2(SE)^2}$). A chi-squared test will examine whether reliable change is significant across the treatment groups.

Table 9.5 The reliable change on Parenting Sense of Competence: intervention group versus control group

	Parenting Sense of Competence			
	Satisfaction		Efficacy	
	IG	CG	IG	CG
Post intervention				
Reliably improved	10 (34.5%)	2 (6.9%)	9 (31.0%)	7 (24.1%)
No reliable change	16 (55.2%)	21 (72.4%)	16 (55.2%)	20 (69.0%)
Reliable deterioration	3 (10.3%)	6 (20.7%)	4 (13.8%)	2 (6.9%)
Chi-square Pre- Post	<i>Fisher's Exact Test =6.950, p<0.05</i>		<i>Fisher's Exact Test =1.364, p=.577</i>	
12 weeks follow-up⁵⁵				
Reliably improved	11 (37.9%)	7 (30.4%)	9 (31.0%)	11 (47.8%)
No reliable change	17 (58.6%)	13 (56.5%)	17 (58.6%)	9 (39.1%)
Reliable deterioration	1 (3.4 %)	3 (13.0%)	3 (10.3%)	3 (13.0%)
Chi-square Pre -12 week f/up	<i>Fisher's Exact Test =1.681, p=0.518</i>		<i>Fisher's Exact Test =2.060, p=0.36</i>	
24 weeks follow-up				
Reliably improved	9 (33.3%)	-	14 (51.9%)	-
No reliable change	17 (63.0%)	-	9 (33.3%)	-
Reliable deterioration	1 (3.7%)	-	4 (14.8%)	-

In terms of parents' sense of efficacy, some surprising effects were found though none are statistically significant. At the post-intervention time point the proportion of parents with reliably improved scores is relatively similar in both the intervention and the waiting list comparator groups. At 12 weeks follow-up nearly half of parents (47.8%) who had not yet attended the parent-training group showed reliable improvement compared to just under a third (31.0%) of those who had attended a group. By 24 week follow-up over half of parents who had received the intervention had reliably improved on the efficacy outcome measure. Again, because of the improvements shown in the waiting list control group at 12 week follow-up, it is unclear how much of this improvement can be attributed to the intervention. These findings may be caused by inadequacies in the outcome measure. However, the potential that this intervention may have a negative impact on parents' sense of efficacy should be investigated further.

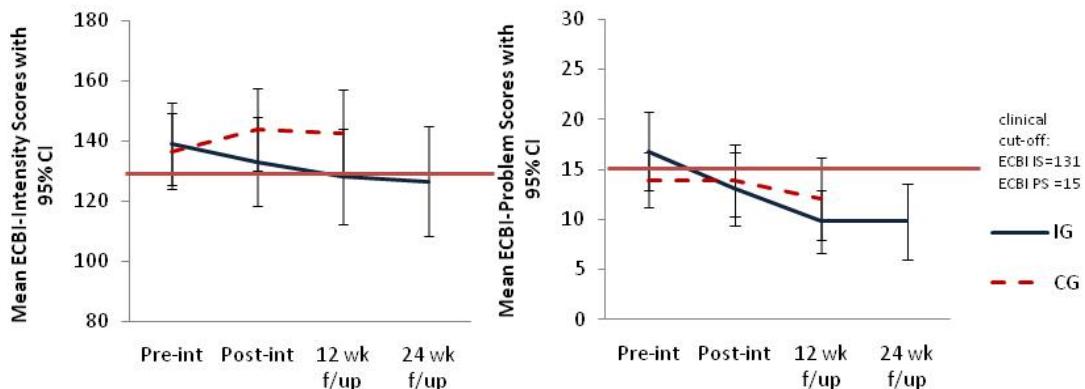
⁵⁵ Twenty-four week post intervention comparisons not possible as data not collected from waiting list control group at this time point.

Parent-report child behaviour

Differences in outcomes for the intervention and waiting list groups

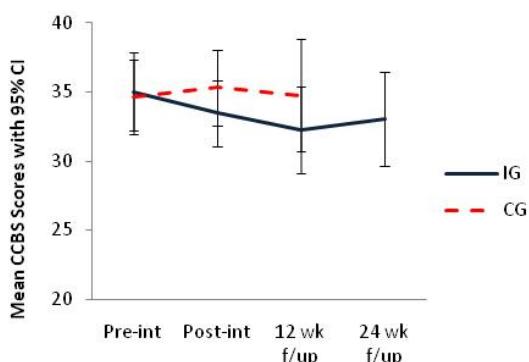
After comparing mean scores from parents who had and had not yet attended the parents training programme, improvements in scores on the ECBI child behaviour measure (Eyberg Child Behaviour Inventory (ECBI)-Intensity,⁵⁶ ECBI-Problem⁵⁷) were associated with attending the parent-training programme but this association did not reach statistical significance (see Table 9.6 and Figure 9.5a).⁵⁸

Figure 9.6a Mean ECBI scores by group over time



Attending the parent-training programme was associated with a statistically significant improvement in scores on the other standardised measure of child behaviour (Challenging Child Behaviour Scale⁵⁹ (CCBS)), see Table 9.6. Improvements were maintained 12 weeks after completion of the programme, but mean scores deteriorated slightly 24 weeks after programme completion, see Figure 9.5b.

Figure 9.6b Mean CCBS scores: pre-intervention - 24 week follow-up



⁵⁶ The ECBI-Intensity scale measures the frequency of disruptive behaviours by summing the frequency of each disruptive behaviour.

⁵⁷ The ECBI-Problem scale is a count of disruptive behaviours that the parent rates as problematic.

⁵⁸ A lower score represents improvements for all child-behaviour (ECBI, CCBS) measures.

⁵⁹ The Challenging Child Behaviour Scale measures parents' reports of the frequency of challenging or difficult to manage behaviours in the home.

Table 9.6 Child behaviour outcomes

		Pre-intervention			Post-intervention			ANCOVA pre-post	12 week follow-up			ANCOVA pre-12 wk f/up	24 week follow-up		
	Group	N	M	SD	N	M	SD		N	M	SD		N	M	SD
ECBI- Intensity	IG	27	139.07	34.45	27	133.13	34.56	$F(1,44)$ $=2.03$, $p=.162$	23	128.13	36.96	$F(1,37)$ $=.856$, $p=.361$	21	126.57	40.13
	CG	27	136.52	31.72	26	143.81	34.09		30	142.75	30.47		--	--	--
ECBI- Problem	IG	23	16.78	9.17	20	13.05	7.86	$F(1,35)$ $=1.61$, $p=.213$	21	9.81	6.87	$F(1,30)$ $=2.95$, $p=.096$	21	9.81	8.28
	CG	27	13.93	6.97	24	13.88	8.46		18	12.06	8.15		--	--	--
CCBS	IG	25	35.04	6.85	22	33.45	5.38	$F(1,43)$ $=5.13$, $p<.05$	22	32.27	7.11	$F(1,37)$ $=4.78$, $p=.051$	20	33.05	7.24
	CG	30	34.63	7.17	26	35.31	6.70		20	34.75	8.72		--	--	--

The scale of improvement in parent-report child behaviour

The size of improvement in scores on parent-reported measures of child behaviour was consistently greater for the intervention group compared to the waiting list control at each measurement point. Large effect sizes were found in the intervention group at 12 and 24 week follow-up on the scale measuring the number of disruptive behaviours perceived by parents as problematic (ECBI-Problem). The size of change in scores for the other two child behaviour outcome measures (ECBI-Intensity and CCBS) was small, see Table 9.7 and Figure 9.6.

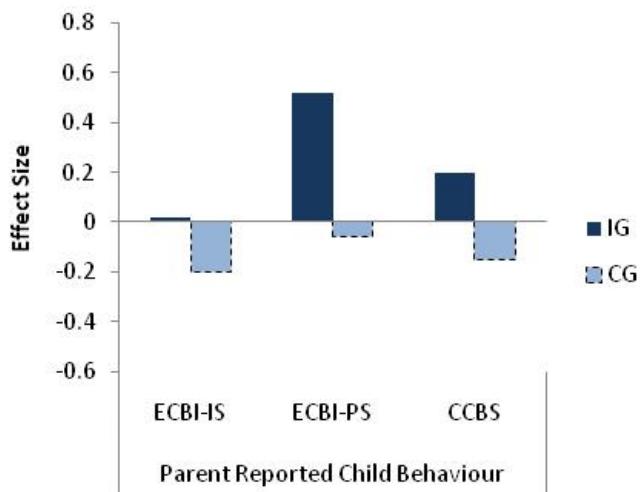
Table 9.7 Effect sizes for changes in scores on child behaviour outcome measures

Outcome indicator	Group	Effect size from pre-intervention (d^2)		
		Post-intervention	12 week follow-up (IG only)	24 week follow-up (IG only)
ECBI Intensity Scale	IG	.02	.18	.24
	CG	-.20 ¹	.07	-
ECBI Problem Scale	IG	.52	.77	.80
	CG	-.06	.28	-
Child's Challenging Behaviour Scale (CCBS)	IG	.20	.32	.20
	CG	-.15	-.04	-

¹ Effect size is categorised in the following way: 0.2='small' effect size; 0.5='medium' effect size; 0.8='large' effect size.

² A negative effect size indicates a deterioration in mean scores between the two time points.

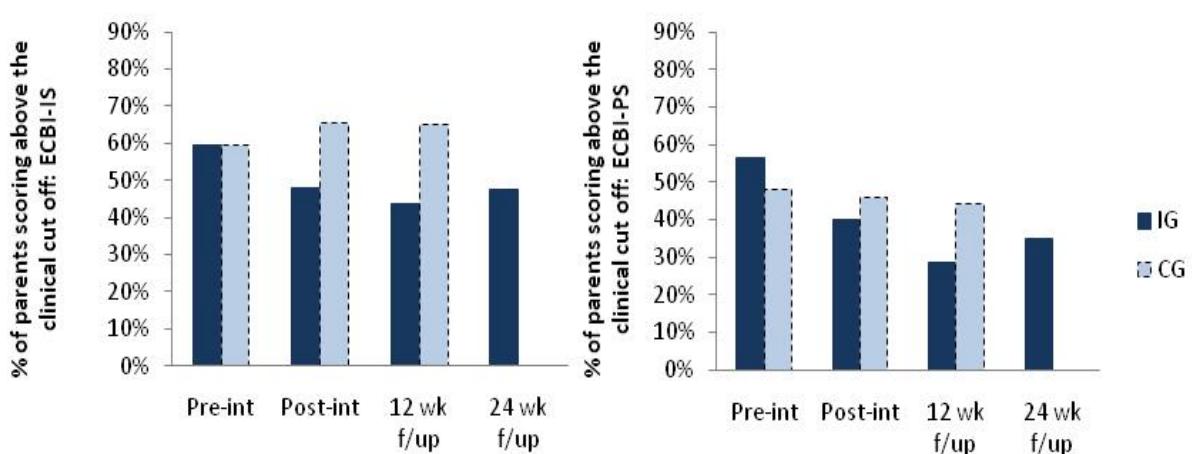
Figure 9.7 Effect sizes for changes in scores on the Eyberg Child Behaviour Inventory and the Challenging Child Behaviour Scale post-intervention



Movement around clinical cut-off points

Clinical cut-off points are available for both the ECBI scales.⁶⁰ Pre-intervention, 60 per cent of the children represented in the investigation were scoring above the clinical cut-off point on the ECBI-Intensity subscale and around 50 per cent were scoring above the clinical cut-off point on the ECBI-Problem subscale. At the end of the parent-training programme a greater proportion of children represented in the intervention group were below the clinical cut-off points on these subscales compared to the waiting list control group, see Figures 9.7 and Table 9.8. However, these differences between the intervention and waiting list groups were not statistically significant, see Table 9.8.

Figure 9.8 Proportion of parents scoring above the clinical cut-off on ECBI scale: pre-intervention- 24 week follow-up



⁶⁰ Clinical cut-off scores are recommended by the author of the manual (Eyberg and Pincus, 1999) to classify children as having behaviour problems are 131 (ECBI-IS) and 15 (ECBI-PS).

Table 9.8 Movement about clinical cut-off points by group and time

		N (%) above clinical cut-off		McNemar's χ^2 pre-post	12 week follow-up	McNemar's χ^2 pre-12 wk f/up	24 week follow-up
		Pre-intervention	Post-intervention				
ECBI - Intensity	IG	16 (59.3%)	$p=1.000$	11 (47.8%)	10 (43.5%)	$p=0.625$	10 (47.6%)
	CG	16 (59.3%)	$p=0.625$	17 (65.4%)	13 (65.0%)	$p=1.000$	-
ECBI-Problem	IG	13 (56.5)	$p=.453$	8 (40.0)	6 (28.6)	$p=0.125$	7 (35.0%)
	CG	13 (48.1)	$p=1.000$	11 (45.8)	8 (44.4)	$p=1.000$	-

The proportion of parents reporting changes in their child's behaviour

As with the Parenting Sense of Competence outcomes, Reliable Change statistics were used to test whether observed improvements in child behaviour for the intervention group were clinically significant, see Table 9.9.

Whilst the proportions showing reliable improvement across the intervention and control groups are variable, typically, a slightly greater proportion of parents in the non-intervention group reported deteriorations in their child's behaviour. No statistically significant differences were found in rates of reliable improvement, no change, or reliable deterioration between the intervention and comparator groups on any of the standardised behaviour measures. The proportions of parents in the intervention group where no reliable change occurred are quite high. Between six and eight out of ten parents report no reliable change in the ECBI-Intensity or CCBS at any time point. There is more positive movement for the measure of challenging behaviours parents report as problematic (ECBI-Problem). Here over 50 per cent of parents report a reliable improvement at 12 weeks post-intervention, with this figure falling to just over 41 per cent at 24 week follow-up. However there is also positive movement for parents who have not attended the programme – suggesting that reliable change is not always associated with attending the programme.

Table 9.9 The proportion of parents reporting changes in the frequency of challenging or difficult to manage behaviours in the home: Reliable Change Statistics

	ECBI Intensity Scale		ECBI Problem Scale		Child Challenging Behaviour Scale	
	IG	CG	IG	CG	IG	CG
Post-intervention						
Reliably improved	4 (18.2%)	2 (8.0%)	5 (29.4%)	6 (28.6%)	3 (15.0%)	3 (11.5%)
No reliable change	17 (77.3%)	19 (76.0%)	10 (58.8%)	8 (38.1%)	15 (75.0%)	16 (61.5%)
Reliable deterioration	1 (4.5%)	4 (16.0%)	2 (11.8%)	7 (33.3%)	2 (10.0%)	7 (26.9%)
Chi-square Pre-Post	<i>Fisher's Exact Test</i> =2.242, <i>p</i> =.415		<i>Fisher's Exact Test</i> =2.626, <i>p</i> =.262		<i>Fisher's Exact Test</i> =2.047, <i>p</i> =.404	
12 weeks follow-up						
Reliably improved	6 (27.3%)	5 (27.8%)	9 (52.9%)	5 (20.8%)	6 (30.0%)	4 (20.0%)
No reliable change	15 (68.2%)	11 (61.1%)	7 (41.2%)	16 (66.7%)	12 (60.0%)	12 (60.0%)
Reliable deterioration	1 (4.5%)	2 (11.1%)	1 (5.9%)	3 (18.5%)	2 (10.0%)	4 (20.0%)
Chi-square Pre-12 week f/up	<i>Fisher's Exact Test</i> =.771, <i>p</i> =.882		<i>Fisher's Exact Test</i> =1.749, <i>p</i> =.448		<i>Fisher's Exact Test</i> =1.081, <i>p</i> =.612	
24 weeks follow-up						
Reliably improved	6 (30%)	-	7 (41.2%)	-	7 (36.8%)	-
No reliable change	13 (65%)	-	10 (58.8%)	-	12 (63.2%)	-
Reliable deterioration	1 (5%)	-	-	-	-	-

9.4 Costs

In this section we present data on the costs of delivering the intervention; evidence about the impact of the child's behaviour problems on parents; and their and their children's use of services which relate to the presence of child behaviour problems. We also present data on changes in use of these services over the intervention and follow-up period.

For this intervention we have pre-intervention data on service use and the impact on work or daily life from 35 parents in the intervention group (IG) and 33 in the comparator group

(CG).⁶¹ At 12 weeks post-intervention the samples had reduced slightly; 29 and 22 respectively. The data on service use is based on a slightly smaller sample size.

It is important to remember that, for all behaviour management interventions we investigated, increases in overall service use may be expected. By attending the intervention parents may hear from other parents about services (statutory and voluntary sector) of which they were not previously aware. Signposting to other sources of voluntary sector or statutory support was also something practitioners delivering the intervention may undertake. Practitioners delivering this intervention also expected, on occasion, to need to refer a parent for additional one-to-one work from the CAMHS LD team.

A longer follow-up period (or prospective study) would be required in order to establish whether these early intervention/preventive programmes prevented later use of higher cost tertiary or specialist education, health and/or social care services for the child and other family members.

Intervention costs

Typically two or three facilitators were present at each of the six sessions. In one of our research sites the programme was run through the CAMH service facilitated by health and education professionals. In the other site it was based in a voluntary sector organisation and used trained facilitators from health, education or voluntary sector backgrounds. No interpreters were used and occasionally one of the facilitators was absent.

Staff time accounted for the main part of the cost of the intervention, and this included time setting-up the group, planning the sessions and travelling, as well as delivering the intervention and the de-briefing. For the groups run by the voluntary sector organisations *the cost per session* was £185; for the groups run by CAMHS, the costs per session were between £360 and £490 depending on the number of facilitators. The costs refreshments, materials, information sheets, and the venue contributed around ten per cent of the total cost. The *total cost of providing the intervention* varied from £1,190-£3,460 per programme (mean = £2,390).

Typically eight or nine parents attended at the start of the intervention but, although most also finish the course, there is some variation in the number of parents attending each group (between three and nine). This meant that the *cost per person per session* ranged from between £16 and £92 in the voluntary sector organised course, and between £40 and £140 for the course run through CAMHS.

The *cost per person for the intervention* varied, therefore, depending on the number of facilitators (between one and three) and parents at each session and the number of sessions each parent attended (between three and seven; the follow-up session tended to be least well attended). Thus the mean costs for parents attending Programme C was £351.10 but the range was between £141 and £663, the latter representing the cost for someone who attended all the sessions of a course run by CAMHS.

Parents' service use and impact of child behaviour problems on employment and daily life

Prior to the intervention, 37 (61%) of the 61 parents in the 'cost sample' reported that their child's behaviour had affected their health; 14 were in the intervention group. By 12 week follow-up, only 23 (50%) reported their health had been affected, 11 of whom were in the intervention group. However, parents used very few services as a result of their child's problems at either time point (see Appendix R, Table R.1 and R.2).

⁶¹ We refer to this collectively as the 'cost sample'.

Moreover, relatively few days were lost from work because of the child's behaviour problems. Thirty-eight (62%) of the 61 parents in the pre-intervention 'cost sample' were in paid employment of whom six had taken days off work because of their child's behaviour problems; five reported they had been absent from work for a total of 22 days. By 12 weeks follow-up, 32 of the 48 (66%) parents in the 'cost sample' who responded to this question were in employment of whom seven had taken between one and six days off work.

Thirteen parents said that there were days in the three months prior to the pre-intervention time point in which the child's problems had prevented them undertaking their normal activities (34%). Again these figures had reduced (to 25%) at the 12 week follow-up time point.

Service use for the children and associated costs

At the pre-intervention time point, seventeen children (25%; IG=5, CG=12) had between one and 15 days off school because of their behaviour. However, exclusions were rare with only one child excluded permanently (3 months), and three each excluded formally or informally for up to a week. The figures for the 12 week follow-up time point were very similar. Seven children had been excluded and slightly fewer children than at pre-intervention had taken days off school because of their behaviour problems (13%; one from the intervention group and eight from the control group), commonly for less than a week, but 25 days for one child.

As with the parent data, there was a generally sparse pattern of service use for children during the three months prior to receiving the intervention and at the 12 week follow-up time point. Details can be found in Appendix R (Table R.1). This pattern of low levels of service use for most families was common for all services. Perhaps what is surprising is the extent to which the families manage with so few formal supports except school.

Given the sparse use of any individual services, Table 9.10 presents the support costs information using broad service groups, organised around groupings of services (see Appendix R, Table R.2). The table shows the mean costs and range for each group by service category and for the total costs of public sector support.

Table 9.10 Service costs over 3 months prior data collection time points

Service/support	Pre-intervention time point		12 week follow-up time point	
	Intervention n=35	Comparator, n=33	Intervention n=29	Comparator, n=22
		Mean £ (range)		Mean £ (range)
Hospital services	£60.00 (£0-£489)	£74.20 (£0-£824)	£35.50 (£0-£329)	£111.10 (£0-£489)
Mental health services	£45.40 (£0-£326)	£118.90 (£0-£864)	£48.00 (£0-£235)	£131.00 (£0-£561)
Community health	£35.40 (£0-£148)	£50.40 (£0-£438)	£67.40 (£0-£444)	£98.70 (£0-£1369)
Primary care	£51.20 (£0-£245)	£81.90 (£0-£426)	£23.50 (£0-£149)	£75.60 (£0-£401)
Social care	£142.00 (£0-£1912)	£123.20 (£0-£991)	£162.20 (£0-£1181)	£311.70 (£0-£4234)
Total cost of child's service use	£333.80 (£0-£2210)	£448.50 (£0-£2209)	£336.60 (£0-£1774)	£728.10 (£0-£5797)
Services for behaviour	53.20 (£0-£390)	£127.00 (£0-£864)	£50.10 (£0-£235)	£137.80 (£0-£561)
Total costs of main carer's service use	£9 (£0-£105)	£31 (£0-£328)	£10 (£0-£140)	£68 (£0-£664)

At the pre-intervention time point, observed costs for each of the service categories are higher for the control group with the exception of social care services, but including the total cost of service use. However, simple t-tests suggest that only the costs for mental health services are significantly different (lower for the intervention group, $p=0.29^{62}$); total costs are not significantly different.

The next row in Table 9.10 shows the total costs for all behaviour-related services. This includes the costs for outpatient appointments for behaviour problems, family therapist, CAMHS contacts, and contact with GPs, health visitors and community nurses for behaviour-related problems. These comprise 16 per cent of total costs for the intervention group and 28 per cent for the comparator group and observed costs for the control group are also just over twice as high. The significant difference in mental health services costs drives the significantly lower mean cost for behaviour-related services for the intervention group (services for behaviour; $p=0.032^{63}$).

At the post-intervention time point, the picture of higher observed costs for the comparator group remains. Mean costs for the comparator group have generally increased in comparison to the pre-intervention time point. For the intervention group the pre-intervention to 12 week follow-up comparison is more mixed with an increase in mean costs for community health and social care increasing but a decrease for hospital and primary care. Again using t-tests, we found that despite these observed costs changes, total costs were not significantly different between the groups, although costs for hospital services, mental health services and primary care were significantly lower for the intervention group ($p=0.049$, 0.016 , 0.032 respectively), as were costs for all behaviour services ($p=0.14$).⁶⁴

⁶² Not confirmed by bootstrapped confidence intervals; -101.110 – 30.137.

⁶³ Not confirmed by bootstrapped confidence intervals: -94.243 – 42.754.

⁶⁴ Bootstrapped confidence intervals: hospital services -177.078 – -14.010; mental health services -184.430 – -21.217; primary care -103.633 – 6.841; behaviour services -186.116 – -22.197.

The final row of Table 9.10 shows the total costs of the services used by parents because of their child's behaviour problems. Although these costs were generally quite low, the mean cost is higher at the 12 week follow-up time point than at pre-intervention time point for both groups. However, a simple t-test suggests they are not significantly different between groups (pre-intervention time point; $p=0.168$; 12 week follow-up time point; $p=0.140$).

9.5 Summary of the findings

- Progress in attaining goals for improved child behaviour and standardised measures of parents' sense of competence and parent-report child behaviour were used to assess the effectiveness of the intervention. Outcomes were compared to a waiting list control (or no intervention group) at post-intervention and 12 and 24 week follow-up.
- Significant progress towards attaining parent-set goals for child behaviour was recorded at 12 week and 24 week follow-up.
- Programme attendance was associated with improvements in parents' sense of competence, especially their satisfaction with their role as a parent. Improvements in role satisfaction were maintained at 12 week follow-up. Improvements in the waiting list control group on the efficacy subscale meant that improvements in the intervention group could not be attributed to attendance of the programme.
- The sizes of improved scores on the measure of Parenting Sense of Competence for the intervention group were relatively small at the end of the programme but increased at 12 (Satisfaction subscale) and/or 24 week follow-up (both Satisfaction and Efficacy Subscale). The substantial improvement on the subscale capturing parents' sense of efficacy seen at 24 week follow-up needs to be interpreted with caution due to the moderate effect size found at 12 week follow-up for the waiting list control group.
- Programme attendance was associated with a reported improvement of the frequency (ECBI-IS) and severity (ECBI-PS) of challenging behaviours. These improvements were maintained at 12 and 24 week follow-up but were not large enough given the study's sample size to be statistically significant.
- Programme attendance was also associated with statistically significant improvements in parents' reports of the frequency of challenging or difficult to manage behaviours in the home (CCBS). These improvements were maintained at 12 week follow-up with a slight deterioration at 24 week follow-up.
- The larger effect sizes and increased reliable change scores for the ECBI-Problem Scale in comparison to the ECBI-Intensity Scale indicate that to some extent, whilst their child may still be exhibiting some of the problem behaviours – they are no longer seen as problematic to the parents who have attended the parent-training group.
- The consistent positive movement of mean scores from parents who attended the parent-training group for the goal-attainment ratings and reports of parent competence and child behaviour in comparison to those on the waiting list, are encouraging evidence for the positive impact of the programme. However reliable change statistics, when compared to the comparator group, are more equivocal.
- At the pre-intervention time-point 61 per cent of parents said that their child's behaviour affected their health. By the 12 week-follow-up time point, this reduced to 50 per cent of the whole sample. Few of those in employment had to miss days at work, but the child's behaviour had a larger impact on parents' ability to undertake daily activities.
- For the three months prior to the 12 week follow-up time point, observed service-use costs generally increased for the comparator group and were similar or slightly lower for the intervention group. However, again total costs were not significantly different between the groups.
- The total cost of providing the intervention varied from £1,190-£3,460 per programme (mean = £2,390). Mean intervention costs were £351 per person (range £144-£663).

- Small sample sizes and wide cost variation mean that the statistical findings should be interpreted with care. With that in mind we found that no significant cost differences in the between-group mean total costs.

Conclusions

- There is evidence that at least some parents of children with ASC would benefit from attending this programme, both in terms of their sense of satisfaction as a parent, and in their child's behaviour.
- The findings from the ECBI measures suggest to some extent that whilst the frequency of some problems may not reduce a great deal over the study period, parents may change their perceptions of which behaviours are seen as problematic.
- There is consistent evidence that improvements in parent and child outcomes measured at the end of the programme are maintained at 12 week follow-up.
- The evidence regarding longer-term maintenance of post-programme outcomes is more equivocal.
- Equally, there is some evidence that the benefits of the programme in terms of parents' sense of efficacy may not be fully realised until some time after programme completion.
- Set in the context of the outcome analysis, these cost results suggest that the additional expenditure on this intervention may have the potential to reduce costs to other services over time as well as generating encouraging outcomes for children and parents.

Chapter 10

Intervention D: A Group-Based Parent-Training Programme for Parents of Children with Disabilities

In this chapter we report findings from a parent-training group developed for parents of disabled children.

Main findings

- The findings on the effectiveness of this intervention suggest that at least some parents of children with ASC or other disabilities would benefit from attending this programme with attendance associated with significant improvements in parents' sense of competence and child's behaviour.
- Whilst there is evidence that improvements are maintained during the immediate months after completing the intervention, there is evidence that the gains in improved child behaviour may, to a greater or lesser extent, be lost in the longer term.
- The total cost of providing the programme ranged from £2,975 to £4,590 per programme (mean = £3,570). The costs per session ranged from £190 to £532.

10.1 Overview of the intervention

RIDING THE RAPIDS: LIVING WITH AUTISM AND DISABILITY	
Aims	To enable parents to understand and manage their child's behaviour in the context of additional needs, using functional analysis, communication and behavioural approaches. To encourage parental confidence and well-being.
Target population	Parents of children with ASC and/or learning and/or physical disabilities. Open to both parents.
Age range	4 – 10 years.
Structure & approach	10, weekly 2 hour sessions. (Max. group size = 12 parents.) Manual sets out session structures and content. Also contains handouts and other teaching materials. The programme comprises: an introductory session; four sessions concerned with behavioural theory and behaviour management; sessions on play, communication, managing stress plus a review and celebration sessions. Training approach incorporates weekly ratings of child's behaviour and parental coping; some formal teaching, modelling; problem-solving exercises; and extensive role play to support parents' learning. Parents' own 'self-care' is emphasised and small 'gifts' are used to encourage parents to look after themselves.

10.2 Overview of the investigation

Design	Controlled trial: intervention (IG) and waiting list control (CG) groups. Well matched at baseline. Outcome measures administered: pre-intervention; post-intervention; 12 week and 24 week follow-up (IG only). Rating of achievement towards parent-set goals: baseline (session 1); post-intervention; 12 & 24 week follow-up.	
Outcomes	<ul style="list-style-type: none"> Parent-set child behaviour goal(s). Standardised measure of Parenting Sense of Competence (PSOC; Johnston and Mash, 1989) <ul style="list-style-type: none"> PSOC-Satisfaction subscale (satisfaction with the parenting role) PSOC-Efficacy subscale (feeling of efficacy as a parent) Two standardised measures of child behaviour: <ul style="list-style-type: none"> Eyberg Child Behaviour Index (ECBI; Eyberg and Pincus, 1999): <ul style="list-style-type: none"> ECBI-Intensity (IS): frequency of disruptive behaviours ECBI-Problem (PS): no. disruptive behaviours problematic to parent Challenging Child Behaviour Scale (CCBS; Bourke-Taylor et al, 2010) 	
Sample	Intervention Group	Waiting List Control Group
Children	n=47	n=29
Age of child (<i>Mean (SD)</i>)	7.07 yrs (2.12)	6.07 yrs (2.68)
Male (%)	38 (80.9%)	21 (72.4%)
Has (or awaiting) a diagnosis of ASC	29 (67.4%)	17 (60.7%)
Specialist education	28 (63.6%)	13 (52.0%)
Parents	n=48	n=28
Mother (%)	42 (87.5%)	25 (89.3%)
Two parent household (%)	35 (79.5%)	13 (48.1%)
Higher Education (%)	16 (35.6%)	9 (33.3%)
White British (%)	25 (52.1%)	14 (51.9%)
English First Language	37 (80.4%)	21 (77.8%)
Response rates:	75% (post intervention); 67% (12 wk f-up); 53% (24 wk f-up).	

10.3 The evidence of effectiveness

Parent-set child behaviour goals

During the first session of the programme, parents⁶⁵ selected a specific problem behaviour that they would like to work on throughout the group with their child. For example: 'to scream and shout less when something does not go his way', 'For child to sleep in his own bed'⁶⁶. Post-intervention nearly 80 per cent of parents reported progress⁶⁷ in attaining these goals, see Table 10.1. Less than ten per cent reported a deterioration with regard to achieving their goal. Twenty-four weeks after the programme, over 90 per cent of parents were still rating positive progress in achieving their goal(s), with a sizeable proportion (18, 50%) reporting additional progress towards the goal post-intervention and 12 week follow-up. Only one parent reported a deterioration in their goal score from pre-intervention to 24 week follow-up.

Table 10.1 Direction of change for parents who set a behaviour goal for their child

Change in goal attainment rating (n=48 goals)	Time Period			
	Pre-int-post int	Pre-int-12 weeks f/up (n=37 goals)	Pre-int 24 weeks f/up (n=25 goals)	12 to 24 weeks f/up (n=36 goals)
Improved	38 (79.2%)	31 (83.8%)	23 (92.0%)	18 (50%)
No change	6 (12.5%)	3 (8.1%)	1 (4.0%)	7 (19.4%)
Deteriorated	4 (8.3%)	3 (8.1%)	1 (4.0%)	11 (30.6%)

The increase in mean goal attainment from when the goals were set in Week 1 of the programme and post-intervention was statistically significant, $t(49)=-8.462$, $p<.001$. This increase was maintained 12, $t(37)=-7.917$, $p<.001$ and 24 weeks $t(25)=-6.797$, $p<.001$ after completion of the programme. Whilst further improvements were demonstrated between post-intervention, 12 and 24 weeks follow-up, these changes were not statistically significant^{68,69}. Table 10.2 shows the mean goal attainment ratings at each time point. These data are also displayed in Figure 10.2.

⁶⁵ Where two parents had set goals for the same child, goals were taken from the 'main carer' (typically the mother).

⁶⁶ A 10 point rating scale was used to indicate the extent to which a goal has been achieved: 1=very far from this goal; 10=I have achieved my goal.

⁶⁷ Improvement/Deterioration based on whether the goal scores have moved 1+ scores in a positive or negative direction.

⁶⁸ Post-intervention – 12 week follow-up: $t(36)=-.296$, $p=.769$; Post-intervention – 24 week follow-up: $t(25)=.837$, $p=.411$.

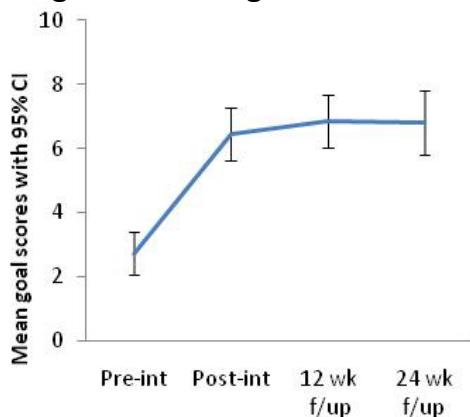
⁶⁹ A Bonferroni adjustment was used to account for the multiple comparisons between the different time points.

Table 10.2 Mean goal attainment rating over time

Pre-intervention			Post-intervention			12 weeks f/up			24 weeks f/up		
N	M	SD	N	M	SD	N	M	SD	N	M	SD
53	2.72	2.42	50	6.45	2.91	40	6.85	2.64	28	6.79	2.57

N=number of goal scores available; M=mean goal attainment rating; SD=standard deviation

Figure 10.3 Changes in mean goal attainment: Baseline to 24 week follow-up



Parents' sense of competence

Differences in outcomes for the intervention and waiting list groups

When the scores of parents who had attended the group were compared to parents on the waiting list, attending the parent-training programme was associated with statistically significant improvements⁷⁰ in parents' sense of competence as measured by the Parenting Sense of Satisfaction⁷¹ and Parenting Sense of Efficacy⁷² subscales (see Table 10.3 and Figure 10.3).

Mean scores show that improvements within the intervention group are maintained for the Satisfaction Scale and, to a lesser extent, the Efficacy Scale at follow-up. The improvement in scores for the intervention group at each time point was statistically significant for the Satisfaction, but not the Efficacy subscale.⁷³

⁷⁰ An increased score represents improvement on the PSOC.

⁷¹ The Satisfaction subscale (9 items) of the Parenting Sense of Competence Scale (PSOC) is an affective dimension, measuring the extent to which parents are satisfied with their role as a parent, capturing parental frustration, anxiety and motivation. Scores can range from 9-54.

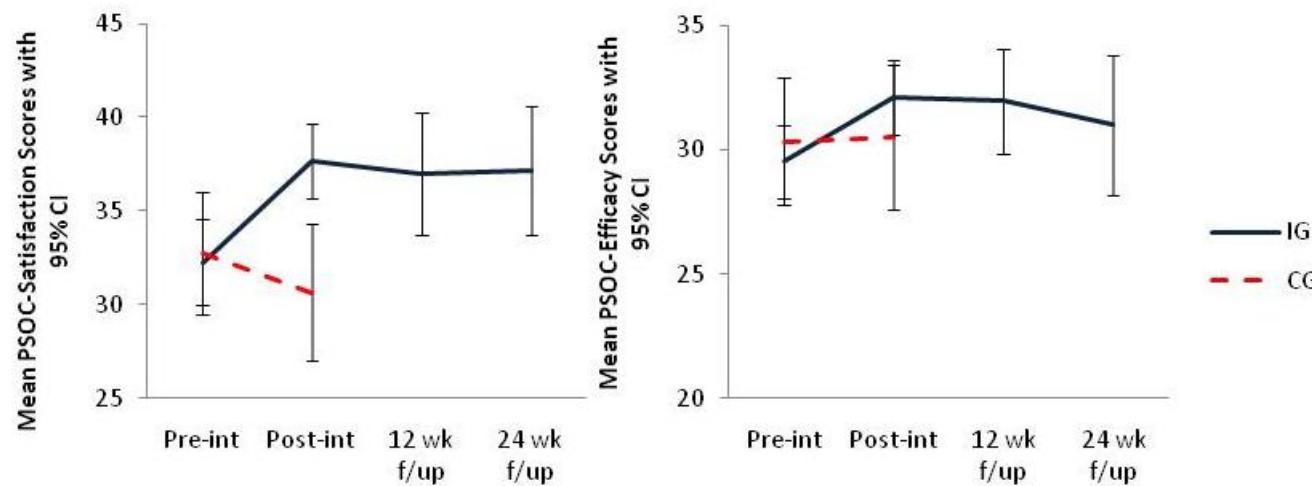
⁷² The Efficacy subscale (7 items) of the PSOC measures the extent to which parents feel they are managing the role of being a parent. It captures parents' perceptions of their competence, problem solving ability and capability in the parenting role. Scores can range from 7-42.

⁷³ Further t-tests explored at which time points the significant change occurred for the Satisfaction Scale. After a Bonferroni adjustment; change in mean scores was found to be significant between pre and post intervention scores: $t(42) = -4.321$, $p < .001$; pre-intervention and 12 week follow-up scores: $t(38) = 3.599$, $p < .001$; and pre-intervention and 24 week follow-up scores: $t(30) = 3.878$, $p < .001$. Further change post-intervention was not significant (post-intervention - 12 week follow-up: $t(35) = -.357$, $p = .723$, post-intervention - 24 week follow-up: $t(32) = -.120$, $p = .906$.

Table 10.3 Parents' sense of competence outcomes

		Pre-intervention			Post-intervention			ANCOVA Pre-post	12 week follow-up			24 week follow-up			Repeated Measures ANCOVA
		Group	N	M	SD	N	M	SD	N	M	SD	N	M	SD	
PSOC- Satisfaction	IG	46	32.26	7.80	36	37.69	5.89	$F(1, 50)=22.06, p<.001$	30	37.00	8.68	24	37.17	8.14	$F(3)=8.308, p<.001$
	CG	27	32.74	8.23	19	30.63	7.55								
PSOC- Efficacy	IG	46	29.54	4.97	36	32.11	4.45	$F(1, 50)=4.586, p<.05$	30	31.97	5.63	24	31.00	6.69	$F(2.296), =1.401, p=.254^G$
	CG	27	30.33	6.45	19	30.53	6.05								

G-Greenhouse-Geisser adjustment as ANCOVA violated assumption of sphericity.

Figure 10.4 Mean Parenting Sense of Competence Scores: Pre-intervention to 24 week follow-up

The scale of improvement in parents' sense of competence

Effect statistics⁷⁴ explored the size (and direction) of changes in parents' sense of competence across the study period, see Table 10.4 and Figure 10.4.

Post-intervention, effect sizes were both larger and more positive for the intervention group than the waiting list control group. For the intervention group, the size of improvement was, typically, greatest post-intervention, diminishing slightly at 12 and 24 week follow-up for the PSOC Satisfaction Scale, where medium effect sizes were found. Effect sizes were medium post-intervention for the Efficacy Subscale, but were half the size by 24 week follow-up (see Table 10.4). (Mean scores and standard deviations can be found in Table 10.3. Changes in mean scores are visually displayed in Figures 10.3.)

Table 10.4 Effect size for changes in scores from Pre-Intervention on Parenting Sense of Competence (PSOC)

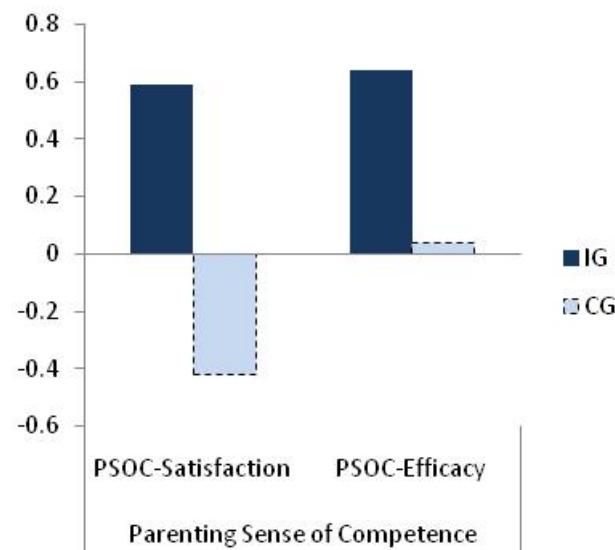
Outcome Indicator	Group	Effect size from pre-intervention (d^2) ¹		
		Post-intervention	12 week follow-up	24 week follow-up
PSOC-Satisfaction	IG	.59	.54	.50
	CG	-.42 ²	--	--
PSOC-Efficacy	IG	.64	.51	.29
	CG	.04	--	--

¹ Effect size is categorised in the following way: 0.2='small' effect size; 0.5='medium' effect size; 0.8='large' effect size.

² A negative effect size indicates a deterioration in scores between the two time points.

⁷⁴ The effect size quantifies the difference between two sets of data or between two groups 0.2 is defined as a 'small' effect size, 0.5 as a medium effect size, and 0.8 as a 'large' effect size. In this study effect sizes were calculated within each sample (e.g. those who had attended a parent group) the effect size between two time – points being calculated. Effect size is calculated by dividing the difference between the means by the pooled standard deviation (Cohen's $d = (MT1 - MTx)/SD$].

Figure 10.5 Effect sizes for post-intervention changes in scores on the Parenting Sense of Competence (PSOC) Scale



The proportion of parents who improved on the measure of Parenting Sense of Competence

Scores on the Satisfaction and Efficacy sub-scales were then examined in order to determine whether individual changes in scores (from pre-intervention) could be regarded as 'true' changes as opposed to spurious changes caused by inadequacies in the measure. The statistic used is known as the Reliable Change Index (RCI).⁷⁵ This is an important indicator of the clinical, as opposed to statistical, significance of any observed changes associated with an intervention.

Table 10.5 sets out the proportion of parents whose scores on the measure of Parenting Sense of Competence improved, did not change, or deteriorated (as classified by the RCI). Comparisons are made between those parents who attended the programme and the no-intervention comparator group.

⁷⁵ A reliable change was defined as those where a score of >1.96 on the Reliable Change Index was achieved (Hawley, 1995; Jacobson and Truax, 1991). The reliable change index (RCI) for each case was calculated by dividing the difference between the Time 1 and 2 scores by the standard error of measurement (SEmeas) [RCI = $Mt1 - Mt2/Sdiff$]. Sdiff will be obtained by calculating the square route of double the standard error squared ($Sdiff = \sqrt{2(SE)^2}$). A chi-squared test will examine whether reliable change is significant across the treatment groups.

Table 10.5 The reliable change on Parenting Sense of Competence: intervention group versus control group

	Parents' sense of competence			
	Parents' sense of satisfaction		Parents' sense of efficacy	
	IG	CG	IG	CG
Post intervention				
Reliably improved	15 (44.1%)	2 (10%)	16 (47.1%)	3 (15.0%)
No change	16 (47.1%)	10 (50%)	17 (50.0%)	12 (60.0%)
Reliable deterioration	3 (8.8%)	8 (40%)	1 (2.9%)	5 (25.0%)
<i>Chi-square: Pre-post intervention</i>	$\chi^2(2) = 10.687, p < .01$		<i>Fisher's Exact Test = 9.063, p < .01</i>	
12 week follow-up⁷⁶				
Reliably improved	18 (62.1%)		15 (51.7%)	
No change	6 (20.7%)		12 (41.4%)	
Reliable deterioration	5 (17.2%)		2 (6.9%)	
24 week follow-up				
Reliably improved	13 (56.5%)		11 (47.8%)	
No change	5 (21.7%)		8 (34.8%)	
Reliable deterioration	5 (21.7%)		4 (17.4%)	

Post-intervention, a greater proportion of parents who had attended the group showed reliable improvement on both the Satisfaction and Efficacy subscale, and fewer had reliably deteriorated, in comparison to the waiting list control group. These differences were statistically significant for both scales (see Table 10.5).

At follow-up, positive reliable change is promising within the intervention group as approximately half of parents responding show reliable improvement for either scale and there is little drop off 24 weeks post-intervention. However, there is also negative movement with one fifth of parents showing reliable deterioration on the PSOC-Satisfaction subscale by 24 week follow-up. The pattern is similar for the PSOC-Efficacy subscale which increases from 1 person (2.9%) showing reliable deterioration post-intervention to four parents (representing 17.4% of the sample at this time) at 24 week follow-up.

Parent-report child behaviour

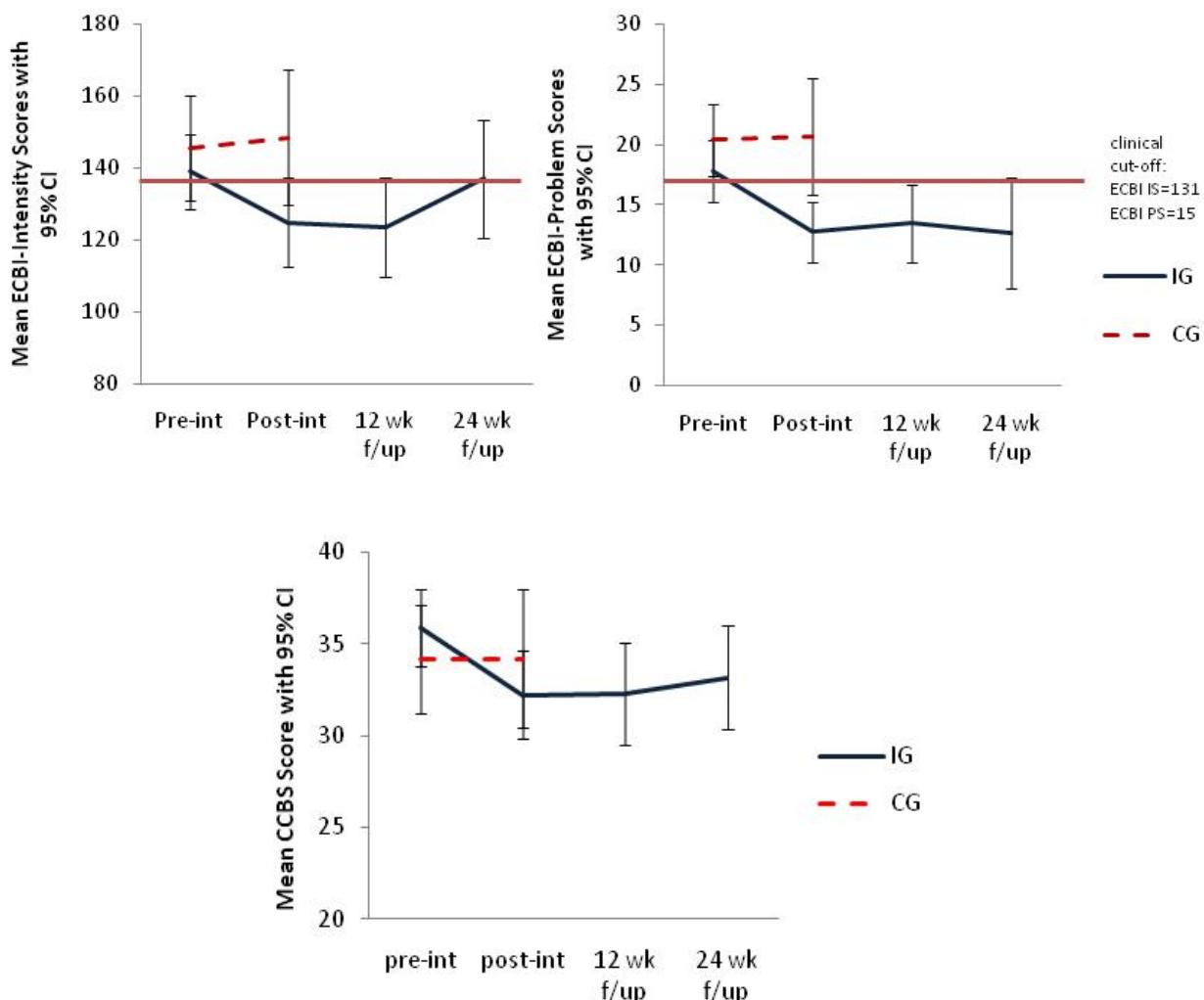
Differences in outcomes for the intervention and waiting list groups

After comparing the mean scores from parents who had and had not attended the parent-training programme, attending the parent-training programme was associated with a statistically significant improvement⁷⁷ in scores on both of the scales of the standardised measures of child behaviour (ECBI), see Table 10.6 and Figure 10.5.

⁷⁶ Twenty-four week post intervention comparisons not possible as data not collected from waiting list control group at this time point.

⁷⁷ A reduced score on the ECBI and CCBS indicates a reduction in problem behaviours.

Figure 10.6 Mean child behaviour outcomes: Pre-intervention – 24 week follow-up



The change in mean scores within the intervention group was statistically significant for the Problem scale ($F(3)= 5.970$, $p<.01$). Exploration of the paired scores found that post-intervention⁷⁸ and 12 week follow-up⁷⁹ scores were significantly improved from pre-intervention scores⁸⁰. Likewise, the paired scores for the Intensity scale found post-intervention change⁸¹ and at 12-week follow-up.⁸² Significant findings were not maintained for either scale at the 24 week follow-up point.⁸³

⁷⁸ $t(30)=4.789$, $p<.001$.

⁷⁹ $t(28)=2.749$, $p<.001$.

⁸⁰ A Bonferroni adjustment was used for multiple comparisons. P set at .01 for statistical significance.

⁸¹ $t(38)=3.675$, $p<.001$

⁸² $t(34)=3.423$, $p<.01$.

⁸³ Pre-intervention – 24 week follow-up (ECBI-Intensity) $t(25)=.165$, $p=.870$; (ECBI-Problem) $t(21)=1.750$, $p=.095$.

Table 10.6 Child behaviour outcomes

	Group	Pre-intervention			Post-intervention			ANCOV A pre- post	12 week follow-up			24 week follow-up			Repeated Measures ANOVA
		N	M	SD	N	M	SD		N	M	SD	N	M	SD	
ECBI- Intensity	IG	40	138.97	32.24	32	124.78	34.43	$F(1,43)=9.138$ $p<.005$	28	123.46	35.72	21	137.00	35.94	$F(3)=2.742$, $p=.051$
	CG	27	145.56	36.70	18	148.44	38.04		--	--	--	--	--	--	
ECBI- Problem	IG	34	17.82	7.17	30	12.73	6.69	$F(1,37)=15.70$, $p<.001$	28	13.46	8.34	21	12.67	10.07	$F(3)=5.970$, $df(3)$, $p<.01$
	CG	25	20.40	7.25	17	20.64	9.43		--	--	--	--	--	--	
CCBS	IG	37	35.86	6.34	35	32.23	6.91	$F(1,45)=1.523$, $df(1)$, $p=.224$	28	32.32	7.19	23	33.17	6.50	$F(3)=6.231$, $p<.001$
	CG	28	34.18	7.58	20	34.20	8.05		--	--	--	--	--	--	

Whilst not significant post-intervention when compared to parents who had not attended the group, a test looking at the scores of parents who had attended the groups over time also revealed significant change for the second measure of child behaviour, the Challenging Child Behaviour Scale (CCBS). The paired scores found that, whilst change post-intervention approached significance: ($t(37)= 2.598, p=.013$)⁸⁴, paired pre-intervention and 12 week and 24 week scores were statistically significant: (12 weeks $t(33)=3.451, p<.01$; 24 weeks: $t(25)=3.971, p<.001$. As has been typical with outcomes presented earlier, further comparisons were not significant.⁸⁵

The scale of improvement in parent-report child behaviour

Post-intervention, positive effect sizes were found for parents who had attended the parent training group for each of the behaviour measures. In contrast, effect sizes for those who had not attended the group were consistently negative, representing a deterioration in scores for these parents. The largest effect size was found for the ECBI-Problem Scale post-intervention ($d^2=.67$) where a medium-large effect was found. This was not maintained at 12 and 24 week follow-up. Additionally, a small negative effect size was found at 24 week follow-up for the ECBI-Intensity Scale. In contrast, the effect sizes for the CCBS steadily increased to a medium effect size at twenty-four week follow-up (see Table 10.7 and Figure 10.6).

Table 10.7 Effect size of changes in child behaviour outcomes

	Effect size from pre-intervention (d^2)			
		Post-intervention	12 week follow-up (IG only)	24 week follow-up (IG only)
ECBI-Intensity Scale	IG	.27	.37	-.06
	CG	-.19	--	--
ECBI-Problem Scale	IG	.67	.35	.15
	CG	-.23	--	--
Child's Challenging Behaviour Scale	IG	.39	.48	.53
	CG	-.01	--	--

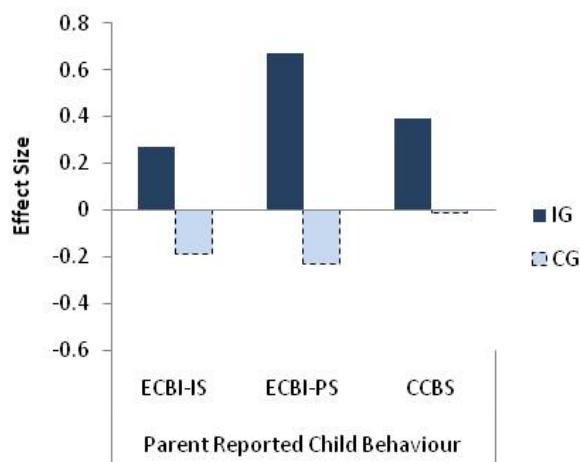
¹ Effect size is categorised in the following way: 0.2='small' effect size; 0.5='medium' effect size; 0.8='large' effect size.

² A negative effect size indicates a deterioration in mean scores between the two time points.

⁸⁴ A Bonferroni adjustment for multiple comparisons sets the p value at a conservative .01.

⁸⁵ Post-intervention – 12 week follow-up: $t(36)=.708, p=.484$, Post-intervention – 24 weeks: $t(31)=.351, p=.728$.

Figure 10.7 Effect sizes for changes from pre-intervention scores on the Eyberg Child Behaviour Inventory & Challenging Child Behaviour Scale post-intervention



Movement around clinical cut-off points

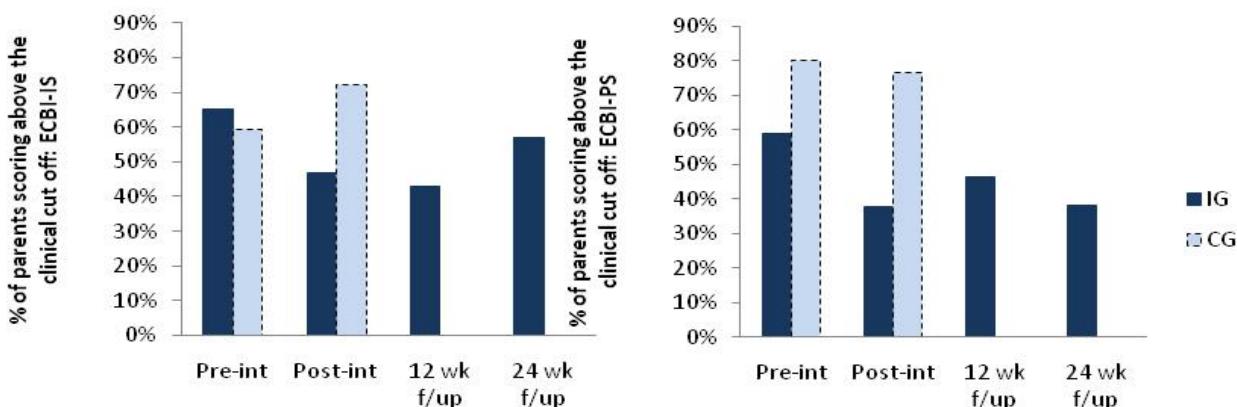
Clinical cut-off points are available for both the ECBI scales.⁸⁶ At baseline, 63 per cent of the children represented in the investigation were scoring above the clinical cut-off point on the ECBI-Intensity scale and around 68 per cent were scoring above the clinical cut-off point on the ECBI-Problem scale. At the end of the parent-training programme a greater proportion of children represented in the intervention group were below the clinical cut-off points on these scales compared to the waiting list control group, see Table 10.8 and Figure 10.7. However, movement in proportions above the clinical cut-off points were not statistically significant (Table 10.7). Improvements were not maintained for the ECBI-Intensity Scale. The proportion of parents scoring above the clinical cut-off increased again at 24 week follow-up.

Table 10.8 Movement about clinical cut-off points by group and time

		N (%) above clinical cut-off					
		Pre-intervention	Post-intervention	McNemar's χ^2 pre-post (p)	12 week follow-up	McNemar's χ^2 Pre-12 week f/up (p)	24 week follow-up
ECBI - Intensity	Int	26 (65%)	15 (46.9%)	.344	12 (42.9%)	.219	12 (57.1%)
	WLC	16 (59.3%)	13 (72.2%)	.188			
ECBI-Problem	Int	20 (58.8%)	11 (36.7%)	.344	13 (46.4%)	.727	8 (38.1%)
	WLC	20 (80%)	13 (76.5%)	1.000			

⁸⁶ Clinical cut-off scores are recommended by the author of the manual (Eyberg and Pincus, 1999) to classify children as having behaviour problems are 131 (ECBI-IS) and 15 (ECBI-PS).

Figure 10.8: Proportion of parents scoring above the clinical cut-off on the ECBI scale: pre-intervention – 24 week follow-up



The proportion of parents reporting changes in their child's behaviour

As with the Parenting Sense of Competence outcomes, Reliable Change statistics were used to test whether observed improvements in child behaviour for the intervention group were clinically significant, see Table 10.9.

Post-intervention, nearly a third of parents who had received the intervention showed reliable improvement for the ECBI-Intensity Scale and nearly half showed reliable improvement for the ECBI-Problem Scale. This compared to only one parent showing reliable improvement in the control group. Additionally, few parents who had attended the group showed reliable deterioration on the ECBI, compared to nearly a third of the control group for the ECBI-PS. These differences were statistically significant for the ECBI-PS.

The story for the CCBS is more mixed. Whilst nearly half of parents who had attended the parent training group showed reliable improvement post-intervention, a third of those who had not yet received the intervention also showed improvement. Proportions of parents showing reliable deterioration was also similar in both those who had and had not attended the parent training group.

At 12 week follow-up approximately half of parents who had attended the parent training group showed reliable improvement on the ECBI scales. This drops slightly at 24 week follow-up to just over 40 per cent. Whilst the proportions showing reliable improvement for the CCBS are also positive, meaningful interpretation of this is more difficult due to the mixed picture post-intervention.

Table 10.9 The proportion of parents reporting changes in the frequency of challenging or difficult to manage behaviours in the home: Reliable Change Statistics

	ECBI Intensity Scale		ECBI Problem Scale		Child Challenging Behaviour Scale	
	IG	CG	IG	CG	IG	CG
Post-intervention						
Reliably improved	9 (31%)	1 (5.9%)	11 (47.8%)	1 (11.8%)	13 (46.4%)	7 (35.0%)
No reliable change	18 (62.1%)	13 (76.5%)	11 (47.8%)	10 (58.8%)	9 (32.1%)	8 (40.0%)
Reliable deterioration	2 (6.9%)	3 (17.6%)	1 (4.3%)	5 (29.4%)	6 (21.4%)	5 (25.0%)
Chi-square Pre-Post	<i>Fisher's Exact Test = 4.602, p=.101</i>		<i>Fisher's Exact Test=8.004, p<.05</i>		$\chi^2(2) = .634, p=.728$	
12 weeks post-intervention						
Reliably improved	13 (52.0%)	--	10 (50.0%)	--	15 (65.2%)	--
No reliable change	7 (28%)	--	6 (30.0%)	--	4 (17.4%)	--
Reliable deterioration	5 (20%)	--	4 (20.0%)	--	4 (17.4%)	--
24 weeks post-intervention						
Reliably improved	8 (44.4%)	--	6 (42.9%)	--	11 (61.1%)	--
No reliable change	6 (33.3%)	--	5 (35.7%)	--	4 (22.2%)	--
Reliable deterioration	4 (22.2%)	--	3 (21.4%)	--	3 (16.7%)	--

10.4 Costs

In this section we present data on the costs of delivering the intervention; evidence about the impact of the child's behaviour problems on parents; and their and their children's use of services which relate to the presence of child behaviour problems.

Pre-intervention data (pertaining to the 12 weeks leading up to the start of the intervention) on the children's service use was available from 59 parents in the intervention sample and 20 in the comparator group.⁸⁷ At the 12 weeks post-intervention time point it was only possible to collect costs-related data from the intervention group as most of the parents in the comparator group had started to receive the intervention. Thus it was not possible to test

⁸⁷ Referred to collectively as the 'cost sample'.

whether any changes in costs to parents and families' service found at 12 week follow-up could be ascribed to the intervention. These data (for the IG) are not, therefore, reported.

Intervention costs

This ten-session programme was facilitated mainly by CAMHS staff and delivered in schools, children's centres and other community settings. Typically the course was led by a clinical psychologist with two or three facilitators per group.

Staff time account for most of the cost of delivering this intervention, and this includes time setting-up the group, planning the sessions and travelling, as well as delivering the intervention and the de-briefing. The costs per session varied depending on the number, profession and grade of the facilitating staff. *Costs per session*, that is the cost to the provider organisation, were between £190 per session and £532 across the seven groups for which we could estimate costs. Additional costs for refreshments, materials, information sheets and the venue contributed between 5% and 13% to the cost of the sessions. The total cost of providing the programme ranged from £2,975 to £4,590 per programme (mean = £3,570).

Typically eight to ten parents attended the group at the beginning but although most also finish the course, there is some variation in the number of parents attending each session over the ten-week period (between three and thirteen). This meant that the *cost per person per session* ranged from between £19 and £89.

The *cost per person for the intervention* therefore also varied, depending on the number of facilitators (between two and five) and parents at each session, and the number of sessions each parent attended (between three and eleven; the follow-up session tended to be least well attended). Thus the mean costs for parents attending this course was £407 but the range was between £80 and £685, the latter representing the cost for someone who attended ten sessions of a course for which the early sessions had four facilitators.

Service use and impact of behaviour problems on employment and daily life

Prior to the intervention, only 13 of the 76 parents in the 'cost sample'⁸⁸ who provided information about themselves were in paid employment; 11 were in the intervention group. At this time point four parents in the intervention group and one in the control group had taken time off work in the previous three months because of their child's behaviour problems, for between one and eight days.

Just over a third of parents (38%) said there were days (in the three months prior to start of the intervention) in which their child's problems prevented them from undertaking their normal behaviour. At the pre-intervention time point, nearly half the sample said that their child's behaviour had affected their health (IG=50%; CG=32%). The most commonly used service parents went to for help with their child's behaviour was the GP (for details see Appendix S, Table S.1).

Primary care services formed the backbone of support for children in this sample, although GPs were rarely consulted about the child's behaviour. See Appendix S (Table S.2) for the utilisation rates for all services used.

⁸⁸ We use this term to refer to the total sample (IG and CG) where costs data was available.

10.5 Summary of findings

- Progress in attaining goals for improved child behaviour and standardised measures of parents' sense of competence and parent-report child behaviour were used to assess the effectiveness of the intervention. Outcomes were compared to a waiting list control at post-intervention and assessed within the Intervention group 'before and after' at 12 and 24 week follow-up.
- Significant progress towards attaining parent-set goals for child behaviour was recorded post-intervention and at follow-up.
- Programme attendance was associated with improvements in parents' feelings of satisfaction and efficacy with their role as a parent. Improvements in role satisfaction were maintained at 12 and 24 week follow-up. There were initial improvements in parents' sense of efficacy, but these were not fully maintained at follow-up.
- The sizes of improved scores on the measure of parents' sense of competence for the intervention group were largest immediately post-intervention, becoming smaller at 12 and 24 week follow-up. This was particularly the case for the efficacy subscale.
- Programme attendance was also associated with improvements in parents' reports of the frequency of challenging or difficult to manage behaviours. These improvements were maintained at 12, but not 24 week, follow-up. The number of behaviours reported as a problem for parents fell post-intervention and these improvements appeared maintained to a greater extent.
- The scale of improvement in scores on the parent-report child behaviour measures, and greater movement around clinical cut-off points for the intervention group compared and waiting list control groups are also evidence for the positive impact of the programme.
- Mean costs of delivering the intervention ranged from £2,975 to £4,590 per programme (mean = £3,570). Mean intervention costs were £407 per person (range £80 - £685).

Conclusions

- There is evidence that at least some parents of children with ASC or other disabilities would benefit from attending this programme, both in terms of their sense of competence as a parent, and in their child's behaviour.
- There is consistent evidence that improvements in parent and child outcomes measured at the end of the programme are maintained at 12 week follow-up.
- The evidence regarding longer-term maintenance of post-programme outcomes is more equivocal with behaviour deteriorating again by 24 week follow-up for some parents.

Chapter 11

Parent-Centred Outcomes of Attending a Parent-Training Programme for Behaviour

11.1 Introduction

Chapters 7-10 report the findings on the outcomes of behaviour parent-training programmes as measured by quantitative indicators of child behaviour and parents' sense of competence. These outcomes were measured as they were identified as the two main desired outcomes by the authors of the parent-training programmes under investigation.

In this chapter we turn to parents' own accounts of the outcomes they experienced as a result of attending a parent-training programme. These can be (somewhat loosely) organised into four categories: knowledge and skills outcomes, parental well-being outcomes; service support outcomes; and wider benefits.

It is important to stress that the outcomes set out below, and discussed in more detail subsequently, are simply the areas where parents reported changes and achievements associated with receiving a parent-training programme. There were considerable individual differences in the extent to which these outcomes were achieved. However, overall the very consistent story from parents was highly positive.

Knowledge and skills outcomes

Parents reported four outcomes related to their knowledge and skills around parenting a disabled child. They concerned either the acquisition of new knowledge or skills and/or a deepening of understanding and were as follows:

- a greater understanding of the principles of behaviour management
- acquisition of new parenting skills and strategies
- a greater understanding about how to communicate with a disabled child
- a greater understanding of their child's condition.

Parents described how the knowledge and skills they had acquired had impacted on their parenting approach and practices and, in consequence, their child's behaviour. The findings from analysis of the quantitative outcome indicators support this.

Parental well-being outcomes

As noted above, the impact of the programmes on parents' sense of parenting competence was measured using quantitative outcome measures. This was because all the programmes had identified this as a key desired outcome for parents attending the programmes. However, in addition to this a number of other outcomes related to parental well-being were reported by parents. Thus, overall, the following parental well-being outcomes were identified from parents' accounts:

- a reduced sense of social isolation
- emotional support needs met
- increased sense of parenting competence
- increased sense of self-confidence.

For the parents attending the ASC specific programmes two further outcomes were also described:

- greater adjustment to child's diagnosis of ASC
- having a more positive outlook about child's ASC.

Service support outcomes

The third area of outcomes concerned parents' access to services and support, namely:

- feeling better informed about services and support available
- access to individual behaviour management support.

Wider benefits

Finally, there were two wider benefits to attending a parent-training programme identified by parents:

- an improved family life
- a greater sense of partnership with the child's school.

Negative outcomes and experiences

As noted earlier, the great majority of parents were extremely positive about what they had achieved and their experiences of a parent-training programme. However, a small number of parents reported negative outcomes. These centred entirely within the domain of parental well-being.

A slightly larger group of parents, whilst not reporting negative outcomes *per se* expressed dissatisfaction with (or with some elements of) the programme they had attended. Primarily this lay with the programme not supporting them to achieve their desired outcomes.

Chapter overview

The next section of this chapter reports in more detail on the outcomes set out above. Following this, parents' views on aspects of the programme they attended which particularly supported achieving the knowledge and skills outcomes will be reported. Finally, we return to the evidence concerning negative and/or less than optimal outcomes.

11.2 Knowledge and skills outcomes

A greater understanding of the principles of behaviour management

Developing or formalising an understanding of the principles of behaviour management was a key learning outcome of all the programmes. This included understanding that: behaviour can be conceptualised as a response, the concepts of positive and negative reinforcement in understanding and responding to behaviours, and the importance of consistency.

One of the other things was the, making you look at your own behaviour. The things you do that you don't realise you're doing ... You, you understand more about why they do what they do, so you're inclined to take a step back before you react to it.

[49 (Mother) Programme D, focus group]

but they've made us aware why he does certain things that make me more understanding and which makes me act differently, rather than shouting and aggravating the situation, it's trying to calm it down.

[2 (Mother) Programme A]

Some parents reported that learning simple behaviour analysis techniques had been their key learning outcome. Simple behaviour analysis involves observing and recording the situation, events and behaviours of the child and others present which precede, occur during, and follow an episode of difficult to manage behaviour. Identification of the factors

which encourage (positive reinforcers) or discourage (negative reinforcers) a problem behaviour places parents in a better position to work out how best to prevent, pre-empt or better manage a difficult behaviour.

... that was a useful technique to have learnt at that 'cause it's very general, you can apply it to any situation. It's not a specific strategy, it's about analysing the behaviour and trying to spot the trends ...
[38 (Father) Programme C, focus group]

Acquisition of new parenting skills and strategies

As well as learning behaviour management principles, each programme also teaches, or exposes parents to, a range of strategies derived from this approach. Nearly all the parents interviewed were able to describe principles and strategies they had learnt. Many had also found that, when implemented, they had brought about improvements in their child's behaviour.

And then I still do all the sticker charts and just giving her lots of praise because I didn't [in the past] ... I really didn't know what to do. And she, like, thrives on praise.

[31 (Mother) Programme B]

It's calmed down a lot. She's not as angry as she used to be because we know what to do. We know to ignore the bad behaviour, and look at the good behaviour and reward the good behaviour and ignore the bad behaviour, which we thought we were doing, but we weren't.

[41 (Mother) Programme C]

It's [now] the very calm approach, rather than the het up mummy, and, "I've had enough," approach.

[41 (Mother) Programme C]

The encouragement and support of the programme facilitators was a key factor in putting into practice and persevering with new parenting skills and approaches.

You can't just take tips and do it once and say: "Oh, it's not working!". You've got to like really work hard, you know, and do it all the time
[26 (Mother) Programme B]

Reassurance from facilitators, for example, that it was acceptable or even necessary to say 'no' to their child or to 'let them cry' was also crucial. This was particularly evident in the accounts of parents attending a group where one of the facilitators was also the parent of a child with learning disabilities.

[One of the group facilitators], she'd got children with learning disabilities, through her experiences like she shared as well, it was great to hear that, that she disciplined her children. It made you just feel a bit better.
[50 (Mother) Programme D]

A greater understanding about how to communicate with a disabled child

Parent-child communication was a core feature of all the programmes. Parents described new communication strategies or approaches to communicating with their child which accommodated, or took account of, a child's learning and/or communication disabilities.

The sorts of generic communication strategies that parents reported learning about and, consequently, putting into practice included making sure they had their child's attention before talking to them; using simple language (verbal or sign) and using it consistently and repeatedly; and giving their child more time to process information before expecting a response.

I know with [child] now that I've got a ten second window to tell him what he needs to do. I've got to say it short, sharp so he understands, get him to repeat it back and then nine times out of ten he'll do it, you know, he'll do it at some point.

[10 (Father) Programme A, focus group]

I couldn't communicate with me daughter because I, I was talking too much and just talking to her as if she was an older child when really they sort of said to me, well she, you're probably talking a bit too much ... So I sort of went right back to when she was a toddler and started talking to her with not so many words and using symbols and signs and then I started to communicate with her ... that was like a massive breakthrough because once I could communicate with her I could like understand why she was getting frustrated and having tantrums and stuff.

[31 (Mother) Programme B]

Some parents reported learning about 'feelings boards' to help their child express their emotions, and had since used such a board to improve communication with their child.

... we also had a feelings board, cos a lot of the way he is was always around his feelings, and sometimes, you, you're not picking up any, you didn't pick up on his feelings, so we, we made a feelings board ... it's just a dead simple square, a bit of laminate paper and it's got faces on where I think we're sad, we're angry, we're a bit in between. And he ... puts on there where what he feels which is, it's now actually moved on to, we have a red/green, a red/yellow/ green system. The green one means we're fine, we're doing OK, the yellow one is, you know, I'm feeling a bit stressed, and the red one is I need time out ... and if he needs time out he gets time out.

[28 (Mother) Programme B]

Communicating with a child with ASC

Parents attending the ASCC specific programmes were able to describe what they had learnt about communication with a child with ASC, and had developed new skills and/or resources to support communication with their child.

Yeah, well one thing we've realised is that when [our child] is focused on something - and getting her attention isn't the same as getting the attention of our son. So you do have to say her name and then wait a couple of seconds for her to register that you are wanting to speak to her - and just repeating the same thing over and over again isn't going to help, so a few times you have to, to get her attention, and then she'll realise that you want to speak to her or you want to discuss something.

[42 (Father) Programme C]

'cause when he's in – focusing on one of his really – things that he has to do, I don't know, Doctor Who, or whatever, he'll still probably not even hear me, but it helped me not get frustrated and irate and start shouting at [name of child] for it.

[20 (Father) Programme A, focus group]

Many parents reported that they had begun using tools and strategies to improve communication with their child including: visual aids (such as simple stick figure drawings, picture cards, photographs, or symbol) as 'objects of reference'; visual schedules/timetables and social stories. Typically, parents found these aids very effective in improving communication with their child and, consequently, the child's behaviour.

Like we had a long running problem with [our child] going to sleep and so we'd – we've managed to put together a routine for him, which we did with pictures and cards and he could sit down every night and he knew that he'd have a bounce on his trampoline and then a hot chocolate and then read his book for a bit and then had his bath.

[13 (Mother) Programme A, focus group]

[If] I'm not able to get anything across to him then I will write it down and say this is what you're not allowed to, you know, like write the whole thing, like a [story] (...) probably saying, oh you are not allowed to do this because, whereas before I would just say, you're not allowed, end of.

[43 (Mother) Programme C]

Opportunities to create such tools during a session were highly valued as parents reported it could be difficult to make time to do such things outside of the sessions.

A greater understanding of their child's condition

Greater parental understanding of autism was one of the primary learning outcomes of both of the autism-specific programmes. Parents of newly diagnosed children attending these programmes appeared to particularly benefit from this aspect of the programme. A greater knowledge and understanding of autism resulted in parents being able to see a situation from their child's perspective. In so doing, many parents reported that their perceptions of their child's behaviour changed, and led them to become more accepting of the idiosyncrasies of their child's behaviour and adopt a different parenting approach.

If I'm just accepting of him, he's happy with things done his way, I accommodate that & it makes everyone's life easier.

[8 (Mother) Programme A]

You, you understand more about why they do what they do, so you're inclined to take a step back before you react to it.

[49 (Mother) Programme D, focus group]

We'd have got a lot more frustrated if we weren't understanding that he can't help it, he just doesn't get it. I think it has helped me definitely with that, it's helped me keep calmer ... [and] I think sometimes – well before, I was treating him like he was being a naughty boy when he can't help it ...

[16 (Mother) Programme A]

And I think the light bulb moment for me was thinking oh, right, he's doing that because he doesn't make sense. The world doesn't make sense to [name of child] and he's frightened and I didn't realise how frightening that the world is to him and I thought, well, poor kid, you know, he needs me to understand that I need to understand this because he needs me to be there for him.

[12 (Mother) Programme A, focus group]

I mean we still have a lot of the same problems with [name of child] that we've always had, but it's just, going on the course has enabled me to see the bigger

picture and, and also the smaller pictures as to, you know, why, why he can't, why he's getting upset and frustrated, because he can't understand that, having been on the course and knowing why he can't understand, you know, all the things that we were, we were taught, taught that, you know, that, that just helps me I suppose keep calmer.

[17 (Mother) Programme A]

Yeah, I think it's just more about understanding and recognising how he's feeling, especially when we go out somewhere that, you know, he can be quite anxious, that, he doesn't really know and he doesn't say that but I can tell by the way he's behaving now that, you know, it's a bit of a strain for him (..) I mean I feel more relaxed about it now (laughs).

[40 (Mother) Programme C]

11.3 Parent well-being outcomes

Changes or improvements in parents' own well-being were, potentially, wide-ranging and included:

- a reduced sense of social isolation
- emotional support needs met
- increased sense of parenting competence
- improved self-confidence.

For the parents attending the ASC specific programmes there were two more potential outcomes:

- greater adjustment to child's diagnosis of ASC
- having a more positive outlook about child's ASC.

A reduced sense of social isolation

Across all the programmes, many parents reported that hearing other parents talk about their experiences and difficulties had been a valuable therapeutic experience, providing reassurance that they were not alone in their feelings and experiences and, critically, that others were equally struggling with parenting their disabled child.

Cos sometimes when you're sort of in what I call the normal world, you, you feel very much, you can feel very much alone with your problem, but going along to a group like that, it made you feel that, well, actually you weren't on your own and some people had worse problems than yourself to deal with and so you just felt less isolated really and able to share your experiences

[17 (Mother) Programme A]

Just realising that we weren't isolated and that, sort of, everyone, sort of, was going through the same, sort of, worries and questions that we had really, with the diagnosis being fairly recent for everybody in the group.

[42 (Father) Programme C]

[Name of programme] was a lifeline because at the time I was very, at extremely low point and I was close to breakdown and everything, because I'd just got to a point where I just couldn't handle him anymore and I felt like I was just on me own with it. And obviously I got there and everyone's in the same boat and it was just, it really brought me up out the depths.

[50 (Mother) Programme D]

it's nice to go there thinking that you're not a bad mother I mean cos you're feeling like that, and when you go to that group it makes you feel much better that other parents have actually been through the same thing. You're not a bad mother, it's just natural (laughs).

[26 (Mother) Programme B]

Emotional support needs met

The sense of emotional support derived from sharing with others with similar experiences was also recurrent theme in parents' accounts of attending a programme. Parents identified the unique empathy and understanding that shared experience engenders.

It's like a relief, you know, after actually going to them. I know it sounds daft, but it's like you've opened up to people and that, you know, and you feel much, so much better and happier after the group ... yeah, and listen to everyone else's problems, and like mine's not really that bad when you hear something else's ...

[26 (Mother) Programme B]

The so-called professionals, they might know, they might have read the textbook, but they don't understand. They don't understand the situation ... until you've been in that situation, you don't know. But to have people around who does know and does understand, that makes a [difference].

[45 (Father) Programme C, focus group]

Increased parenting confidence

It was clear from parents' accounts that struggling to manage their children's behaviour, coupled with the sense that theirs was a unique experience, could reduce parents' sense of confidence as parents. Increased parenting confidence was a strong theme emerging from parents' accounts of the outcomes of attending a parent-training programme.

Yeah. I think [the programme] just brings you back to normal. 'Cos it makes you feel so low if you're not coping with your whole family life and stuff. I mean it just gives you ... I don't think you realise it at the time ... they're obviously building your confidence all the way through.

[31 (Mother) Programme B]

The knowledge and skills acquired by attending the programme, the reduced sense of social isolation, feeling supported emotionally, and experiencing successes in tackling problem behaviours all contributed to this improved sense of parenting competence.

And it's very affirming 'cause you're so used to having to explain to people that your child is not just being badly behaved, that there are things that he genuinely does not understand and cannot cope with. And I think that's why it was so reassuring to know that it's not because you're a bad parent or whatever, but actually they genuinely do have [problems].

[13 (Mother) Programme A, focus group]

... once you've done like little things like that [successfully taking child to supermarket] you feel great. You know, it's like tiny to other people, [but] you feel really good and then that like gives you the confidence to go to soft play and swimming and ... where there's like loads of other people around. [Before] you just thought "no, I'm not going to go out", 'cos you're frightened in case something happens.

[31 (Mother) Programme B]

Interestingly, however, an increased sense of confidence was reported by parents even if their child's behaviours remained difficult to manage.

[Our child's behaviour is still fluctuates like] a roller-coaster but we've learned to manage, we cope better with it.
[28 (Mother) Programme B]

I'm more relaxed and I feel more, I feel more in control. I may not have been doing anything significantly different but at least my attitude towards managing [my child] has changed.
[43 (Mother) Programme C]

Improved self-confidence

It was also clear from some of the interviews that parents believed that attending the parent-training programme had increased their self-confidence more generally. There were instances of parents reporting feeling more confident in their dealing with the child's school and other agencies, feeling more able to challenge mis-beliefs within their family about their child's condition as well as, less frequently, taking on quite significant challenges (e.g. returning to college to study for a new career; volunteering at their child's school).

... before [the parent programme] I was right at rock bottom. I just, I, I didn't go out, I just didn't know what else to do. I did nothing but cry. And through [the parent programme] and [the facilitators' help] they got me the confidence as well as the help, you know, to get in touch with different people, through MAP and everyone, to get references and letters and everything. So it's through them and through myself going through school that we got all the letters and the help and the back-up to get on the list for medical assistance.
[50 (Mother) Programme D]

I would never have brought the school in before [to help deal with a problem with child], I wouldn't have had the confidence to go to the school.
[49 (Mother) Programme D, focus group]

To some extent this increased self-confidence can be attributed to the parents feeling more competent as parents. However, there are also indications from some parents accounts that more subtle or 'hidden' processes associated with attending a group-delivered intervention are also contributing to this sense of improved self-confidence. This parent is describing how she had come to be training to be a facilitator for a support group for parents who had attended a parent-training programme:

Cos I mean when I first went to the groups I was like even frightened to say me name and, it was just so awful. And, and now I'm thinking: "God, like next week I'm going to be doing an exam, standing up in front of people trying to facilitate a group". It's just, it's just unbelievable really, just gives you so much confidence ...
[31 (Mother) Programme B]

Finally, a core element of Programme D is to encourage parents to make time for themselves. Parents are taught that treats and time-out for them are important as it means they will be better equipped to cope with the day to day demands of parenting. At each session participants are given small gifts (e.g. a candle, face pack) to support this. This focus on 'looking after me' also carries an implicit message about self-value.

"Self-therapy" is like your food ... [it's] essential. So it's really important. Without that you cannot do anything else. [55 (Mother) Programme D]

One of the biggest things as well was the time for me: you had to do something for you. I really enjoyed that one. You were making time to do nothing a lot of the time, wasn't it? You know, to find some time during that week to do absolutely nothing (...) I must admit ... making that time made you feel good.
[49 (Mother) Programme D, focus group]

... you have to enjoy your life as well, as a human being (...) you could even commit suicide [if not able to do that].
[47 (Mother) Programme D]

Programme B also reiterates the importance of personal well-being. Here parents are invited to attend one or two additional sessions to learn relaxation techniques to help them unwind as a parent but also to help relax and calm their child. Principally, these 'pamper' sessions consist of aromatherapy massage, relaxation and meditation.

Well they're good them as well cos it makes you relaxed and that, it's nice (...) They taught us how to like massage our children as well like on the seat and stuff. So we get tips on how to make your child more comfortable and, and relaxed, and give us tips on stuff like, you know, like candle things, scents.
[26 (Mother) Programme B]

Yeah, I had [the pamper sessions], it was really good. We did, we had one where there was like a relaxation DVD where somebody came in and did that and then there was a meditation one, and I think the other one was like using oils and stuff to help yah relax. So that was really nice that like to have the two sessions at the end.

[31 (Mother) Programme B]

Greater adjustment to the ASC diagnosis

The two autism specific programmes are routinely offered to parents of a newly diagnosed child. In addition to supporting their parenting, the information received through the parent-training programme also appeared to support their adjustment to the news of the diagnosis:

'Once you understand more about the condition you can come to terms with the way things are'.
[44 (Father) Programme C]

I think we just, sort of, we understand autism more, sort of thing, now, and we, sort of, see how she ticks and I think we've just, sort of, changed as parents as well, sort of thing, and we just, sort of, accept things, that certain things, either will happen or won't happen, and we just, sort of, are more relaxed in a way, sort of thing, than we were before.

[42 (Mother) Programme C]

Having a more positive outlook about child's ASC

In addition, a few parents also reported that having a better understanding about ASC had made them feel more positive about their child's diagnosis. This was either in terms of longer-term outcomes for their child and/or feeling that, as parents, there was something they could do to actively support their child.

I think one of the big things for us as a result of attending the course was starting to see the positive side of Asperger's.
[13 (Mother) Programme A, focus group]

And one of the main things that ... nobody had mentioned before, was that brain development changes when they get into, sort of, late teenage years, and some of the mannerisms ... do diminish. [So] everyone in the group ... had a big sigh of relief, knowing a little bit about what would happen maybe in the future, sort of thing, which was very reassuring, yeah.

[42 (Father) Programme C]

I think it gave a more positive outlook to [son's] diagnosis. Now I was, when you first get told that he's on the autistic spectrum it can feel like a bit of a dead end, like that's it and, you know, something he's gonna have to live with forever and there's nothing you can do about it. So I think going to [programme] made me realise that there were things that we could do and, and it was very positive in that way.

[40 (Mother) Programme C]

11.4 Service support outcomes

There were two ways in which attending a parent-training programme improved outcomes in terms of getting support from services.

- feeling better informed about services and support available
- access to individual behaviour management support.

Feeling better informed about services and support available

Many parents reported that attending a parent-training programme had resulted in them feeling more informed about the services and sources of support available to parents of disabled children. Parents gave examples of learning about benefits and grants; local disability play schemes and sports activities; respite support/short break provision; local support groups and the parent partnership service.

Programme D incorporates providing this sort of information routinely in the final session. In other programmes, the sharing of information between parents and from professionals was more *ad hoc*. Perhaps, as a result, some parents were disappointed that the programmes they attended did not routinely provide this information, particularly concerning other local support services.

Access to individual behaviour management support

In some instances the parent-training programme was used as a 'stop gap' for families on a waiting list for one-to-one work. In addition, though, a small number of parents were referred for individual work within the service which had delivered the parent-training programme.

11.5 Wider benefits to attending a parent-training programme

The final set of outcomes identified by parents were not specific to themselves or their child but rather reflected the wider impact of the parent attending a parent-training programme.

These were:

- an improved family life
- a greater sense of partnership with the child's school.

An improved family life

Unsurprisingly, improvements in family life were a knock-on effect of improvements in the child's behaviour, changes in parenting approach and parents' increased sense of confidence.

Parents reported interactions between family members were calmer and less antagonistic, and trips out of the family home were less difficult and more likely to be positive and successful occasions. Some parents were clear that they, as a family, were going out more because they felt confident they would be able to manage their child's behaviour.

Our house is a lot calmer now, an awful lot calmer. I used to get frustrated, and when I get frustrated I used to shout and that kind of snowballed into that behaviour for everybody. And I've given up shouting now. ... And it's so much nicer [laughs].

[41 (Mother) Programme C]

We're getting on much better ... it's just nicer for going out on weekends and holidays and stuff, it's just so much easier.

[31 (Mother) Programme B]

But even though we didn't achieve that [specific behavioural goal], I still achieved an awful lot with [name of child]. And obviously my relationship with [name of child] and the way we dealt with him did improve an awful lot and our life. My mental health improved a lot as well.

[50 (Mother) Programme D]

A greater sense of partnerships with the child's school

One of the programmes (B) was delivered in the school attended by the children of parents attending the parent-training programme and was co-facilitated by a member of the school staff. The DVD used as a teaching aid included footage of school staff modelling good behaviour management techniques. Here all the staff had received training on the content of the programme and were aware which parents were attending the programme each term. The two other programmes (C and D) sometimes, but not routinely, had staff from the children's school as co-facilitators.

Parents believed that the active involvement of schools/school staff in the delivery of the programme resulted in enhanced 'teamwork' between home and school in terms of managing the child's behaviour.

The groups actually bring everyone together and the teachers ..., it's really good.

[26 (Mother) Programme B]

Parents attending Programme D frequently spoke about using teaching staff as a source of on-going advice on behaviour management issues. These parents also described feeling a greater sense partnership with their child's school following attendance on the programme. For example, several reported having a greater understanding of how their child was being taught and managed in school and had adopted similar approaches at home (e.g. using the child's symbol-based communication system); enabling, as one parent described, a 'double-pronged attack' [44 (Father) Programme C].

Parents also reported passing on 'tips' from the parenting programmes to their child's school.

And I've passed on 'cause I feel that I've been able to pass on some of the ideas ... to people [who] are working with [my child] to help them, so I felt, you know, that's been a really positive thing from it really.
[46 (Mother) Programme C, focus group]

11.6 Features of the programmes which supported achieving knowledge and skills outcomes

In the interviews parents were asked to reflect on what they had found particularly useful in helping their learning and understanding. Three aspects of the programme were identified:

- teaching approach and teaching tools
- homework
- course materials: handouts and other resources.

Teaching approach and teaching tools

Parents' accounts suggest that certain features of the way the programmes were delivered during the sessions supported learning:

- an emphasis on learning from other parents
- the use of imagery
- experiential learning through group activities
- the use of audio-visual resources

An emphasis on learning from other parents

All the programmes are based on a collaborative approach to parenting support in which parents' expertise is valued as much as professionals' expertise. There is, therefore, a great emphasis on parents sharing ideas and experiences and group problem-solving. One of the key themes that emerged from parents' accounts across all the programmes was the value they put on learning from other parents not least because this was felt to be based on experience rather than theory.

Where I can see parents have gone through that process ... that is a practical experience for me to want to follow. So I would prefer maybe somebody who has a practical experience of dealing with it rather than somebody just telling me this is what you do.

[43 (Mother) Programme C]

Parents reported getting many practical ideas of things to try out at home from listening to and sharing experiences with other parents.

We were at a point where we'd all used some sort of reward chart, but they wear off. So it was nice to get, you know, fresh ideas of how to reward them and how other people did it.

[50 (Mother) Programme D]

In one of the autism-specific programmes, the group discussions also appeared to serve to clarify thinking in some parents' minds about what constitutes autistic behaviour.

There was a lot of discussion within the group ... you realise things that I didn't know were connected to autism ... from talking to other parents really.

[40 (Mother) Programme C]

So to look at other people's issues and what they were saying in the group session I felt was really interesting, and ... gave me a better idea of what aspects I should look at for James.

[10 (Father) Programme A, focus group]

The use of imagery

Parents reported that using imagery also helped to illustrate particular points. Several parents, for example, referred to the iceberg imagery used in programme C as particularly helpful.

[The iceberg imagery] put it in an easy to understand way in that what you see in how a child is behaving is just a tip of the iceberg and it's working out what's the root cause of it and what's going on underneath [that matters] and I thought that was a really interesting model.

[46 (Mother) Programme C, focus group]

Experiential learning through group activities

Various group activities within the autism-specific training programmes (A and C) had helped parents to understand the impact of autism on their child's communication, social development and sensory and other pre-occupations.

I could see suddenly why that sort of environment [toddler group] that you think is lovely for children is not.

[13 (Mother) Programme A, focus group]

You just came away with such a level of understanding of how difficult it must be for our children ...

[20 (Father) Programme A, focus group]

The use of audio-visual resources

Three programmes (A, B, C) used short films to support teaching on autism. The fact that these included the accounts of individuals with ASC appeared to be particularly powerful:

Yeah, the video clip was particularly good ... because it was somebody with Asperger's or people with Asperger's talking directly to you. It had so much more impact than somebody sitting talking about Asperger's. So, you know, while the course material was good, I think the video clips were a really good idea.

[38 (Father) Programme C, focus group]

The video ... had children talking about what happens with words when they look at words on the page and also how their senses can, sort of, switch on and switch off and there was all this stuff that we just didn't know and it was just amazing and it made you – it, sort of, it completely opened our eyes and it made us look at how [our son] responds to things in a different way.

[39 (Mother) Programme C, focus group]

DVD: Programme B

Parents attending this Programme B were visited prior to its commencement. During this visit a specific scenario which presents parenting challenges is set up and filmed.

The scenario

First, the parent introduces something they know their child will enjoy, for example playing with a particular activity. The parent is encouraged to play with their child, in the way that they would normally do this, and encourage the child to join in. After a couple of minutes the parent then asks the child to clear everything away.

Whilst being filmed in this way was initially 'scary' and 'embarrassing' for parents, watching the videos of themselves with their children helped make parents aware of how they behaved with their child:

Well it, it's quite scary at first because like you, you don't really like to see yourself on telly. But I think it's a really good thing though, cos you see yourself and you think, "Oh my god! I can't believe I do that!". So, you know, it makes you aware.

[26 (Mother) Programme B]

It could also give them new insight into their child's abilities:

Well that's [footage filmed in school] good as well ... you see him at school with the teacher and you think, "Eeeh he would never do that for me!", you know what I mean? And then you see a total different side of him and you're like, "Eeeh my god!", and it shows that he can actually do stuff, you know, and it, it's quite good to see.

[26 (Mother) Programme B]

Homework

All the programmes encouraged parents to reinforce or implement their learning in the period before the next session. Some programmes incorporated reviewing homework tasks (for example: trying out a new parenting strategy, conducting a simple behaviour analysis) as a key part of each session and parents typically found this a very helpful part of the programme.

I think the most helpful [homework tasks] were where we discussed something, I mean, like, for example, if we'd been talking about mind blindness and the homework was to go home and think about some examples in which that manifested itself in your child. Those were the most helpful sort of homework's ... to transfer the general learning into particular examples for your child. And then you could move onto the how might we deal with these particular instances of mind blindness or communication or whatever the issues were.

[13 (Mother) Programme A, focus group]

However, it is important to note that many parents admitted that they did not complete all the homework assignments.

I didn't always get round to [the homework], if we're going to be honest [laughter].

[11 (Mother) Programme A, focus group]

Course materials: handouts and other resources

All the programmes provided parents with course materials from the different sessions. These varied in content and format (see Table 11.1).

Table 11.1 Details of course materials

Programme	Materials provided to parents
A	Handouts including summary of sessions on particular topics (e.g. 'mindblindness' and 'getting the gist'); illustrative vignettes; exercises; homework; OHP slides; behaviour analytical tools (e.g. behaviour template and FIRE wheel); behaviour management strategies, etc.
B	A4 colour-printed sheets illustrated with graphics on: top tips for managing behaviour; giving directions; communication; praise; distractions; and consistency. Each week parents were also given a typed summary of topics that had been discussed in the session.
C	A ring-binder file containing an introduction to the programme and colour-printed copies of the power point slides from each of the weekly presentations on which to make notes if desired.
D	A course folder in which to file handouts. Parents are also given small gifts (e.g. face pack, candle) to encourage them to do something for themselves, and rewards (chocolates, stickers) for doing homework, etc, as a means of modelling positive reinforcement.

Some parents reported finding these course materials very useful for referring back to as a 'reminder' and for 'new ideas' because:

... you can't take everything in at once.

[26 (Mother) Programme B]

Paper copies of templates which enabled parents to carry out their own simple behavioural analyses were also valued and encouraged parents to implement their learning.

The format of the handouts was not something specifically probed in the interviews but was something parents raised. Locating all the information within a single, 'portable' source may increase some parents' use of materials during and after a programme.

I mean the handouts were very useful, but I just find it so much easier to have one book that you can allude to and perhaps put in your handbag to read when you've got an idle moment waiting for another child to come out of school, or a bit of bedtime reading or whatever

[17 (Mother) Programme A]

A few parents reported accessing additional materials (books, websites) recommended by the facilitators. They found these helped consolidate their learning.

So they recommended books we could read and different websites to access and things so, yeah, that was invaluable really.
[42 (Father) Programme C]

Interestingly, parents also described using these materials to help them explain to other family members about why they had changed their parenting approach:

I did [find the handouts useful] cos we could obviously show them to other family members, you know, and stick 'em on the fridge [...] for everyone to see. We actually laminated them, kept them in a book so we could look back over them as well.

[28 (Mother) Programme B]

I found one of the things that got in the way was the fact that I've been on the course and nobody else has. So I'm coming from this angle with [child] and, 'cos obviously I've got two teenagers and, and dad, and so you're coming from this angle and then you're fighting them. You want to say "No, right, well sit down while I teach you this!"... there were times, yeah, they, they got the folders launched at them "Read that".

[49 (Mother) Programme D, focus group]

Features of specific programmes which supported acquiring new parenting skills and strategies

Some of the programmes used techniques to particularly support parents' acquisition of new parenting skills. Programme A offers a one-to-one consultation with a clinician during one of the sessions. Programmes B and D use rating scales completed and reviewed at the start of each session to enable parents to monitor changes in child behaviour and their feelings as a parent. Finally, Programme D uses film footage of examples of good behaviour management strategies. This section reports parents' views of these techniques.

Programme A: One-to-one support

A unique feature of Programme A is that in session 8, each parent/couple spends most of the time with an individual therapist (psychiatrist, psychologist, learning disability nurse, etc) to identify a specific behaviour goal they wanted to work on with their child and then, by using a simple behaviour analysis, to develop a strategy to manage that behaviour.

Overall, most parents welcomed this opportunity to focus on their own child, describing this individualised input as: 'useful', 'beneficial', 'really helpful' and 'enjoyable'.

Some parents reported that, initially, they found it hard to select a single problem behaviour on which to focus in this session. Reflecting back, however, they were able to describe how they had generalised that learning in order to deal with other problem behaviours.

It was very 'illustrative for other issues that you were dealing with as well'.

[15 (Mother) Programme A, focus group]

Not all parents, however, found this opportunity for a one-to-one session helpful. They questioned how much could be achieved in this time.

For me dealing with that specific thing ... it just – it fed into a whole heap of other problems and it ... I knew what they were trying to say, but dealing with that one specific in an hour wouldn't ... there's no way in a million years that we could have solved the problems that there were, so it just, sort of, felt a bit pointless really

[25 (Mother) Programme A, focus group]

The fact that practitioners with different levels of expertise and qualifications were used for this sessions was also seen as potentially giving rise to differences in the quality of support received.

Perhaps another person might have been a better person, and the one we got perhaps wasn't.

[25 (Mother) Programme A, focus group]

Programmes B and D: Reviewing change and progress

Two of the programmes (B, D) used ratings exercises at the start of each session in order that parents can reflect and record changes and progress. One programme (D) uses parent-set goals and the other (B) asks more generally about the child's behaviour. For both, parents rate their feelings of competence as a parent.

Parents typically reported enjoying this part of the sessions, and that charting and recording each other's progress was rewarding and encouraging. There was a sense of the group sharing and supporting each parent's own goals:

... it was always nice because you, you were working towards everybody else's as well.

[49 (Mother) Programme D, focus group]

Every session was started with, you know, parents reflecting back how the week had gone and what they'd done and whether it, they'd carried out the rewards and whether it went good or bad, and I think that was really good.

[50 (Mother) Programme D]

However, there was some feeling amongst parents in both individual and focus group interviews that reviewing goals on a weekly basis was unnecessary and could take up too much session time.

Programme B: Film footage of good behaviour management strategies

As reported earlier a DVD of parents and teaching staff managing the problem behaviours was used as an aid for teaching the principles of behaviour management and behaviour analysis. Parents also reported that watching footage of teaching staff managing their child's (and others children's) problem behaviours was also extremely valuable in terms of giving them ideas of strategies and approaches to try out at home.

... because [the video] showed you how, well it showed me how slowly they do everything, where I was always in a rush to get things finished and a rush to get her to finish a piece of work or a piece of Play-Doh or whatever. But when you saw the one from school it showed you how patient they were and how they sat back and let the child do their own thing and then step in when they needed to rather than sort of being on their case all the time. So that was really nice to see.

[31 (Mother) Programme B]

[The teachers] sort of took [my child] away and said, you know, "If you're not going to share then unfortunately you can't play the game". He got very upset about it but they just left him to get upset. Someone was monitoring him but they just left him, and then eventually he came back and asked could he be part of the [game]. And he came back and he, he took turns without a problem and you're thinking, "Oh, my god!".

[28 (Mother) Programme B]

11.7 Negative and less than optimal outcomes

Parents were more likely to report they had not achieved their desired outcomes from attending a parent-training programme as opposed to reporting negative outcomes.

Less than optimal outcomes reported by parents concerned knowledge and skills outcomes. Here a handful of parents reported being disappointed that either: the advice being given about parenting was not always relevant or appropriate, or the strategies they had been taught worked initially but that their effectiveness had diminished. Some parents were seeking a more didactic approach from the programme, saying that they wanted the facilitators to tell them what they were doing 'right' or 'wrong' as a parent.

A very small number of parents reported that the programme had not resulted in any positive outcomes in terms of their child's behaviour, or their ability to manage it. A number of reasons were given for this experience. They included both a lack of any new learning; not understanding what was being taught; and finding the teaching and advice was too generic and difficult to interpret and apply to their own situation. In addition, amongst those attending programmes where a range of disabilities were represented, some parents were disappointed that they had not learnt more from the facilitators about how their child's disability (as opposed to their age or stage of development) may impact on their behaviour. These experiences perhaps capture one of the risks of delivering a group intervention: it is not possible to tailor it to all group members.

Finally, one or two reported that, whilst some of their behaviour management concerns had been addressed, the most significant one (e.g. incontinence, self-harm) had been too complex to be dealt with within the programme.

Negative outcomes

Amongst the parents interviewed who had attended an ASC-specific programme, a very small minority reported finding the information about ASC unsettling. They either recognised ASC traits in themselves which led them to question whether they and/or other family members were on the autistic spectrum themselves. The research team are aware that at least one parent failed to complete the programme because it forced them to confront the possibility that they, too, had an ASC.

In addition, where a parent perceived their child or situation to be worse than others represented in the group, the experience of being in the group could be isolating and demoralising. This was not a frequently reported experience but, where it did occur, parents described the experience in particularly negative terms.

Finally, a small number of parents described attending the programme as demanding and draining: both in terms of the amount of new learning which took place and the emotional nature of some of the sessions.

I think it was just so much information, talking and listening to other people and the emotion and everything that went with it, it just made you feel really tired and drained and, you know, but I think it was just something you had to do.

[24 (Mother) Programme A, focus group]

11.7 Summary

This chapter relays the very rich accounts of parents who had attended a parent-training programme in terms of their own outcomes.

It is clear that the parent-centred outcomes of attending a group-based parent-training programme are wide-ranging and, on the whole, these outcomes are positive. Parents reported that attending a programme had increased their knowledge and skills and improved their well-being. To a lesser extent, some parents also experienced an increase in service support as a result of attending one of these interventions. Further benefits, such as an improved family life and better relationships with the child's school, were also reported.

The primary outcomes identified by the clinicians who developed these interventions align closely with the outcomes parents identified as actually experiencing. In addition, however, the positive impact of attending a programme on parents' sense of isolation was a very dominant theme in parents' accounts. The sense of support and relief gained from spending time with other parents is a striking feature in parents' accounts, about which parents spoke very eloquently.

Negative outcomes were very unusual, centring entirely on deteriorations in well-being. For a couple of parents, having to face their own autistic spectrum characteristics had been very unsettling. Parents who felt isolated and did not identify with other group members reported this experience in very negative terms. Finally, it is important to flag up that attending such a programme can be mentally and emotionally draining.

It is apparent from parents' accounts that these outcome areas were inter-related. Gains in skills and knowledge (about behaviour management and/or autistic spectrum conditions) were the bedrock on which some other outcome were achieved, including improved sense of competence. We therefore explored what parents said about what had helped them have a better understanding of behaviour and how to manage it. The family-partnership approach which these programmes adopted, in which parents' expertise is valued as much as that of professionals, was viewed very positively by parents. Parents unanimously welcomed the use of visual imagery, experiential exercises and film footage to vary and supplement verbally delivered information. Whilst recognising the value of homework, a note of realism was struck by some parents in terms of their ability to achieve homework tasks every week. Finally, handouts and other resources were welcomed and there was evidence that portable, easy to access and use resources (for example, simple behaviour analysis templates; 'handbag-sized' handouts) were more likely to be continued to be used after completion of the programme.

Chapter 12

Changing Parenting Approaches and Improving Child Behaviour: Parents' Beliefs about the Factors which Hinder Positive Outcomes

12.1 Introduction

In this chapter we report on the factors which parents identified as moderating the positive impact of parent-training programmes on parenting approaches and child behaviour.

A number of factors were identified, namely:

- the content of the parent-training programme
- child- and condition-centred factors
- the nature of the problem behaviours
- competing demands on time and attention
- parents' ability to generalise and integrate new parenting skills
- the support offered by the immediate and wider family
- changes in the child's and family's lives
- school involvement
- housing
- reactions of the general public.

Each is now explored in turn.

12.2 Factors affecting outcomes: parents' views

The content of the parent-training programme

Across all the programmes there were one or two parents who reported that some of the parenting skills and strategies introduced to them by a parent-training programme were not effective when implemented with their child.

They believed their child's cognitive abilities and/or physical or sensory development meant that some of the parenting techniques or strategies were not appropriate for their child. For example, one parent felt that praise and reward techniques were not successful with children who did not understand the concept of incentives. Another felt that some strategies were too childish.

Child- and condition-centred factors

A number of parents believed their child's communication impairments made implementing new parenting approaches more difficult and rendered them less likely to be effective. Parents also talked about how it was difficult to make progress when their child did not understand what was or was not appropriate behaviour (e.g. sitting at a table to eat, sharing with others, not hugging strangers, how to dress properly).

A couple of parents believed their child's personality (for example, timidity, stubbornness) and/or condition influenced the effectiveness of the skills and strategies taught to them on the parent-training programmes. Finally, parents of teenage children reported that they were not always sure of the extent to which their child's 'strops' were being influenced by hormonal changes.

A few parents noted that they had observed that their child's understanding and behaviour had improved as they grew older. They believed this supported any positive gains achieved through changes to their parenting approach, or was even the primary reason for observed improvements in their child's behaviour.

Whereas before it was a massive problem, but now, I don't think it's the tips and the things that I've given him, it's just a thing that he's had to go through in his development.

[1 (Mother) Programme A]

The nature of the problem behaviours

Two particular features of the behaviour problems were identified by parents as impacting on the extent to which they could implement their new parenting skills and strategies.

First, parents reported that where the child's behaviour was unpredictable, it made identifying triggers to problematic behaviours impossible. Second, parents reported that, sometimes, their child's behaviour could deteriorate to such an extent that all the tips and techniques they had learnt were either forgotten or did not seem appropriate.

Cos sometimes he gets into such a state, such a meltdown ... that, you've got all these tips and techniques that, they just go out the window really. And it doesn't matter what you do, you can't get him out of that state that he's in.

[1 (Mother) Programme A]

Competing demands on time and attention

A lot of parents talked about the challenge of implementing new parenting approaches whilst juggling their other family commitments and caring responsibilities, and busy working lives. Conducting simple behavioural analyses, developing and using communication tools, adopting different parenting strategies demands time, attention, energy and commitment. Several parents reported finding this hard to sustain.

Most of us have, you know, jobs, other children, houses to look after, you know, the whole bit and so this somehow, to have an opportunity on these Monday afternoons to look at these issues was a privilege really because it was very, very useful. ... But putting it back into your own life again when you pick up the threads again of all those responsibilities wasn't easy.

[15 (Mother) Programme A, focus group]

I think if we both were able to commit ... 24/7 to [our child], it would be better, but obviously with work commitments and things you just can't do that ...

[42 (Father) Programme C]

You don't have these huge chunks of time that you [need] if you're giving them one-to-one, you've got pressure with the rest of the family and, and one thing and another.

[17 (Mother) Programme A]

It [programme] was very, very useful and I've really found lots of value from the training and from speaking with other parents. But I've got the rest of my life and, you know some of the things I've taken on board and it's helping me in many, many ways, but ... you deal with everything on a day to day situation, minute by minute situation as best you can, being a, sort of, you know, just a parent, you know, not a trained person in that sense, and I think that's just how you've got to look at it. [46 (Mother) Programme C, focus group]

In the face of everyday pressures, parents described how they did not always have the time to put new skills or strategies into practice and, instead, reported reverting to habitual parenting behaviour. They described how difficult it was to remain consistent in 'real life', and how they did not always have the inner strength to remain calm and to persevere.

14 (Father): I think the most difficult, or at least barrier to learning, was your pre.... I don't know how to put it really ... the, sort of, reactions you already had in-built into you with your child. So it was very difficult, I found, to transfer the, theory into practice, even down to the point of, "Oh, that's what's going on", let alone getting to the point of, "Ooh, this is how I should behave", 'cause you're so, sort of, conditioned ...

11 (Mother): ... And let's be honest, half the time with your children you have to meet it head on, don't you? What's going on and you've got to deal with it there and then. You don't have the time sometimes to take a step back and think, "Okay ...", and you can't say to our children "Wait a minute".

[Programme A, focus group]

Parents' ability to generalise and integrate new parenting skills

There were clear differences between parents in terms of the level of personal resources they had which supported achieving successful outcomes. A prior knowledge of their child's condition and its impact on behaviour, a 'positive attitude', and the ability to use their knowledge of their children in a 'common sense' way were all identified by parents as personal resources which enabled some parents to get more out of a parent-training programme.

There was evidence from parents' accounts that parents varied in the extent to which they had been able to generalise their learning on the principles of behaviour management and parenting skills and strategies. Thus parents reported struggling with newly emerging behaviours and/or did not know what to do when a particular strategy was not proving to be effective in managing a behaviour. For some parents, therefore, their new knowledge and skills were, to a greater or less degree, constrained to managing specific behaviours which had been discussed during the sessions.

Parents also reported difficulties with recalling what they had learnt, noting how new insights 'drifted away' as the days and the weeks went by, particularly once the programme ended.

[After] every session I came away feeling so much more understanding and trying [to implement learning]. Probably, as the week went along it, sort of, like, drifted away 'til the next Monday and then there was – after the session again I was like, "Oh, I've got to try harder".

[20 (Father) Programme A, focus group]

For me, it's – some of it is about remembering the stuff that happened on the course 'cause I've got a shocking memory and so, you know, in order to be able to implement the guidance, you've got to be able to remember it. So I – when we was talking about the iceberg thing, I'd, kind of, forgotten about that, even though it's a key part of the course.

[38 (Father) Programme C, focus group]

There's a lot of information to take in, isn't there? And you do forget, like you say, you forget so much about it

[21 (Father) Programme A, focus group]

The support offered by the immediate and wider family

Parents reported that partners and/or the wider family could help or hinder positive changes being achieved in parenting approaches and child behaviour outcomes.

Many parents also spoke of their awareness of the need for consistency in the way the child's behaviour was managed by all family members. Achieving this could, however, be difficult and become a source of conflict. Some parents reported that the fact their parent-training programme was being delivered by senior practitioners had been very important in giving credibility to their desire to change the way the family managed the child's behaviour.

Being able to attend a programme together was seen by some as a solution to ensuring a consistent parenting approach; however, it was acknowledged this could be difficult to achieve.

You can't beat being here at the time really. It was a shame [name of wife] couldn't get to them all. She did get to some, but yeah, it would have been better if we'd both been here, definitely.

[20 (Father) Programme A, focus group]

Looking back, I would think it would have been better if we'd done it together rather than, like, doing it separately. I don't think it's ideal doing it separately. I think it works better doing it as couples.

[37 (Mother) Programme C, focus group]

In contrast, others made it clear that they preferred to attend alone and then feedback to their partner at a time of their choosing:

Mother: *I just think it's easier, much easier to go along to it, bring the information back and then of a night time obviously when the kids was in bed, sit and talk about what we did that day and then we've been, because he's not there. I think in a way it was easier him not being there.*

Researcher: *Do you think you might have fallen out then?*

Mother: Yes, oh god, yes. (laughs).

[28 (Mother) Programme B]

In addition, parents also described the importance of having the support of their partners and wider family in terms of the practical (e.g. informal child care) and emotional support they could provide as new parenting approaches were implemented

However, some parents had found that other family members were not prepared to change how they parented the child. There were reports of the way partners, siblings, grandparents and other family members could exacerbate behaviour problems by refusing to change their parenting approach.

... he gets away with lots with me mam. But here, he doesn't get away with as much as he does at me mam's. Like she spoils him and stuff. So I just let, let her get on with that and it's ... and just work around that really ...

[26 (Mother) Programme B]

I have tried to explain to my sister that – how he sees things differently, but I don't know if she gets it really.
[16 (Mother) Programme A]

I tried to help [child's brother] understand how [child] is feeling, but with them being both teenagers I think it's, yeah, that's difficult really, to get them both to be more relaxed.
[40 (Mother) Programme C]

Changes in the child's and families' lives

Many parents reported that their children found it difficult to cope with change, and that this often unsettled their behaviour. The changes encountered by parents interviewed for this project which, they believed, had caused set-backs in their child's behaviour included: parent re-marrying or meeting a new partner; birth of a sibling; illness or death of a close family member; school holidays; starting school; moving to a new school; short-term care arrangements changing; moving home; renovating home; and British Summer Time (BST) clock changes. These sorts of changes had a two-fold effect: they unsettled the child and they threatened parents' abilities to remain consistent and have the resources available to implement their new approaches to parenting. Many of these changes are unavoidable or unpredictable and, as a result, there was a sense from some parents' accounts that they believed that, inevitably, their aspirations for how they parented their child and tackled problem behaviours had to be realistic. Specifically, they needed to take account of everyday life and the unpredictable and uncontrollable events and situations that occur.

Sometimes you just have to get on with the, you know, there's nothing we can do about [it], we just have to, to tackle it the best way we can'.
[17 (Mother) Programme A]

School involvement

Some of the programmes in this evaluation were co-facilitated by staff working in the schools attended by the parents' children. Many parents attending these programmes highlighted the benefits of involving teaching staff in delivering the programme, particularly in the way it ensured consistency between the approach taken at home and at school to managing difficult behaviour. In contrast, parents attending programmes where there was no involvement by school staff highlighted this as barrier to achieving positive changes in their child's behaviour. Furthermore, some parents of children with ASC attending mainstream school believed that the behaviour management strategies being implemented in school were positively counter-productive due to their lack of understanding of ASC.

And school was telling him one thing, we were telling him another thing and other members of the family were telling him every, everything else. He was getting very confusing messages. So everybody, everybody together now, we're all doing the same thing and it works.
[28 (Mother) Programme B]

Housing

Housing, and the constraints of indoor/outdoor space, were also reported by parents as factors which could influence the effectiveness of parent-training programmes and the extent to which difficult-to- manage behaviours occurred. They remarked upon how their children squabbled more when sharing a cramped living space, or how their child benefited from having an outdoor area in which to burn off energy and let off steam.

Maybe if we had a bit more space and were a bit more organised ... there's a feeling at the minute that we're kind of on top of each other, and I think that doesn't help. That, you know, they're both fighting over the same bit of space, you know.

[40 (Mother) Programme C]

I haven't got an outside play area for them. ... And I noticed [that] ... whenever he went to the Saturday playgroup and he came home, he was much calmer and didn't do all these things, you know. It took a (..) lot longer for him to, for any of this behaviour to kick in, and it was because he was out all morning playing outside and playing, you know, at that group, and I, I've just noticed that total difference.

[2 (Mother) Programme A]

Reactions of the general public

Finally, parents commented on the lack of understanding of autism and learning disability in wider society. The judgemental and disapproving attitudes of the general public (or sometimes acquaintances and other family members) served to feed parents' 'embarrassment' and 'shame' when they were trying to manage their child's difficult behaviours outside the home. Hence, parents described how their attempts at new approaches to parenting often fell apart when dealing with their child's behaviour in the public eye:

You know, you're in the middle of Tesco's and they start and you've got the, the pressure of everybody else around you, and you, you don't react the way you should do because you react the way you're expected to react.

[49 (Mother) Programme D, focus group]

12.3 Summary

Parents identified a diverse set of factors which could impede or prevent positive outcomes being achieved from attending a parent-training programme. In essence, three different sets of factors emerged. First, inadequacies in the content of the programme. Second, between-session or post-intervention 'drift' and/or ability to generalise learning. Third, external factors which made it difficult to implement new ways of parenting.

On the whole the barriers to effectiveness were not primarily perceived as lying with the content of the programme. However, a minority of parents reported that the programme they attended was not sufficiently tailored to their child's needs, abilities, difficulties and/or developmental stage.

Many parents acknowledged that the resolve to change parenting practices felt at the end of a session weakened in the period before the next session. Equally, what had made sense to them during a session was harder to grasp and implement once back home. It was also clear that some parents had struggled to generalise their learning from the specific examples discussed during a session and apply it to new or different problem behaviours. It is important to note that there was an element of self-reproach in some parents' accounts: this is something practitioners should be aware of.

Parents also frequently attributed less than positive outcomes to events, situations or circumstances which had prevented them implementing new learning and new parenting strategies gained from attendance at a parent-training programme. Some, if not many, of these factors were beyond parents' control or, certainly, difficult to change such as:

inadequate housing, competing demands on time, unpredictable events, and the reactions of the general public. The verbatim quotes included in this chapter vividly capture the situations and demands which parents returned to at the end of a session. However, there was very little evidence of rancour over the disparity between what the parent-training programmes were encouraging parents to do and the reality of their everyday lives. Instead parents were, on the whole, realistic about what could be achieved and were grateful for the input and support the programme provided.

Chapter 13

Parents' Take-Up and Experiences of Parent-Training Programmes for Sleep

13.1 Introduction

In this chapter, we report the findings from the individual and focus group interviews with parents on their take-up and experiences of the sleep programmes.

The following section describes the factors which parents reported influenced their decision to take up the sleep programme offered. We then move on to describe parents' subsequent experiences of receiving or attending the programme. In contrast to the behaviour programmes in the study which all used a group delivery mode, the sleep programmes varied and included: one-to-one work with a 'sleep practitioner'⁸⁹ (Programmes E and F); a group-based, four session intervention (Programme G); and a one-day workshop (Programme H). In presenting the findings, we have taken the opportunity to compare parents' accounts of these different modes of delivery, in addition to identifying cross-cutting themes.

It is important to note that, while the interviews included a small number of fathers (4 from 35 participants), one of whom was also the sole black and ethnic minority interviewee, the analysis of these 'minority' accounts did not reveal any issues distinct from the experiences of the other interviewees.

13.2 Factors influencing take-up of a sleep programme

In this section, we report the factors which parents said influenced their decision to take up a sleep programme. Factors fell into five categories:

- personal motivation
- the intervention was disability and/or sleep specific
- referral by a trusted practitioner
- positive perceptions of the sleep practitioners
- timings and location.

Given that all the interviewees had taken up a sleep programme, perhaps unsurprisingly these factors were all cited as positive influences, with reservations about taking up the programme rarely recalled. The exception was the prospect of the time commitment for those attending the group intervention (Programme G), given the extra demands already placed on parents of disabled children.

I have to be completely honest, when it was first mentioned I thought, "Oh no ... I just don't know whether I can fit everything in". I can see why other people might be put off. It's such a long time to commit to."
[84 (Father) Programme G, focus group]

⁸⁹ We use the generic term 'sleep practitioner' to refer to professionals delivering the sleep interventions. They were from a range of professional backgrounds (see Chapter 4)

Personal motivations

Clearly, all the parents were interested in obtaining information and advice on how to tackle their child's sleep problem(s). Examination of the goals parents generated as part of their participation in the study reveals that the children were experiencing a range of difficulties, which took place at bedtime and/or during the night. The interviews with parents shed light on the negative impact of these problems and parents' underlying motivations for taking up the programme they had been offered.

Goals related to bedtime identified by parents were focused on establishing/maintaining a routine for going to bed, and/or improving the child's ability to settle to sleep. Many parents reported bedtime as emotionally fraught and were motivated by a desire to reduce their child's fear or anxiety about going to bed and to reduce the likelihood of the associated nightly parent/child conflict. A desire by parents to strengthen their resolve could be important, for example not 'giving in' when the child didn't want to go to bed. A single mother who had slept with her child since his birth spoke about the part she had played in her son's reluctance to go to sleep on his own and realised that she needed to act, despite the fact that she envisaged the programme would be "heart-wrenching" for herself [76 (Mother) Programme E].

Parent-identified goals relating to problems experienced during the night most commonly concerned reducing night wakenings and improving the child's ability to self-soothe and/or stay in his or her own bed. Some said their child was getting up too early, after insufficient sleep, and so wanted advice about this. These parents were motivated by wanting their child – and the rest of the family – to have a good length of sleep. Several parents said that they had been motivated to take up the programme so as to avoid using the sedation medication they had been offered (from a GP, paediatrician, psychiatrist), seeing this as a last resort.

I'd had psychiatrist but they come at it from a very, very kind of clinical angle and, how do I say this?, sometimes they're a little bit down the route of offering medication, and that wasn't something that we as a family felt was appropriate. Yeah, you know, things like Melatonin and things to aid sleep, and we didn't, we didn't want to use medication.

[96 (Mother) Programme H]

A few parents reported very specific sleep problems such as night terrors and excessive rocking which they hoped a specialist sleep programme could resolve, having not found the solution in their searches so far. A couple of parents mentioned the motivator of wanting their child to be able to spend a night away from home (for example, at a grandparent's house) without a difficulty sleeping.

Whether the problems related to bedtime and/or during the night, several parents mentioned the child's disability as an additional motivator to taking up a sleep programme. There were two reasons for this. First, to attempt to confirm (or eliminate) a medical reason underlying the sleep problem. Second, parents were looking to boost their confidence about applying to their disabled child the general strategies they already knew about for dealing with sleep. For example, one mother [73, Programme E] who had enjoyed success with sleep strategies with her non-disabled child was experiencing a "mental block" about trying these with her disabled son. This was partly owing to his condition affecting sleep and not being sure he would understand, but also because during the "bewildering" time immediately post-diagnosis she had felt "sorry for him" and inclined to respond to his sleep problems by "panicking or feeling despair." She wanted to take up a sleep programme to gain confidence to tackle the problem and not let her child's condition "fog" what she could still do to help him.

Overall, a prolonged bedtime and repeated night-time disturbances meant that neither the child nor other family members were getting enough sleep, leading to exhaustion and difficulties during the daytime:

You know, when you don't sleep well through the night, in the morning he was really in a bad mood, you know, crying, refusing to dress.

[79 (Father) Programme F]

Exhaustion was cited by several parents as having made them ready – indeed desperate – for support and so a motivator for taking up a programme, regardless of whether they knew anything about it or whether it was likely to solve their problem:

We were absolutely exhausted and prepared to grab anything [when the programme was offered].

[75 (Mother) Programme E]

It was just sheer desperation ... our lives were just hell really.

[85 (Mother) Programme G, focus group]

We had no idea what to expect [from the programme] ... we didn't have any idea what it was. We just hoped that somebody would be able to help.

[84 (Father) Programme G, focus group]

Generally, regardless of the programme they subsequently attended, parents' motivations and goals were similar. However, for those attending the group-based intervention or one day workshop, the opportunity to meet other parents was mentioned as an additional motivator.

All these motivations and goals fitted within the aims of the programmes. The possible exception was Programme H which, being restricted to a one-off event could only offer a more 'superficial' level of input; this is captured by their stated aim as 'raising awareness of good sleep practice and basic strategies to support parents in establishing new routines'. As such, it might be expected that this programme would serve better those parents with less existing knowledge about sleep strategies and/or more common sleep problems. This bias was not, however, reflected in the characteristics of those taking up this programme (see Chapter 4). An explanation for this might be that parents did not have access to any other sleep interventions. Equally, a lack of detailed information about the content of the workshop meant that parents were unable to discern whether or not it would be suitable for them and their situation.

The specificity of the programmes

Some parents explicitly mentioned that the disability-specific nature of the programme had been an important factor behind their decision to embark on a sleep intervention. For example, in respect of Programme G, a mother explained that it had been important to know that the programme would be run by the Learning Disability team, who understood the special challenges for parenting:

You can't reason with children [who have learning difficulties] in the same way [as other children], so you didn't feel guilty or a bad parent because you couldn't do it.

[81 (Mother) Programme G, focus group]

Other parents simply welcomed an intervention which was going to specifically focus on their child's sleep as opposed to something more generic.

Referral by a trusted practitioner

Many parents had been referred to the programme by practitioners in regular contact with the family, for example a Health Visitor, paediatrician, Community Learning Disability Team nurse, General Practitioner, or school Special Educational Needs Co-ordinator. Parents were willing to rely on the judgement of these trusted practitioners as to the suitability of an intervention.

So I was really up for anything she, you know, suggested would be useful.
[91 (Mother) Programme G]

Positive perceptions of the practitioners/service delivering the programme

Positive perceptions, based on an existing relationship with practitioners delivering the intervention and/or good experiences of other interventions delivered by a service, supported parents' decisions to take-up a sleep programme.

I just thought with it being the CAMHS [LD] team it would be professional, everyone we've met ... have been great ... really helpful.
[86 (Father) Programme G]

It was the same format [as a behaviour management intervention] and I'd found that really, really useful ... so I knew that practically it would be beneficial, you know, and they'd come up with lots of practical ideas cos they'd done that with the previous course."

[84 (Father) Programme G, focus group]

Some parents' previous involvement with these practitioners had been in-depth and over a considerable time, which gave them confidence that they would receive the support they needed, for example:

She used to come out on a regular basis, just come and reassure me ... and basically prop me up. ... She was prepared to go beyond the means ... she's just one of them people, if you told her what was on your mind ... she'd make sure that if she couldn't do it she'd put you in touch with who could. You know, she didn't just leave it.

[78 (Mother) Programme F]

Even where prior contact had been slight, it could nevertheless help parents feel comfortable about encountering the same practitioner in a new intervention. For example, having occasionally come across her sleep practitioner in a Health Visitor role, one parent envisaged that her home visits would be:

... just like the Health Visitor coming round, not a "biggie".
[73 (Mother) Programme E]

Parents attending a one-day workshop (Programme H) were least likely to mention having had prior contact with the practitioner leading the programme or that this was relevant to their decision to attend. However this was to be expected, owing to the different way in which the workshops were set up meaning that parents were not likely to have been in routine contact with the facilitator.

Timings and location

The scheduling and location of the programme had been relevant to taking up the sleep programme offered. Parents being offered one-to-one support with a sleep practitioner (Programmes E and F) liked the prospect of being able to fit contact times around their

personal commitments, such as variable work patterns, their child's frequent hospital appointments, and other family demands, all of which it was said would have made a commitment to fixed appointments or group meetings tricky.

Virtually all the parents attending the group (G) or workshop (H) intervention valued the daytime slots allocated. For full-time parent-carers the main benefit was its "perfect fit" within the school day and no parent raised a problem with childcare for younger siblings. While for many of these families this timing prevented both parents attending (since the other parent was typically out at work), this was seen as the usual and acceptable corollary of daytime events, with the parent who was able to attend expecting to feed the information back to their partner afterwards. Parents who worked shifts, nights or flexible hours had also managed to attend this intervention. However caution was expressed that other working parents might find daytime sessions difficult.

The issue of location was a pertinent issue for those attending the group or workshop interventions. Venues were generally regarded as convenient, for example near to their child's school, or to home. Where parents lived in a more rural area (Programme G), needing to travel to a venue was seen as routine and parents with cars could arrange to give others a lift.

Some parents commented on how the familiarity of venue had helped them feel more confident about attending an intervention. Several who signed up for the group intervention (Programme G) had visited the venue for previous courses. The workshop (Programme H) typically used familiar community venues, such as Children's Centres.

It's good to go to a familiar environment.
[103 (Mother) Programme H]

13.3 Parents' experiences of a sleep programme

We now move on to report parents' subsequent experiences of the sleep programme. Of particular interest in the analysis was to identify the aspects of the programme valued by parents, which supported their engagement. Clearly many of the factors identified as influencing initial take-up, and described above have continued relevance, for example personal motivations, the fit of timing with other commitments etc.

The different types of programme experienced among the interviewees has enabled us to draw out the findings separately for the three modes of delivery (one-to-one work with a sleep practitioner, group intervention work and a one-day workshop) in addition to identifying cross-cutting themes. We have structured the majority of this section accordingly. First, however, we briefly report the evidence regarding reasons for not completing the intervention.

Reasons for early 'exit' from a programme

Among the 35 interviewees, two parents had chosen not to complete the intervention. In one instance the parent had felt the programme was not appropriate for her child. For the second parent, a problem associated with the neighbours' house meant that the child was temporarily unable to sleep in his bedroom. Embarking on the intervention was therefore postponed.

In a further two cases, non-completion was due to the fact that the sleep practitioner judged that, following a detailed assessment, there was a physiological cause to the child's sleep

problem. This meant behavioural approaches to managing the difficulty were not appropriate.

Parents' experiences: mode of delivery

This section presents our findings on parents' experiences of the mode of delivery: one-to-one work with a sleep practitioner (Programmes E and F); a group intervention (Programme G); and a one-day workshop (Programme H). Our aim in doing so is to draw out the benefits and drawbacks parents associated with these different ways of supporting them to tackle their child's sleep problems. Our analysis also revealed a number of cross-cutting themes, which we report in the following sub-section.

A general point to make at the outset is the very positive way in which parents spoke about their experiences, including what they had enjoyed and valued in terms of the mode of delivery.

One-to-one work with a sleep practitioner (Programmes E and F)

The be-spoke nature of the intervention

The key theme to emerge from the accounts of parents experiencing these programmes was the value of its bespoke nature, by which they meant both a focus on their individual child/family and flexibility to suit the family in the timing, overall length and format of the support.

it [the initial assessment] felt personal to the family, not just something from a book.

[71 (Mother) Programme E]

You have a personal plan.

[76 (Mother) Programme E]

Programmes E and F both began with a detailed assessment of the child's needs, including a home visit. Parents said that having a disabled child meant that they were used to home visits and liked them, as they felt more comfortable and relaxed:

it's easier to talk to someone in your own home.

[75 (Mother) Programme E]

Parents judged the home visit key for this assessment, as it enabled the sleep practitioner to see the child's home environment and/or how he or she behaved in it. For example one mother in Programme E thought that being in the house meant that the sleep practitioner could "pitch" [75] her advice to the environment, having seen it for herself. Another mother from the same programme (E) talked about the sleep practitioner having got "a clear picture" [76] from visiting the home of how demanding her son could be and so what he might be like during the evenings.

The output of that assessment was a child/family specific 'sleep strategy' which parents implemented with support from the sleep practitioner. The bespoke nature of the one-to-one mode was also valued for its flexible delivery of support during the implementation phase.⁹⁰ Parents said they felt able to influence the overall number, frequency and type of contacts to suit the other demands on their time, this flexibility was valued. For example, one mother

⁹⁰ Implementation support is delivered through regular, on-going contact by the sleep practitioner to the parent. This is either delivered by home visits, telephone calls, or the parent visiting the sleep practitioner's 'base' (e.g. Child Development Centre, Children's Centre). This support is provided until it is mutually agreed that desired outcomes regarding the child's sleep have been achieved.

appreciated being able to choose the frequency of implementation support home visits as she felt she needed a very regular (weekly) visit to keep her momentum going, otherwise it was too “easy to give in” [71] during the night when she was tired.

Telephone-delivered support

For some of the parents receiving programme E, implementation support was delivered via telephone calls from the sleep practitioner as opposed to home visits. All the parents receiving implementation support in this way believed it was at least as effective face-to-face support.

It's a great service ... it's a point of contact for reassurance and keeps bringing you back to the importance of consistency, of maintaining a routine, it keeps that fresh in your mind".

[75 (Mother), Programme E]

Indeed it was seen as having advantages over home visits because it was less intrusive and time-consuming. This was particularly valued in the context that many parents already had multiple appointments regarding their child.

The group-based intervention (Programme G)

Parents who had attended the group-based intervention identified a number of advantages to this mode of delivery.

The value of meeting with other parents

The opportunity to be with other parents was highly valued. Parents said they had gained reassurance from realising that they were not the only family with a sleep problem and that this had helped them feel less isolated and to gain perspective on their own problems by having had the chance to listen to the stories of others in worse situations; even if, as one mother admitted, saying so might “sound awful” [82]. This could help parents feel more confident about tackling their own child’s sleep problem.

It makes you more confident just because you know in that group that there are other people going through exactly what you're going through. And it's just knowing that there are other people out there in the same boat as you and you're not all alone.

[94 (Mother) Programme G]

Sharing with others undergoing similar problems and experiences was very supportive. As one mother pointed out, professionals could not understand problems in the same way as: “it's not 24/7 like being a parent” [88].

Whilst parents respected the input of their group facilitators, this was felt to be limited compared to the chance to access expertise of parents, which had been gained through personal experience. As one father argued, parents had more direct experience of having had to work out problems, whereas practitioners had gained their learning “from books and courses ... some don't even have children” [92]. Parents valued the way the group format enabled them to access a range of practical ideas for tackling sleep problems. Even when the sleep scenario was not immediately relevant to a parent’s own situation, ideas could be stored away for possible future use. Parents valued this diversity and the ethos of sharing ideas among equals.

to bounce ideas off ... discuss whether something is suited to your child and then go away and try something new.

[94 (Mother), Programme G]

The experiences described above are a clear example of the 'family partnership' approach,⁹¹ where parents feel empowered and as equally expert as the practitioners delivering the intervention.

Views on the group-mode

An additional advantage of group-mode delivery identified by one parent was that it shifted the focus of attention around the group. This mother appreciated the way this gave her "time to think" [89] and rejoin the discussion later, not possible in a one-to-one format where scrutiny remained on herself. Indeed, parents generally felt it was more 'relaxing' to participate in an intervention via a group mode as opposed to working one-to-one with a practitioner. Nevertheless, it had been stressful or uncomfortable at times to have to talk openly about their child's problems. Parents coped with this by reminding themselves that openness was key to getting the most from the group and, hence, for their child.

I think if you're shy and you don't want to discuss, you just want to sit and listen, then they [group programmes] are not for you, because unless you're going to give, you're not going to get back either ... if you can't discuss your problems, they can't help you with them ... and you've got to be honest. You've got to be prepared to be honest.

[81(Mother) Programme G, focus group]

However, it is important to note that the fact that the group sometimes discussed issues which were very personal and emotionally charged could be draining; one mother described the sessions as "intense, hard-going" [82]. A drawback of being part of such a group was the sense of loss when the programme came to an end. One mother summed this up as follows, along with a suggestion as to how these feelings might be ameliorated:

You meet up with people and you, and you get to know them and they're sharing quite big things really, and then it just comes to a halt ... you do wonder how they're getting on ... so it might be good, you know, at some point, maybe just to have a, like a get together in a few months or six months or something.

[93 (Mother) Programme G]

One-day workshops (Programme H)

Although the workshop was a one-off event and less interactive, similar valued experiences to parents who had attended the four week group intervention (Programme G) were reported. These included: reassurance from realising theirs was not the only family with a sleep problem; gaining perspective through hearing about families with 'worse' problems; and mutual support and learning from parents with experience in tackling sleep problems. For example, one mother [101] said that realising that hers was not the only family with a sleep problem had helped her to "accept" the ways things were with her son. Another mother commented more generally on the impetus she had gained from spending a day with other parents:

What really helped was other parents were sharing their ideas of what had worked or what hadn't worked. It's so empowering, you know, being in a group of people where they've got similar experiences and you take that kind of take that on, don't you?

[96 (Mother) Programme H]

⁹¹ The Family Partnership Model (Davis *et al.* (2002); Day, C. & Davis, H. (2009)) advocates a collaborative approach to working with families in which professionals seek to combine parents' and professionals' expertise in order to develop and build parental self-efficacy and identify effective and realistic problem management strategies.

While parents experiencing both types of group programme (G and H) spoke about valuing the sleep knowledge of the facilitators, the workshop parents were more likely to draw attention to this and the accompanying “*valuable insight*” [96] the facilitator brought from work with other families. This difference may have arisen simply owing to differences between the aims and length of the two programmes. Programme G, with a longer timescale, focused on parents generating sleep strategies (with facilitator guidance) and trying these out over a number of weeks, reporting back for peer and facilitator support. By contrast, as a single event, Programme H was necessarily more focused on ensuring parents left the day with their awareness raised about good sleep practice and knowledge about basic strategies. As such Programme H was arguably more reliant on formal facilitator input to ensure that all this information was passed on in the short timeframe and, as such, may have been received by parents with more immediate impact.

Facilitators who are also parents

One of the workshop facilitators was also a parent who had experienced sleep problems with her child. This facilitator overtly drew on this experience during the workshop and parents clearly valued this connection. For example, one mother felt it meant that the facilitator and parents were “*on the same wavelength*” [102] and another mother felt that it meant the workshop was delivered “*all kind of on your level*” [103]. This parent had found her paediatrician dismissive of her child’s sleep problem, so also valued the facilitator’s personal experience because “*she knew what you meant when you were saying how tired you were and how sick of it*” [103].

Mode preferences

Mode preference was more mixed among parents who had attended a workshop compared with the other programmes, where parents tended to favour very strongly the mode of delivery they had received. There was definite support for the workshop format from those parents whose needs were most closely consistent with its aims; that is, a basic grounding in dealing with sleep problems. For some of these parents a workshop was seen as having a definite advantage over one-to-one encounters in this respect:

I think if it had been one-to-one I'd have been feeling it was just me and feeling guilty.

[97 (Mother) Programme H]

The chief drawback of the workshop mode was its brevity as a programme, given the large subject area of sleep and participants having varying starting points in terms of their existing knowledge. As a result, parents who already knew “*the basics*” [103] (such as the importance of a bedtime routine) were less likely to find from the workshop the more specific sleep solutions they were seeking. Two interviewees commented along such lines. However, there was a difference of opinion as to whether this shortfall existed simply owing to time constraints or because the facilitator did not seem to have the very specialist knowledge required.

Three suggestions were made by these parents. First, it was thought that the advertising had been unclear as to what the workshop would cover; so more information in advance would help individual parents to decide whether it was likely to meet their needs. Second, it was suggested that parents who had signed up for a workshop should be asked in advance about their needs, so that the facilitator could tailor the content as far as possible to the specific audience. The third suggestion was for more specialised, or advanced, workshops to be developed; for example, sleep problems of children with autism.

Having practitioners as co-participants

Finally, the workshops were open to both parent and practitioners. As one mother commented, such a mix was “*unusual but interesting*” [101], another mother calling it a rare

“bridge” [96] across the parent - practitioner divide. While, as one mother said, the workshop had enabled both parents and practitioners to see where the other was “*coming from*” [99], on balance practitioners were seen as the main beneficiaries. As one mother said, “*they learned from us, we didn't learn from them*” [103]. However this was thought appropriate, parents seeing the role of the practitioners on the day as to learn. Finally, one mother thought that a parent - practitioner mix might make the workshop off-putting for those parents who felt “*intimidated*” [101] by practitioners.

13.4 Parents' experiences: cross-cutting themes

In parents' accounts of their sleep programme experiences, some common themes emerged which had supported their engagement irrespective of the specific mode of delivery. These were all associated with positive characteristics which parents felt were held by the practitioner running their programme and included their personal qualities, knowledge and skills. A set of valued attributes emerged from among parents experiencing all the programmes, along with some skills specific to group work.

Valued practitioner characteristics

Irrespective of the sleep programme, parents identified aspects of the practitioner's personal qualities – their personality, style and ethos – which had supported their engagement. Practitioners were valued for their warm and empathetic personality and for a style which was relaxed, informal and 'down to earth':

she was lovely, really helpful, a good listener.
[79 (Father) Programme E]

they [the group facilitators] were relaxed, friendly and approachable.
[89 (Mother) Programme G]

she was fantastic ... empathetic to the needs of parents ... a really warm person.
[96 (Mother) Programme H]

In terms of ethos, parents valued practitioners' non-judgemental approach; it showed respect for a parent's expertise, parenting style and knowledge of their own child when deciding how to tackle problems. For example, a mother from Programme E said that she had liked “*not being dictated to*” [71], explaining that the sleep practitioner had offered advice and talked through options, but then left it up to her as the parent to decide what to do with her child. A parent in the group intervention felt, being with other parents and the facilitators, that:

... everyone was equal. It felt like a group of friends sitting together: learning was two-way.
[92 (Father) Programme G]

Another parent from Programme G valued the non-judgmental approach of the group facilitators for boosting her confidence:

They were very understanding ... you were never made to feel as if what you were doing was wrong.
[94 (Mother) Programme G]

Programme H was also valued for the inclusive, rather than didactic, style of the facilitator:

It wasn't like, right, you will do this, this & this, or you're doing it all wrong, it was more of a let's all see how we can get some ideas and help each other.
[97 (Mother) Programme H]

Parents also welcomed not being pushed too hard by practitioners. For example, at the end of a sleep practitioner's first home visit she gave the parent a plan for the first week which was:

... modest, a step. It felt comfortable to do, not too hard.
[71 (Mother) Programme E]

Group facilitators in Programme G were also said to have intervened appropriately when it seemed that parents might be thinking of changing bedtime routines or sleep management strategies too much at once.

At the same time, the strength of practitioners' genuine commitment to supporting parents was appreciated. For instance, a sleep practitioner who spent extra time to listen and offer reassurance when progress was slow:

She was supportive, said we were making progress, kept me going when I felt it had been a flop after all the hard work.
[76 (Mother) Programme E]

The practitioner's specialist knowledge of sleep was valued by parents, especially by those who had previously struggled to access the information they needed from 'generalists' (such as paediatricians, or community-based nurses). Practitioner insights gained through working with other families were valued, both in one-to-one programmes (where this could help counter feelings of isolation) and in group settings (where these examples widened the range of ideas parents could draw upon beyond the group).

Valued practitioner skills in group settings

Parents in Programmes G and H also drew attention to the contribution of practitioner skills in group settings. It was clear that group facilitators had skills in enabling parents quickly to feel at ease with one another, which had been key to parents' willingness to share their sleep problems. Explaining what would happen, encouraging parents to talk about their children, and agreeing ground-rules were cited by parents as used successfully at the outset to enable them to feel comfortable.

During group work, facilitators were praised for their skills in time management. In the workshops (Programme H), this meant that the facilitator had covered the right amount of topics in sufficient depth. While a few parents had their more specific needs unmet, it was nevertheless thought that the facilitator had covered the general material well. In the group intervention (Programme G), where parents had taken more of a lead, facilitators skilfully managed the use of time overall, for example by:

... knowing when to wind it up and bring it round kind of thing so you didn't drift off and stayed focused.
[86 (Father) Programme G, focus group]

Similar judgement was also made by group facilitators in general, to balance their input with that of parents. For example, in Programme G, facilitators would offer advice when requested by parents and in Programme H, parents liked it that the facilitator did not use a

script, so was able to respond directly to participants. Other valued group facilitation skills were associated with varying the activities/aids for increased impact and maintaining attention.

13.5 Summary

This chapter has reported the study's findings regarding the factors which influenced parents' decision to take-up a sleep intervention and their subsequent experiences of receiving it.

A very strong theme in parents' accounts of the reasons why they underwent a sleep programme was the desire to improve their child's sleep because of the impact it was having on them, as parents, their child and, sometimes, other family members. Interestingly, the presence of disability appeared to interfere with at least some parents being able to judge whether or not the difficulties they were experiencing with their child's sleep were inevitable or whether something could be done to improve it. Equally the presence of disability sometimes seemed to disempower parents in terms of addressing the problem. Not surprisingly, therefore, the fact that the intervention they were being offered was 'disability-specific' appealed to parents. Finally, the chance to try to resolve their child's sleep problems without resorting to medication was valued by a number of parents.

As with the decision-making processes which parents underwent regarding taking-up a behaviour management programme (see Chapter 6), referral to a sleep intervention by a trusted practitioner and positive perceptions of the professionals and/or service delivering the intervention, both supported parents' decision to accept help with their child's sleep. Similarly, the 'fit' of the intervention with pre-existing commitments, and a convenient and familiar venue, also helped parents to feel able to take-up the intervention.

In terms of mode of delivery, the overall tenor of parents' accounts of the intervention they received was very positive. The primary benefits of a one-to-one approach perceived by parents was that their child received a detailed assessment, which included an assessment of the child's bedroom; a personalised 'sleep strategy' was developed from that assessment; and that the support they received as they implemented that strategy could, to a greater or lesser extent, be tailored to their needs and other commitments. One of the programmes was trialling telephone support, as opposed to home visits, during the implementation phase. The parents interviewed who had received support in this way viewed it very positively with a suggestion that it was, perhaps, more suitable and effective than a home visit.

The parents who had attended the group-based intervention had not received a detailed, home-based assessment of their child's sleep problems. Furthermore, strategies to manage their child's sleep were developed during the group sessions and were implemented without any further support apart from that garnered at subsequent sessions. This support was also limited to the duration of the intervention (four sessions over a five week period). Yet the parents who received this intervention also spoke very highly of it and the mode of delivery appeared as a very strong influence on these positive experiences. First, it meant that their child's sleep problem was, in a sense, 'normalised' as accounts of the children's sleep problems were shared. For some parents, this in itself seemed to give them the confidence to tackle their child's sleep. Second, and building on this increased confidence, parents felt that, together, they themselves were developing solutions and strategies to better manage their child's sleep. Parents' accounts painted a clear picture how adopting a family-partnership approach empowers parents. The impact of this cannot be underestimated within the context of supporting parents whose confidence and sense of efficacy has been undermined by their struggles to manage their disabled child's sleep and/or behaviour,

particularly if their parenting experiences with their other children have been generally positive.

Some additional and interesting aspects of experiencing a group-delivered intervention were also identified. It was seen as less demanding than one-to-one work in that it allowed individual parents to 'hide' within the group and to have more control over when they actively participated. At the same time, however, the personal and emotional nature of some of the discussions could be emotionally draining.

The final sleep intervention in this study is a one-day workshop. Its aim is, necessarily, different to the other interventions. It seeks, instead, to provide parents' with an overview of sleep and sleep management principles which has been tailored to the needs of parents of children with special needs. Parents noted that it is important that the aims and content of the workshop are made very clear in all publicity material in order that parents can make an informed decision about whether attendance would be of benefit. Despite the very short-lived nature of the groups formed at these workshops, parents still reported considerable benefit from spending time sharing with other parents experiencing difficulties with their child's sleep. As with the group-based intervention, the notion that 'normalising' a problem can be very empowering emerged from parents' accounts. Finally, the workshop intervention was sometimes delivered by a practitioner who was also a parent of a disabled child. This was consistently spoken about as adding value and credibility to the advice being given.

Lastly, this chapter reported the characteristics and skills of the facilitators which parents valued and had, clearly, had an influence on their positive experiences. These had clearly supported initial and on-going engagement in an intervention.

Chapter 14

Interventions E and F: Individually Delivered Sleep Management Interventions

In this chapter we report findings from two exploratory studies of individually delivered sleep management interventions for parents of disabled children aged 0-5 years. Both interventions conduct detailed assessments of the child's sleep (including a home visit and parental completion of a sleep diary for two weeks) from which a sleep strategy or 'sleep plan' is devised. Parents are then supported as they implement the new sleep strategy.

Intervention E, based in a Child Development Centre and delivered by a Specialist Health Visitor, delivers implementation support through either home visits (HV) or telephone support (TS). Intervention F is based in Children's Centres and delivered by Early Years Workers who have been additionally trained as sleep practitioners. Parents are supported as they implement a sleep strategy through home visits or the parent attending the sleep clinic at the Children's Centre.⁹²

Main findings

- Small sample sizes, the lack of a no-treatment comparator group, and a before and after research design and poor response rate (Intervention F), means that conclusions are necessarily tentative. However, these studies did allow an exploration of the delivery of one-to-one sleep support in the context of routine practice and in areas of relative social deprivation.
- The direction of changes in scores on measures of the child's sleep, parents' sense of competence and progress towards attaining parent-set goals for their child sleep support were consistently positive.
- For Intervention E, the findings support further investigation into the relative effectiveness of telephone support and home visits whilst parents are implementing their sleep strategy. The mean observed difference in cost between providing telephone support as opposed to home visits was £125 (£165 vs. £290).
- The skill level of staff delivering the two interventions varied. Whilst small sample size prohibits comparison of relative effectiveness, as noted above positive changes were observed for both interventions.
- The mean cost of a single delivery of Intervention F was £195.

⁹² Due to the small numbers recruited to these studies comparisons cannot be made between them, rather we are looking at general evidence across them of the effectiveness of one-to-one sleep support.

14.1 Overview of the investigations

INTERVENTION E: Specialist Health Visitor Sleep Support Programme			
Design	Exploratory, two-arm randomised control trial: home visits (HV) vs. telephone support (TS) as mode of support as parents implement a sleep strategy. Outcomes measured pre- & post-intervention and 12 week follow-up. Two arms well-matched at baseline.		
INTERVENTION F: Specialist Health Visitor Sleep Support Programme			
Design	Exploratory, before and after study. Outcomes measured pre- & post-intervention and 12 week follow-up.		
Outcomes	<ul style="list-style-type: none"> Parent-set child sleep goal(s). Standardised measure of Parenting Sense of Competence (PSOC; Johnston and Mash, 1989) <ul style="list-style-type: none"> PSOC-Satisfaction subscale (satisfaction with the parenting role) PSOC-Efficacy subscale (feeling of efficacy as a parent) Standardised measures of sleep problems (Children's Sleep Habits Questionnaire (CHSQ), (Owens, 2000) <ul style="list-style-type: none"> Total Sleep Disturbance Score Bedtime Resistance subscale Sleep Anxiety subscale Night Wakings subscale 		
Sample		Intervention E	Intervention F
		Implementation support: home visit	Implementation support: Telephone call
Children	N=6	N=7	N=12
Age of child (Mean (SD))	2.67 yrs (0.82)	2.86 (1.07)	2.88 (1.25)
Male (%)	6 (100%)	5 (71.4%)	6 (50%)
Description of child's additional needs	ASC 3 (50%), learning disability= 1 (16.7%), physical/sensory disability=1 (16.7%), awaiting diagnosis=1 (16.7%)	ASC= 5 (71.4%), learning disability= 1 (14.3%), physical/sensory disability= 1 (14.3%)	ASC= 3 (25%), learning disability= 2 (16%); (with physical disability)= 3 (25%); awaiting diagnosis = 6 (50%)

Parents (all mothers)	N=6	N=7	N=12
2-parent household (%)	5 (83.3%)	6 (85.7%)	7 (58.3%)
Higher Education (%)	2 (33.3%)	3 (42.9%)	3 (25%)
White British (%)	6 (100%)	7 (100%)	7 (58.3%)
Response rates:	92% (post-intervention); 62% (12 wk f-up).		50% (post-int); 42% (12 wk f-up).

14.2 Intervention outcomes

Goal attainment

Following the assessment appointment, parents receiving one-to-one support from either the specialist health visitor, or a SEN/ Disability Link Worker set up to three sleep-related goals for their child. For example, 'For [daughter] to settle by herself', 'Stay in his own bed all night.'

The number of goals that were set and the ratings given at either post-intervention or 12 week follow-up are displayed in Table 14.1. Mean goal ratings improved⁹³ across both services and across all types of support.

Table 14.1 Mean goal attainment rating: Pre-intervention – 24 weeks follow-up

Type of support provided	Pre-Intervention			Post-intervention			12 week follow-up		
	N	M	SD	N	M	SD	N	M	SD
SHV – Home visits (E)	13	2.15	1.63	12	3.92	2.84	10	6.50	3.03
SHV – Telephone support (E)	12	2.33	1.72	12	6.75	3.77	8	9.38	.744
SEN/Disability Link Worker (F)	11	2.64	2.11	8	6.50	2.14	7	6.71	3.09

N=number of goal scores available; M=mean goal attainment rating; SD=standard deviation.

For Intervention E, immediately post-intervention, attainment ratings set by parents who were receiving telephone support from the Specialist Health Visitor had all improved.⁹⁴ For those parents who were receiving home visits from the Specialist Health Visitor, 60 per cent

⁹³ A 10 point rating scale was used to indicate the extent to which a goal has been achieved: 1=very far from this goal; 10=I have achieved my goal.

⁹⁴ Improvement/Deterioration based on whether the goal scores have moved 1+ scores in a positive or negative direction.

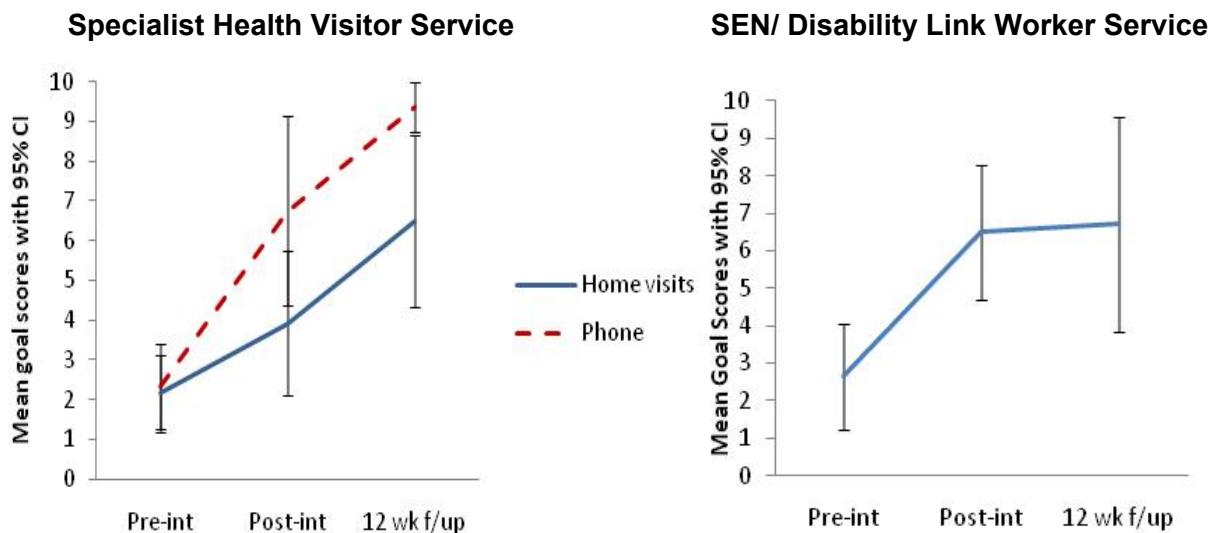
of their goals had improved. At 12 week follow-up improvement appeared maintained with approximately half of parents reporting further improvement (Table 14.2; Figure 14.2).

Looking at those parents who received support from a SEN/Disability Link Worker (Intervention F), three-quarters of goals set improved post-intervention. In contrast to Intervention E there were no further improvement for the two parents for whom post-intervention, 12 week follow-up was available (see Tables 14.1 and 14.2; Figure 14.2).

Table 14.2 Direction of change for parents who set sleep goals for their child

Change in goal attainment rating	Type of support provided	Time period		
		Pre-intervention to post-intervention f/up	Pre-intervention to 12 week f/up	Post-intervention to 12 week f/up
Improved	SHV – Home visits	6 (60%)	8 (80%)	3 (42.9%)
	SHV – Telephone support	7 (100%)	7 (100%)	5 (62.5%)
	SEN/Disability Link Worker	6 (75%)	5 (71.4%)	0 (0%)
No change	SHV – Home visits	3 (30%)	0 (0%)	2 (28.6%)
	SHV – Telephone support	0 (0%)	0 (0%)	2 (25%)
	SEN/Disability Link Worker	1 (12.5%)	1 (14.3%)	0 (0%)
Deteriorated	SHV – Home visits	1 (10%)	2 (20%)	2 (28.6%)
	SHV – Telephone support	0 (0%)	0 (0%)	1 (12.5%)
	SEN/Disability Link Worker	1 (12.5%)	1 (14.3%)	4 (100%)

Figure 14.2 Mean goal attainment ratings: Pre-intervention – 12 week follow-up

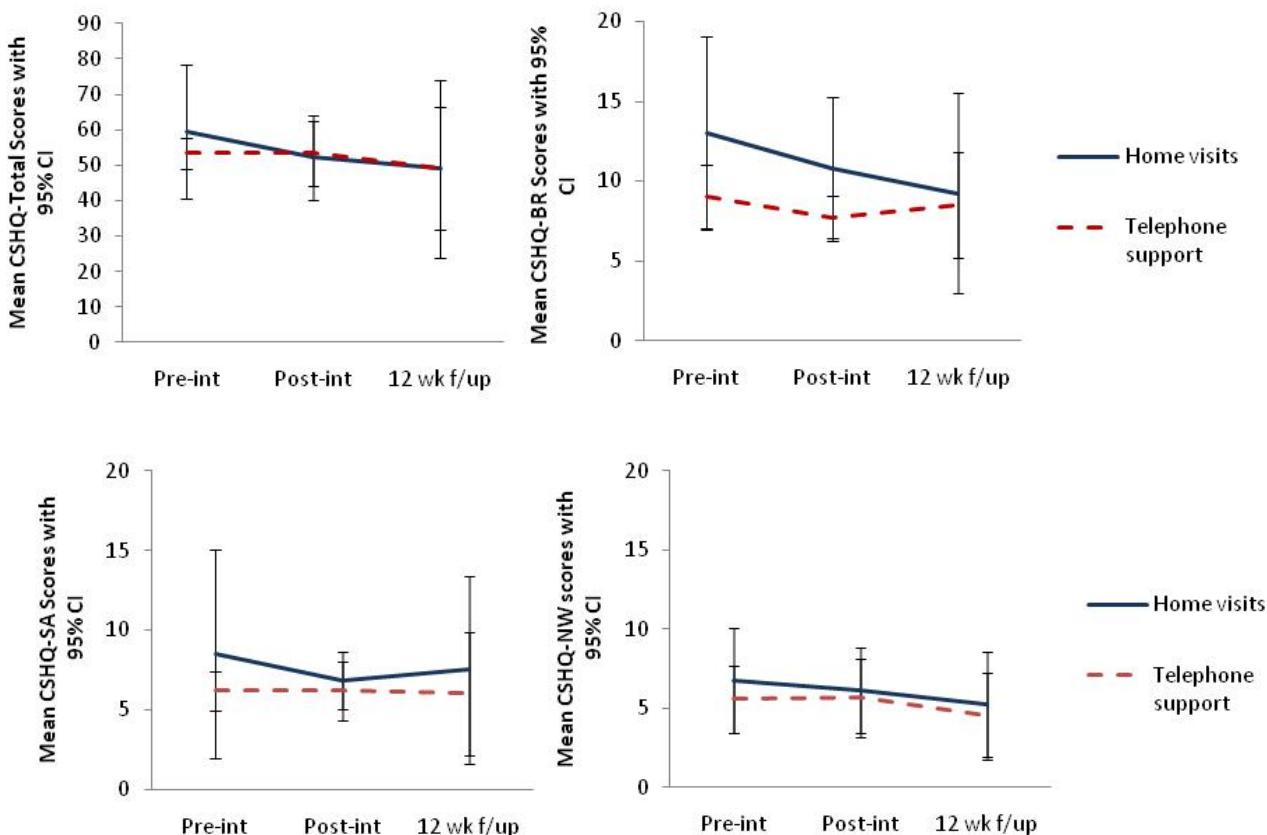


Parent-reported sleep problems

Changes in parent-reported sleep problems

Post-intervention, there were reductions in mean scores for the Total Sleep Disturbance Score and each of the subscales of interest for parents receiving home visits⁹⁵ from the specialist health visitor. For parents receiving telephone support, improvement was only for the Sleep Anxiety⁹⁶ subscale (See Table 14.3 and Figure 14.3).

Figure 14.3 Mean Total Sleep Disturbance and Subscale Scores for parents receiving support from a specialist health visitor: Pre-intervention – 12 week follow-up



Parents receiving support through an SEN/Disability Link Worker (Intervention F) showed initial improvement on the Total Sleep Disturbance Score and on the Bedtime Resistance subscale (See Table 14.3 and Figure 14.4).

By twelve week follow-up, further reductions are noted across all the scales apart from the sleep anxiety subscale for parents receiving home visits from the specialist health visitor. In contrast there were improvements for the Total Sleep Disturbance Score and each of the subscales of interest other than the Bedtime Resistance Subscale⁹⁷ for those parents receiving telephone support or support from a SEN/disability link worker.

⁹⁵ A reduced score reflects an improvement in the parent's perception of their child's sleep problems.

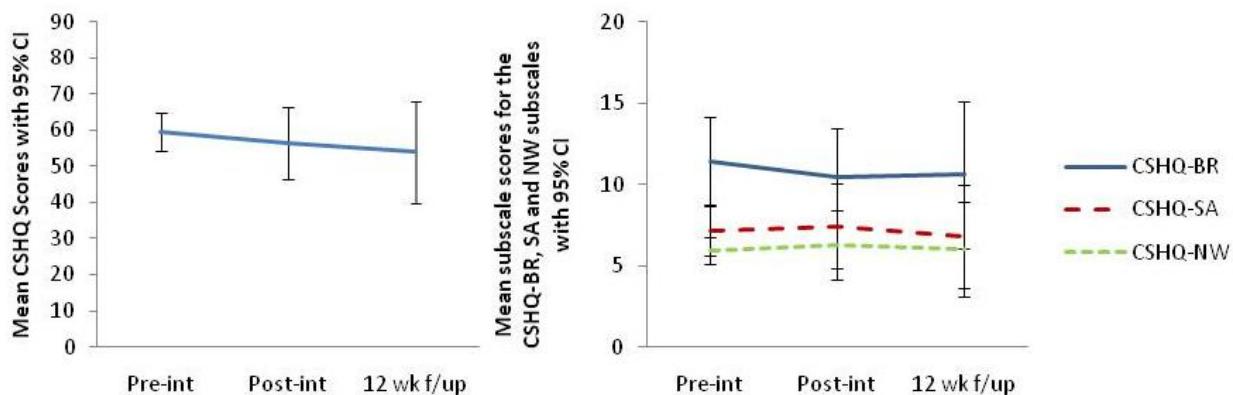
⁹⁶ Examples of items on Sleep Anxiety sub-scale are: 'Needs parent in room to sleep'; 'Afraid of sleeping alone'.

⁹⁷ Examples of items on the Bedtime Resistance sub-scale are: 'Goes to bed at same time' (reverse score); 'Falls asleep in other's bed'.

Table 14.3 Sleep Outcomes

CSHQ Scales	Type of support	Pre-intervention			Post-intervention			12 week f/up		
		N	M	SD	N	M	SD	N	M	SD
Total Sleep Disturbance	SHV – Home visits	4	59.50	11.82	6	52.17	11.44	4	49.0	15.77
	SHV – Telephone support	6	53.33	4.27	6	53.33	8.76	4	49.25	10.90
	SEN/ Disability Link Worker	11	59.55	7.59	7	56.57	10.77	5	54.0	11.40
Bedtime Resistance	SHV – Home visits	4	13.00	3.83	6	10.83	4.22	4	9.25	3.94
	SHV – Telephone support	6	9.00	1.90	6	7.67	1.37	4	8.50	2.08
	SEN/ Disability Link Worker	10	11.40	3.84	7	10.43	3.26	5	10.60	3.65
Sleep Anxiety	SHV – Home visits	4	8.50	4.12	6	6.83	1.72	4	7.50	3.70
	SHV – Telephone support	6	6.17	1.17	6	6.17	1.72	4	6.00	2.45
	SEN/ Disability Link Worker	11	7.18	2.36	7	7.43	2.82	5	6.80	2.59
Night Wakings	SHV – Home visits	4	6.75	2.06	6	6.17	2.56	4	5.25	2.06
	SHV – Telephone support	7	5.57	2.23	6	5.67	2.34	4	4.50	1.73
	SEN/ Disability Link Worker	12	5.92	1.24	7	6.29	2.29	5	6.00	2.35

Figure 14.4 Mean Total Sleep Disturbance and Subscale Scores for parents receiving support from a SEN/ Disability Link Worker: Pre-intervention – 12 week follow-up



The size and direction of change in parent reported sleep problems

Effect size statistics⁹⁸ explored the size (and direction) of changes in parent-reported sleep problems across the study period, see Table 14.4. For those parents receiving home visits from the specialist health visitor – effect sizes were positive across the Total Sleep Disturbance Score and each of the subscales of interest at post-intervention and 12 week follow-up, with the exception of night waking where there was no effect post-intervention. Effect sizes typically increased slightly at the 12 week follow-up point, the largest being for Bedtime Resistance.

For parents receiving telephone support from the specialist health visitor – they also experienced typical improvements in standardised mean scores after receiving the intervention. Apart from the Bedtime Resistance Subscale – all effect sizes increased further at 12 week follow-up (See Figure 14.5). Large effect sizes were found for the Sleep Anxiety and Night Wakings subscales.

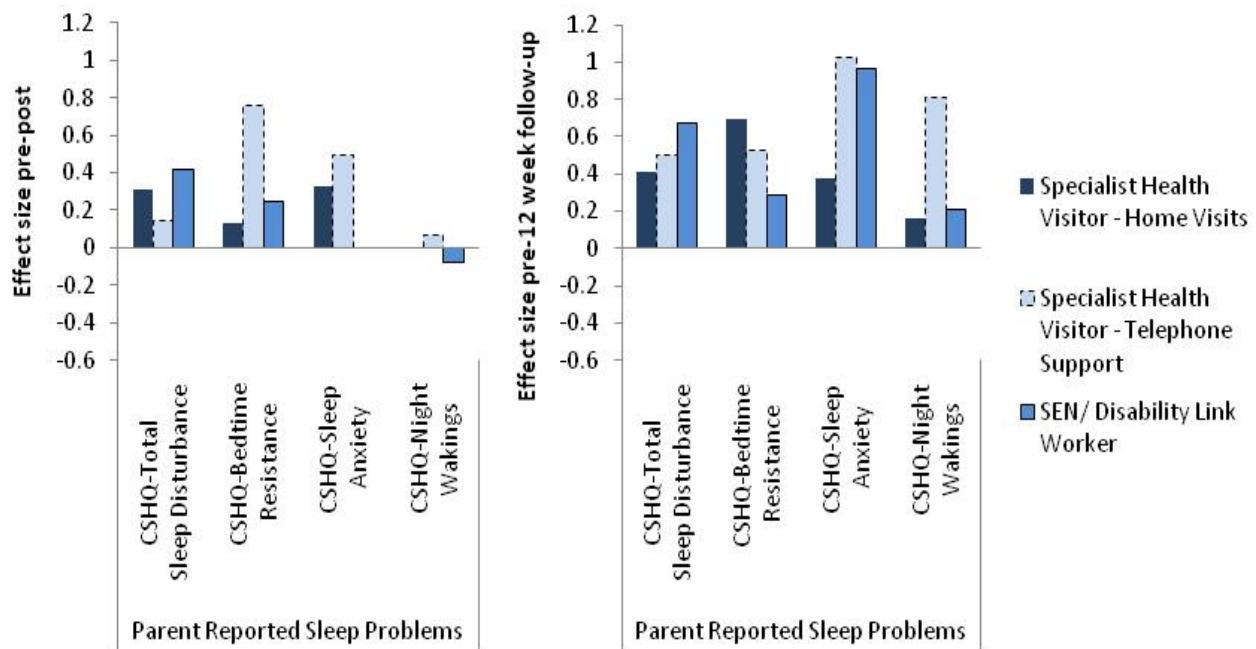
Change was also largely positive for parents receiving sleep support from an SEN/ Disability Link Worker (Intervention F). Twelve weeks after the sleep support had finished, medium to large effect sizes were found for the Total Sleep Disturbance Score and Sleep Anxiety Subscale. Positive change was not immediate however, with no or negative effects found post-intervention for sleep anxiety and night wakings.

⁹⁸ The effect size statistic quantifies the difference between two sets of data or between two groups. 0.2 is defined as a 'small' effect size, 0.5 as a 'medium' effect size, and 0.8 as 'large' effect size. Effect sizes are reported by the abbreviation: d^2 . In this study effect sizes were calculated within each sample (e.g. those who had attended a parent group) the effect size between two time points being calculated. Effect size is calculated by dividing the difference between the means by the pooled standard deviation (Cohen's $d = (MT1 - MTx)/SD$).

Table 14.4 Effect sizes for changes in scores on sleep problem measure (CSHQ)

	Type of support	Effect sizes from pre-intervention	
		Post-intervention	12 weeks post-intervention
Total Sleep Disturbance	SHV – Home visits	.31	.41
	SHV – Telephone support	.14	.50
	SEN/Disability Link Worker	.42	.67
Bedtime Resistance	SHV – Home visits	.13	.69
	SHV – Telephone support	.76	.53
	SEN/Disability Link Worker	.25	.29
Sleep Anxiety	SHV – Home visits	.33	.38
	SHV – Telephone support	.49	1.02
	SEN/Disability Link Worker	0	.96
Night Wakings	SHV – Home visits	0	.16
	SHV – Telephone support	.07	.81
	SEN/Disability Link Worker	-.08	.21

Figure 14.5 Effect sizes for changes in scores on the Total Sleep Disturbance Score and the Bedtime Resistance, Sleep Anxiety and Night Wakings subscales



The proportion of children with improved sleep

Sleep outcome scores for each child were then examined in order to determine whether any changes in scores could be regarded as 'true' changes, as opposed to spurious changes caused by inadequacies in the measure being used. The statistic used is known as the Reliable Change Index.⁹⁹ This is an important indicator of the clinical, as opposed to statistical, significance of any observed changes associated with an intervention.

Table 14.5 sets out the proportion of children who, according to parent-report sleep outcomes, had experienced a reliable change in their sleep at post-intervention, and then at 12 and 24 week follow-up.

Just fewer than half of parents show reliable improvement on the Total Sleep Disturbance Score post-intervention. Regarding improvement on the subscales, those receiving home visits from a specialist health visitor fared best on the Bedtime Resistance and Sleep Anxiety Subscales whilst only parents receiving support from the SEN/Disability Link Worker (Intervention F) showed reliable improvement on the Night Wakings subscale.

Twelve weeks later, all three of the parents for whom data is available who received home visits from the specialist health visitor had reliably improved on the Total Sleep Disturbance Score. There was less reliable improvement for these parents on the CSHQ subscales. Across the subscales there was little to distinguish between the few parents who had received telephone support to those who had received home visits.

Looking now at those parents who had received support from a SEN/Disability Link Worker (Intervention F), whilst only two of the five parents showed reliable change on the Total Sleep Disturbance Score at 12 week follow-up, three (60%) showed more specific reliable improvement on the Sleep Anxiety and Night Wakings Subscales.

⁹⁹ A reliable change was defined as those where a score of >1.96 on the Reliable Change Index was achieved (Hawley, 1995; Jacobson and Truax, 1991).

Table 14.5 The proportion of children with improved sleep at each time point: Reliable Change statistics

	CSHQ-TOT			CSHQ-BR			CSHQ-SA			CSQA-NW		
	Arm of trial			Arm of trial			Arm of trial			Arm of trial		
	SHV-HV	SHV-TS	SEN/DLW	SHV-HV	SHV-TS	SEN/DLW	SHV-HV	SHV-TS	SEN/DLW	SHV-HV	SHV-TS	SEN/DLW
Post-intervention												
Reliably improved	2 (50%)	2 (40%)	3 (50%)	2 (50%)	1 (20%)	1 (14.3%)	2 (50%)	1 (20%)	1 (14.3%)	0 (0%)	0 (0%)	3 (42.9%)
No reliable change	1 (25%)	2 (40%)	2 (33.3%)	1 (25%)	4 (80%)	6 (85.7%)	1 (25%)	4 (80%)	4 (57.1%)	4 (100%)	6 (100%)	4 (57.1%)
Reliable deterioration	1 (25%)	1 (20%)	1 (16.7%)	1 (25%)	0 (0%)	0 (0%)	1 (25%)	0 (0%)	2 (28.6%)	0 (0%)	0 (0%)	0 (0%)
12 week follow-up												
Reliably improved	3 (100%)	2 (66.7%)	2 (40%)	1 (33.3%)	1 (33.3%)	1 (25%)	1 (33.3%)	1 (33.3%)	2 (50%)	0 (0%)	1 (25%)	3 (60%)
No reliable change	0 (0%)	0 (0%)	3 (60%)	2 (66.7%)	2 (66.7%)	3 (75%)	2 (66.7%)	2 (66.7%)	2 (50%)	3 (100%)	3 (75%)	2 (40%)
Reliable deterioration	0 (0%)	1 (33.3%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

Parents' sense of competence

Changes in parents' feelings about themselves as parents (PSOC-Satisfaction¹⁰⁰) and their perceived efficacy as a parent (PSOC-Efficacy¹⁰¹) were explored (Table 14.6 and Figure 14.6).

Immediately post-intervention, the greatest increase in feelings of parental satisfaction are seen amongst those parents who received home visits from the specialist health visitor or were supported by a SEN/Disability Link Worker (Intervention F). Improvements were even greater at 12 week follow-up for those receiving the home visits from the specialist health visitor, but dropped off (remaining an improvement) for parents receiving support from the SEN/ Disability Link Worker. In contrast, the greatest increases in parental efficacy are seen amongst parents receiving telephone support or support from a SEN/ Disability Link Worker, post intervention. By 12 week follow-up, this improvement has been lost by those parents receiving telephone support, whilst the mean scores of those who received home visits from the specialist health visitor have now increased.

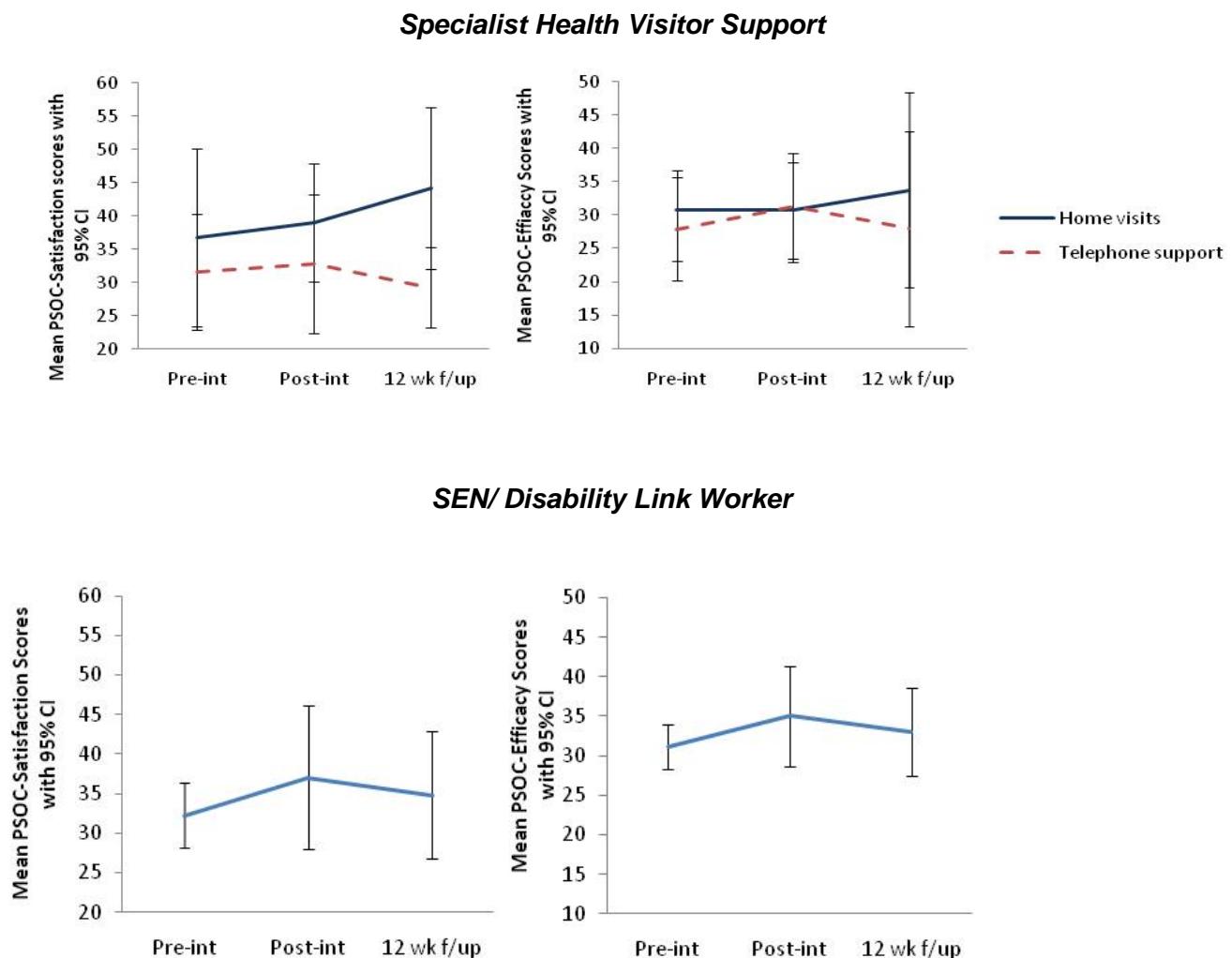
Table 14.6 Parents' sense of competence: Pre-intervention to 12 week follow-up

		Pre-intervention			Post-intervention			12 week f/up		
		N	M	SD	N	M	SD	N	M	SD
PSOC-Satisfaction	SHV – Home visits	5	36.80	10.71	6	39.0	8.50	4	44.25	7.63
	SHV – Telephone support	7	31.57	9.43	6	32.83	9.97	4	29.25	3.77
	SEN/ Disability Link Worker	10	32.20	5.73	6	37	8.63	5	34.80	6.46
PSOC-Efficacy	SHV – Home visits	5	30.80	4.82	6	30.83	6.68	4	33.75	9.18
	SHV – Telephone support	7	27.86	8.38	6	31.33	7.53	4	28.00	9.20
	SEN/ Disability Link Worker	11	31.18	4.21	5	35.0	5.05	5	33.0	4.47

¹⁰⁰ The Satisfaction subscale of the Parenting Sense of Competence Scale (PSOC) is an affective dimension, measuring the extent to which parents are satisfied with their role as a parent, capturing parental frustration, anxiety and motivation.

¹⁰¹ The Efficacy subscale of the PSOC measures the extent to which parents feel they are managing the role of being a parent, it captures parents' perceptions of their competence, problem solving ability and capability in the parenting role.

Figure 14.6 Mean PSOC-Satisfaction and PSOC-Efficacy Scores: Pre-intervention – 12 week follow-up



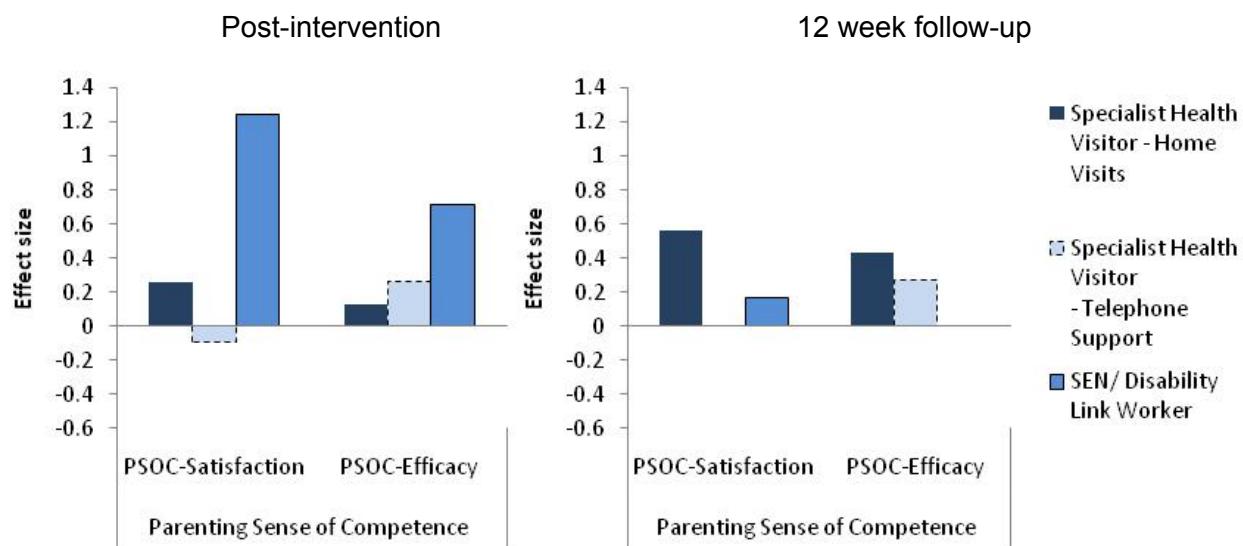
Clinically significant change in parents' sense of competence

Effect size statistics for the changes in scores on the measure of Parenting Sense of Competence are shown in Table 14.7.

Consistent with the means displayed in Table 14.6, effect sizes were largest for those receiving home visits from a Specialist Health Visitor or support from a SEN/ Disability Link Worker for the PSOC Satisfaction Subscale, and for telephone support and support from the SEN/Disability Link Worker for the Efficacy Subscale. Immediately post-intervention, effect sizes are particularly large for those who received support from the SEN/ Disability Link Worker but these effects were not maintained. By 12 week follow-up, effect sizes were largest on both subscales for parents receiving home visits from the Specialist Health Visitor (see Figure 14.7).

Table 14.7 Effect sizes for changes in scores on the Parents' Sense of Competence measure

	Effect sizes from pre-intervention		
		Post-intervention	12 weeks post-intervention
PSOC-Satisfaction	SHV – Home visits	.26	.56
	SHV – Telephone support	-.09	0
	SEN/ Disability Link Worker	1.24	.17
PSOC-Efficacy	SHV – Home visits	.13	.43
	SHV – Telephone support	.26	.27
	SEN/ Disability Link Worker	.71	0

Figure 14.7 Effect sizes for changes in scores on the PSOC-Satisfaction and PSOC-Efficacy subscales

The proportion of parents reporting improvements in their sense of parenting competence

Once again, reliable change statistics were used to present the proportion of parents where 'true' changes in parents' sense of efficacy as parents and their satisfaction with the parenting role competence were observed, see Table 14.8.

Immediately post-intervention, the greatest proportion of parents showing reliable improvement were those who had received support from the EYSW (Intervention F). By 12 week follow-up there was no reliable improvement apart from one parent who had received home visits from the SHV who improved on the Efficacy subscale.

Table 14.8 The proportion of parents improved parenting sense of competence: Reliable Change statistics

	PSOC-Satisfaction			PSOC-Efficacy		
	Arm of trial			Arm of trial		
	SHV-HV	SHV-TS	SEN/DLW	SHV-HV	SHV-TS	SEN/DLW
Post-intervention						
Reliably improved	1 (20%)	0 (%)	3 (50%)	0 (%)	0 (%)	2 (40%)
No reliable change	4 (80%)	6 (100%)	3 (50%)	5 (100%)	6 (100%)	2 (40%)
Reliable deterioration	0 (%)	0 (%)	0 (%)	0 (%)	0 (%)	1 (20%)
12 week follow-up						
Reliably improved	1 (25%)	0 (%)	0 (%)	0 (%)	0 (%)	0 (%)
No reliable change	3 (75%)	4 (100%)	4 (100%)	4 (100%)	4 (100%)	3 (75%)
Reliable deterioration	0 (%)	0 (%)	0 (%)	0 (%)	0 (%)	1 (25%)

14.3 Costs

This section presents the costs data. The small sample sizes achieved during our investigations into these two individually-delivered sleep management interventions means that analysis at a group level on the impact of the child's sleep problems on parents; and their and their children's use of services which relate to the presence of sleep difficulties cannot be carried out. However, we are able to report data on the costs of each delivery of the interventions included in this study. We also present "costed case studies" which illustrate the impact, at an individual case level, of the intervention on parent and child outcomes and, where relevant, use of other services.

Intervention E: specialist health visitor led sleep intervention

This intervention was delivered by a specialist health visitor (SHV) working from a Child Development Centre. The costs of delivering this intervention have been calculated from

time spent by the SHV on pre- and post-intervention activities, contact time with parents, travel for home visits and secretarial support (2 hours each week).

In the *home visit intervention* group, parents received between two and five home visits, and four of the six parents in the study received one or two telephone calls, and one parent saw the health visitor at the Child Development Centre. On average, health visitors spent just over three hours in contact each parent. Costs per person for the intervention ranged from £159 to £521 over a six week period and the mean cost was £290. Although on average participants received more contact hours than for the telephone intervention (see below), the time spent travelling to the parent's home accounts for much of this increased cost

Parents receiving the *telephone support* as they implemented their child's sleep strategy had between three and six contacts with the specialist health visitor. Although predominately by telephone call, for five of the eight parents one of these contacts was a home visit and a further two parents two had been visited two or three times. On average, the specialist health visitor spent just over two hours with each parent. Costs per person for the intervention ranged from £79 to £293. The mean cost/intervention was £166 over a six week period.

Illustrations of the impact of this intervention on service use are provided in the following two 'costed case studies' of Sam (home visit support) (Figure 14.8a) and Alex (telephone support) (Figure 14.8b).

Intervention F: sleep support delivered by trained practitioners in Children's Centres

This one-to-one intervention for families with a pre-school child with sleep problems is provided by specially trained Early Years Workers though local Children's Centre or home visits.

We have no information on the way study participants used this intervention but a broad description suggests the following input from an Early Years Worker for each parent: 30 minutes to contact and recruit parents; 3 hours spent in planning the sessions and debriefing, and 9.5 hours delivering the intervention over the recommended six to eight sessions.

Assuming the Early Years Worker is paid under the same conditions as a NHS Agenda for Change Band 2 clinical support worker (median basic salary of £14,800 per annum) *the cost for the intervention* is £195. To provide a higher estimate, if their working conditions were equivalent to a Band 5 nurse (median basic salary of £24,000) the cost for the intervention would be £325.

An illustration of the impact of this intervention on service use is provided in a 'costed case study' of Connor (Figure 14.8c).

Figure 14.8a Intervention E “costed case study” (a) specialist health visitor led intervention with home visit support during sleep strategy implementation

Before the intervention

Sam is an only child of about two years old who has cerebral palsy and sight impairment but his sleep difficulties did not stem from these health problems. His parents' goal was for Sam to stay in his bed, or go back to bed if he woke at night. Prior to the intervention, his mother was on long-term sick leave but did not feel the child's problems affected her health or her ability to do her usual activities.

Supports

Sam is too young to attend nursery school and prior to the intervention he had support for his health problems from various health professionals, including admissions to hospital. His parents discussed his sleep problems with the health visitor just once. In the three months preceding the follow-up interview, Sam had less contact with the hospital services but the GP remained an important source of support (3 contacts) as did the speech and language therapist and occupational therapist.

Services and costs three months prior to interview

Support	Pre-intervention		Follow-up interview	
	No. contacts	£ cost	No. contacts	£ cost
Inpatient	5 admissions	£4665	None	£0
A&E visit	1 contact	£76	None	£0
Outpatient/ Specialist Dr	2 contacts	£298	None	£0
GP	5 contacts	£160	3 contacts	£96
Prescriptions	1	£39	2	£78
Health visitor (30 minutes)	1 contact	£44	None	£0
S&L therapy (60 minutes)	None	£0	2 contacts	£74
Occupational therapy (60 minutes)	8 contacts	£296	2 contacts	£74
Total		£5578		£322

Intervention

Both parents were present for the home visits. They found the initial assessment “personal to the family, not just something from a book” and the sleep diary helped them plan ways to change bedtime routines and then to see improvements in his sleep patterns over time. The intervention support was very focused on sleep and they had five home visits and one telephone contact at a cost of £227. The home visits were welcomed and the parents felt it helped keep them going, and not revert to earlier ways when discouraged or tired. Both parents liked the personal one-to-one support and that the practitioner talked through different strategies but let them decide which one to use, advising modest steps. However, Mother felt that if she'd been part of a group she might have felt less like the only parent in this situation.

Outcomes

At the interview eight weeks after the sleep intervention, Mother reported that Sam went to bed at 9pm (rather than midnight) and that his sleep had definitely improved; their goals had been achieved. Both parents felt confident at the end of the intervention. At the end of the intervention the practitioner gave them some leaflets with tips for good sleeping and said they could always give her a ring for further support. With child now settling to bed earlier, the parents had time together in the evening to relax and watch TV, and could also get more sleep themselves.

At the research follow-up, Mother reported that she was now self-employed as a part-time cake maker and decorator and that the child's problems had no impact on her health or ability to do usual activities. The parents had established a successful bedtime routine and kept to it consistently.

Figure 14.8b Intervention E “costed case study” (b) specialist health visitor led intervention with telephone support during sleep strategy implementation

Before the intervention

Alex is four years old. He has no formal diagnosis but has difficulties with communication and social interaction and shows some obsessive behaviour. Mother is the primary homemaker but reported that Alex's sleep problems had no impact on her health and did not stop her doing her usual activities for noticeable amounts of time. Mother lives with her partner who was present for one or two of the home visits but generally it was the Mother doing the sleep-related work with child. Her goal was to put in place some 'calm time' before putting Alex to bed.

Supports

Alex and his parents received little by way of additional supports prior to the intervention. They had seen a specialist doctor once, and the health visitor twice for general health matters. The family has a key worker who visited three times in the three months prior to interview. The cost of this support package is £288. Alex spends four days a week at nursery/preschool (£132 per week).

Intervention

Although Alex's parents were allocated to the telephone support service, two of their four contacts with the specialist health visitors were at their home.

The practitioner suggested ways of creating a non-stimulating environment for Alex's bedroom and modifying the bedtime routine to help calm him, making him ready for bed. This included explaining the routine simply and a bedtime story. The sleep diary was very useful as the parents could see that the approach was working. The total cost of the intervention, including non-contact time and travel, was £234.

Outcome

At the interview some nine weeks after the intervention, Mother reported that it was important to have had the home visits as it would have been difficult to go through the sleep diary over the telephone. Otherwise, home visits and telephone calls were "both as good as each other". It was helpful to know that she could telephone the practitioner at any time with any concerns, and that the practitioner would telephone to see how they were doing and

could visit at home if necessary. The parents' evenings and nights were better with the improved bed-time routine and the intervention also brought wider benefits; Alex was calmer during the day and concentrated better. Mother felt fine when the sessions finished. Generally Alex settles to sleep more quickly but he has just started coming downstairs after bedtime. It may be that when he goes to school he will use more energy (thus sleep more) but Mother has the practitioner's telephone number and will contact her again if this pattern does not resolve itself.

Figure 14.8c Intervention F “costed case study”: individual sleep support delivered by trained practitioners based in Children’s Centres

Before the intervention

Connor is about a year old and lives with his parents. He has learning disabilities and complex health needs with a diagnosis that includes cerebral palsy and epilepsy. Prior to receiving the intervention, Connor's mother was on maternity leave but reported that his behaviour/sleep problems affected her usual activities every day. Her health was also affected, but she did not seek any help for this until after the intervention (one visit to her GP). Connor was only sleeping for about three hours at a time and would often wake up after an hour or so. Mother realised that the parents' lack of sleep was not 'doing them any good health-wise'. Her goal was to achieve a consistent bedtime for Connor and her partner was very supportive.

Supports

Prior to the intervention, specialist medical staff provided a lot of support for the family, focusing on Connor's health problems. Mother had spoken twice to the health visitor about Connor's sleep problems (see table below). By Time 3, additional supports had been put in place. The family had seen a key-worker and 12 days respite care per year had been allocated to them. Connor had also just started spending two afternoons a week at the Children's Centre.

Table NEYS Econs1 1 Services and costs three months prior to interview

Support	Pre-intervention		Follow-up interview	
	No. contacts	£ cost	No. contacts	£ cost
Inpatient	2 admissions	£1866	None	£0
A&E visit	2 visits	£152	None	£0
Outpatient/ Specialist Dr	15 visits	£2235	14 visits	£2086
GP	3 visits	£96	None	£0
Prescriptions	3 times	£117	Yes (est. 1)	£39
Health visitor (30 minutes)	4 visits	£176	3 visits	£132
S&L therapy (60 minutes)	2 visits	£74	5 visits	£185
Occupational therapy (60 minutes)	1 visit	£37	1 visit	£37
Key worker (30 minutes)	None	£0	1 visit	£17
Alternative therapy	3 visits	£123	None	£0
Total		£4876		£2496

Intervention

The home visit from the Sleep Clinic practitioner assured Mother that Connor's bedroom was appropriate and the sleep diary helped Mother notice patterns where the bedtime routine could be improved. At a cost of around £195, Mother saw the sleep practitioner once at the Children's Centre and four or five times at home. Connor's health appointments meant the intervention's flexible approach was very helpful. Part-way through the intervention it was discovered that some of Connor's physical health problems may have been the cause of his night-waking.

Outcomes

Mother felt the intervention was about the right length and intensity and that it gave her a lot of support as well as addressing Connor's sleeping problems. The combination of the new bedtime routine, an operation to relieve some of Connor's physical problems, and a short-term prescription for sedatives all helped to ensure Mother's goal was achieved; Connor fell asleep by himself and slept through the night. Five weeks after the intervention, Mother already felt less exhausted and thought Connor was sleeping well. She was pleased that this was happening naturally, without the aid of medication. She was aiming to move Connor's bedtime to about 8pm (currently 10pm). Mother was told she could contact the sleep clinic if she needed any more help: "I think ... I felt better in myself, and obviously that's reflected on him". At the follow-up interview Mother reported that there were just 10 days in the previous three months in which her usual activities were adversely affected by Connor's sleep patterns.

14.3 Summary of the findings

- Progress in attaining goals for improved sleep behaviour and standardised measures of parent-report sleep behaviour and parents' sense of competence were used to assess the effectiveness of the intervention. Due to the few parents for whom data is available for receiving each of the different types of intervention, it is not possible to compare between the different deliveries in any way.
- Before the parents started to work on their child's sleep problems parents identified up to three sleep-related goals. These were shown to improve across all three forms of delivery.
- On the whole changes in scores post-intervention and at follow-up were in a positive direction. Sometimes it would appear to take a while for improvements to be made, or there may be initial improvement and then some relapse.
- For Intervention E, there were differences in costs/intervention according to whether or not the parent was (pre-dominantly) supported through home visits or phone calls during the sleep strategy intervention period. Mean costs of an intervention with home visit support was £290 compared to £165 when telephone calls were used to support parents.
- The estimated cost of each delivery of Intervention F, delivered by specially trained early years workers based in Children's Centre, was £195.

Conclusions

- This investigation was an exploratory piece of work. Because sample sizes are so small it is not possible to attribute any differences between the groups to the different types of delivery. Importantly, it is not possible to ascribe observed changes in parent and child outcomes to the intervention and only tentative and limited conclusions can be drawn.

- As change across each of the different deliveries of sleep support was positive, this in itself suggests that these interventions may be effective in helping some parents with their child's sleep problem. Telephone support needs to be investigated further as a possible economic and time saving alternative for home visits for parents needing sleep support for their disabled child.

Chapter 15

Intervention G: A Group-Based Sleep Management Programme

In this chapter we report findings from an exploratory study investigating a novel group-based sleep management programme for parents of children who had learning disabilities or autism and were experiencing sleep difficulties.

Main findings

- This was an exploratory study. No comparator group was available for this investigation and this is reflected in the way the findings have been interpreted.
- Changes in scores on outcome measures and levels of attainment of parent-set goals suggest that this is a promising intervention, warranting further and more rigorous evaluation.
- There is no evidence suggesting this intervention is harmful in terms of child or parent outcomes.
- The mean cost of delivering the intervention was £1,700. The cost per person per session ranged from between £41 and £212.

15.1 Overview of the intervention

“Managing your Child’s Behaviour to Promote Better Sleep” Group	
Aims	To help parents manage their child’s sleep difficulties.
Target population	Parents of children with ASC and/or learning difficulties and/or sensory disabilities. Both parents are encouraged to attend.
Age range	3-18 years.
Structure & approach	<p>Group delivered intervention comprising 4 sessions delivered over a five week period (2 week break between sessions 3 and 4). Within this evaluation maximum group size=8.</p> <p>Manual sets out session structures, contains handouts and other teaching materials. Didactic teaching, sleep diaries, group discussion and learning activities are used. Sessions cover: identifying and analysing sleep problems and current sleep management strategies; communication; behavioural approaches to sleep management; developing individualised sleep strategy. In between sessions parents complete tasks/activities to reinforce learning and to analyse and evaluate sleep problems and sleep management strategies.</p>

15.2 Overview of the investigation

Design	Exploratory, before and after study. Outcomes measured at the start of the 12 and 24 weeks after attending the workshop. Outcome measures administered: pre-intervention; post-intervention; 12 weeks follow-up; 24 weeks follow-up (IG only). Rating of achievement towards parent-set goals: baseline (week 7 of programme; post intervention; 12 & 24 week follow-up).
Outcomes	<ul style="list-style-type: none"> Parent-set child sleep goal(s). Standardised measure of Parenting Sense of Competence (PSOC; Johnston and Mash, 1989) <ul style="list-style-type: none"> PSOC-Satisfaction subscale (satisfaction with the parenting role) PSOC-Efficacy subscale (feeling of efficacy as a parent) Standardised measures of sleep problems (Children's Sleep Habits Questionnaire (CHSQ), (Owens, 2000) <ul style="list-style-type: none"> Total Sleep Disturbance Score Bedtime Resistance subscale Sleep Anxiety subscale Night Wakings subscale
Sample	
Children	n=22
Age of child (<i>Mean (SD)</i>)	8.91 yrs (3.25)
Male (%)	11 (50%)
Description of child's additional needs	ASC (with & without learning disabilities) N=14 (63.6%), Learning disabilities N=6 (27.3%), physical or sensory disability N=1 (4.5%), No diagnosis N=1 (4.5%)
Parents	n=23
Mother (%)	20 (87%)
Two parent household (%)	22 (95.7%)
Higher Education (%)	8 (34.8%)
White British (%)	22 (95.7%)
Response rates:	70% (post-intervention); 65% (12 wk f-up); 78% (24 wk f-up).
Intervention integrity	100%

15.3 The evidence of effectiveness

Parent-set sleep goals

During the first session of the programme parents¹⁰² set up to three sleep-related goals for their child. Goals typically focussed on getting the child to go to bed without tantrums, settling without needing a parent to stay, and self-settling if awoken during the night. For example, 'To go to sleep within one hour of going to bed', 'To stay asleep in his own bed all night'. Mean goal attainment ratings¹⁰³ improved significantly¹⁰⁴ following the intervention see Table 15.1.¹⁰⁵

Table 15.1 Mean goal attainment rating: Pre-intervention – 24 weeks follow-up

Pre-Intervention			Post-intervention			12 week follow-up			24 week follow-up			Repeated Measures ANCOVA
N	M	SD	N	M	SD	N	M	SD	N	M	SD	
30	2.10	1.16	22	5.0	1.83	21	4.90	2.39	26	5.35	2.842	$F(3)=31.920$, $p<.001$

N=number of goal scores available; M=mean goal attainment rating; SD=standard deviation.

Further analysis revealed that the mean goal attainment rating had significantly improved at each measurement point compared to the pre-intervention rating¹⁰⁶, see Figure 15.2.

Looking now at the direction of change for each parent-set sleep goal, immediately post-intervention, attainment ratings had improved¹⁰⁷ for all but one goal, see Table 15.2. At 24 weeks post-intervention, an improvement in goal attainment rating was found for over three quarters of the goals compared to pre-intervention ratings. None of the goal attainment ratings were lower at this time point compared to pre-intervention ratings. The goal ratings that either did not change or deteriorated between 12 and 24 week follow-up had been set by two parents wanting to work on getting their child to settle down more easily at bedtime and not need the parent there whilst they went to sleep: these were typical of the goals set.

¹⁰² For these analyses, sleep goals collected from fathers who had accompanied mothers were excluded so that the same goals for a child were not double counted.

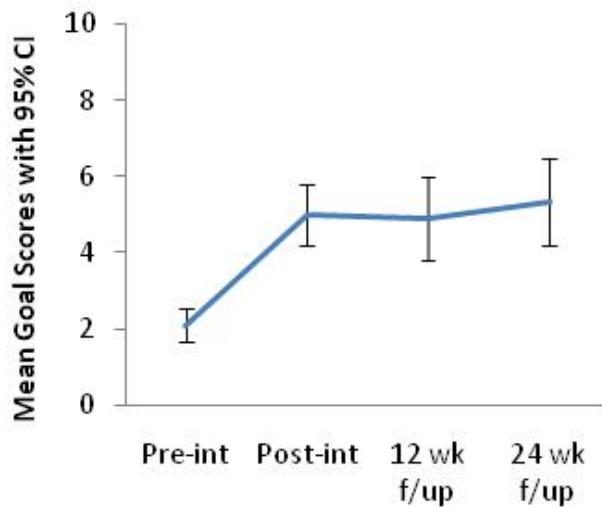
¹⁰³ A 10 point rating scale was used to indicate the extent to which a goal has been achieved: 1=very far from this goal; 10=I have achieved my goal.

¹⁰⁴ The parent's ID code was entered as a between-subjects factor into the ANOVA as some parents had given more than one goal.

¹⁰⁵ Descriptive data in this chapter makes use of all the data we have available. Statistical tests however will only use data where there is a complete set e.g. data available from a person at each time point.

¹⁰⁶ Post-intervention: $F(1)=73.219$, $p<.001$, 12 week follow-up: $F(1)=61.232$, $p<.001$, 24 week follow-up: $F(1)=37.9471$, $p<.001$. Bonferroni adjustments were carried out for multiple comparisons. Further contrasts (post-intervention-12 week follow-up, post-intervention- 24 week follow-up and 12 and 24 week follow-up) were not significant.

¹⁰⁷ Improvement/Deterioration based on whether the goal scores have moved 1+ scores in a positive or negative direction.

Figure 15.3 Mean goal attainment ratings: Pre-intervention – 24 week follow-up**Table 15.2 Direction of change for parents who set sleep goals for their child**

Change in goal attainment rating	Time period		
	Pre-intervention to post-intervention (n=15 goals)	Pre-intervention to 12 weeks follow-up (n=15 goals)	Pre-intervention to 24 weeks follow-up (n=18 goals)
Improved	14 (93%)	13 (87%)	14 (78%)
No change	1 (7%)	0	4 (22%)
Deteriorated	0	2 (13%)	0

Parent-reported sleep problems

Changes in parent-reported sleep problems

Mean Total Sleep Disturbance Scores on the Child Sleep Habits Questionnaire (CSHQ) were lower at post-intervention and at 12 weeks post-intervention, however the extent of this improvement had deteriorated by 24 week follow-up. A similar pattern of change in scores on the Bedtime Resistance¹⁰⁸ and Sleep Anxiety¹⁰⁹ sub-scales were also observed. None of these changes were statistically significant (see Table 15.3 and Figure 15.3).

A significant decrease in scores on the Night Waking¹¹⁰ subscale was observed. Overall, scores on this subscale decreased (i.e. improved) at each time point. However, it was the

¹⁰⁸ Examples of items on the Bedtime Resistance subscale are: “Goes to bed at same time” (reverse score); “Falls asleep in other’s bed”.

¹⁰⁹ Examples of items on Sleep Anxiety subscale are: “Needs parent in room to sleep”; “Afraid of sleeping alone.”

¹¹⁰ Examples of items on the Night Waking subscale are: “Moves to other’s bed in night”; “Awakes more than once during night”.

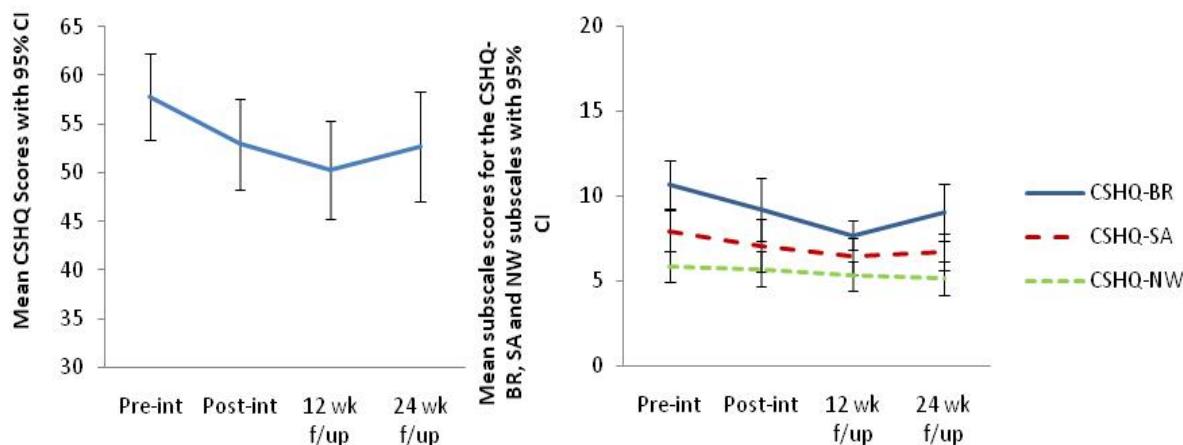
difference between scores immediately after completion of the programme and 24 weeks post-intervention which reached statistical significance.¹¹¹

Table 15.3 Sleep Outcomes

CSHQ Scales	Pre-intervention			Post-intervention			12 week f/up			24 week f/up			Repeated Measures ANOVA
	N	M	SD	N	M	SD	N	M	SD	N	M	SD	
Total Sleep Disturbance	21	57.86	9.76	14	51.79	8.91	14	50.29	8.78	16	52.75	10.57	$F(3)=1.566, p=.216$
Bedtime Resistance	20	10.65	3.07	14	9.21	3.29	13	7.69	1.44	16	9.06	3.17	$F(3)=1.717, p=.185$
Sleep Anxiety	20	7.95	2.52	13	7.08	2.60	13	6.46	1.81	15	6.73	1.94	$F(3)=.141, p=.935$
Night Wakings	20	5.85	1.90	14	5.69	1.70	14	5.29	1.43	15	5.13	1.77	$F(1.871) =5.143, , p<.05^G$

G-Greenhouse-Geisser adjustment as ANOVA violated assumption of sphericity

¹¹¹ Paired t-tests explored this significant effect. After carrying out a Bonferroni adjustment for multiple comparisons (p value set at p<.01) Post-intervention – 24 week follow-up were the only pair that remained significant: $T(12)=3.282, p<.01$. This was because there was a deterioration in scores post-intervention for the data included in the analysis. For this reason it would be incorrect to interpret the significant finding as suggesting that there was a greater effect on the Night Wakings scale than the other subscales.

Figure 15.4 Mean Total Sleep Disturbance and Subscale Scores: Pre-intervention – 24 week follow-up***The size and direction of change in parent-reported sleep problems***

Effect size statistics¹¹² explored the size (and direction) of changes in parent-reported sleep problems across the study period, see Table 15.4.

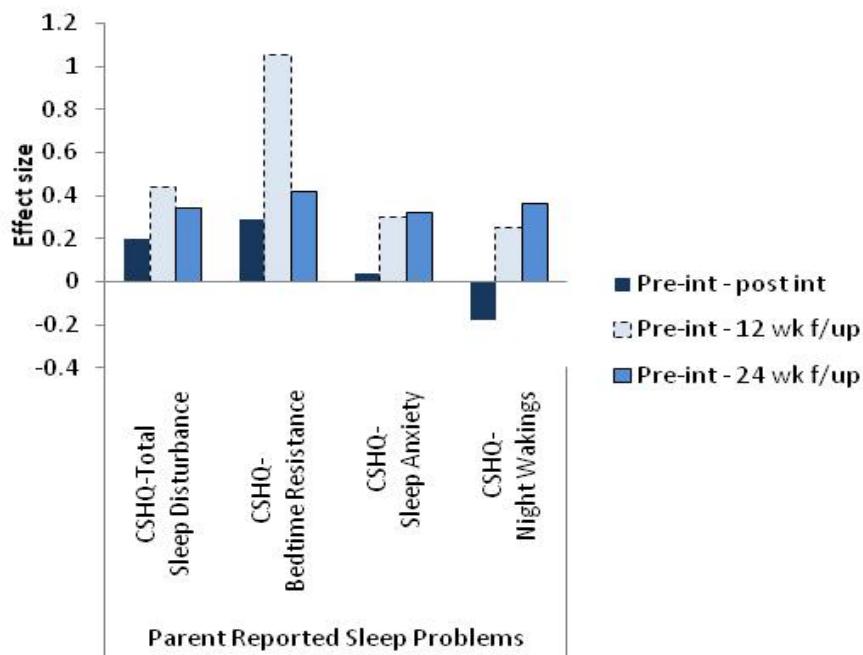
Table 15.4 Effect sizes for changes in scores on sleep problem measure (CSHQ)

	Effect Sizes from Pre-intervention		
	Post-intervention	12 weeks post-intervention	24 weeks post-intervention
Total Sleep Disturbance	.20	.44	.34
Bedtime Resistance	.29	1.05	.42
Sleep Anxiety	.04	.30	.32
Night Wakings	-.18	.25	.36

Effect sizes for Total Sleep Disturbance Scores remain small-medium at each data collection point (see Table 15.4 and Figure 15.4). Looking across the data collection points (Figure 15.4) it can be seen that the largest effect size is consistently for the Bedtime Resistance subscale. In contrast the Night Wakings scale has the weakest effect sizes at the first two data collection points; however it does steadily increase at each follow-up point. Likewise, the effect on the Sleep Anxiety subscale is small initially, but increases over time.

¹¹² The effect size statistic quantifies the difference between two sets of data or between two groups. 0.2 is defined as a 'small' effect size, 0.5 as a 'medium' effect size, and 0.8 as 'large' effect size. Effect sizes are reported by the abbreviation: d^2 . In this study effect sizes were calculated within each sample (e.g. those who had attended a parent group) the effect size between two time – points being calculated. Effect size is calculated by dividing the difference between the means by the pooled standard deviation (Cohen's $d = (MT1 - MTx)/SD$).

Figure 15.5 Effect sizes for changes in scores on the Child Sleep Habits Questionnaire



The proportion of children with improved sleep

Sleep outcome scores for each child were then examined in order to determine whether any changes in scores could be regarded as 'true' changes, as opposed to spurious changes caused by inadequacies in the measure being used. The statistic used is known as the Reliable Change Index.¹¹³ This is an important indicator of the clinical, as opposed to statistical, significance of any observed changes associated with an intervention.

Table 15.5 sets out the proportion of children who, according to parent-report sleep outcomes, had experienced a reliable change in their sleep at post-intervention, and then at 12 and 24 week follow-up.

¹¹³ A reliable change was defined as those where a score of >1.96 on the Reliable Change Index was achieved (Hawley, 1995; Jacobson & Truax, 1991). The reliable change index (RCI) for each case was calculated by dividing the difference between the Time 1 and 2 scores by the standard error of measurement (SEmeas) [RCI = $Mt1 - Mt2/Sdiff$]. Sdiff will be obtained by calculating the square route of double the standard error squared ($Sdiff = \sqrt{2(SE)^2}$).

Table 15.5 The proportion of children with improved sleep at each time point: Reliable Change statistics

	Sleep problem area (measured by the CSHQ)			
	Total sleep disturbance	Bedtime Resistance	Sleep Anxiety	Night Wakings
Post intervention				
Reliably improved	3 (23.1%)	4 (33.3%)	1 (9.1%)	1 (7.1%)
No reliable change	8 (61.5%)	7 (58.3%)	9 (81.8%)	11 (78.6%)
Reliable deterioration	2 (15.4%)	1 (8.3%)	1 (9.1%)	2 (14.3%)
12 weeks follow-up				
Reliably improved	5 (38.5%)	7 (58.3%)	1 (16.7%)	3 (23.1%)
No reliable change	7 (53.8%)	5 (41.7%)	9 (75%)	10 (76.9%)
Reliable deterioration	1 (7.7%)	0	1 (8.3%)	0
24 weeks follow-up				
Reliably improved	5 (33.3%)	6 (42.9%)	4 (30.8%)	4 (28.6%)
No reliable change	9 (60%)	7 (50%)	8 (61.5%)	10 (71.4%)
Reliable deterioration	1 (6.7%)	1 (7.1%)	1 (7.7%)	0

At 12 weeks post-intervention, over a third of the children were classified as having reliably reduced levels of sleep disturbance (measured by the Total Sleep Disturbance Score). Over half of the children had reliably improved on the Bedtime Resistance subscale. There is a small reduction in these proportions at 24 week follow-up. The proportion of children reliably improved in terms of Sleep Anxiety (30.8%) and Night Wakings (28.6%) was greatest at 24 weeks follow-up. It is clear from Table 15.5 that improvements to the children's sleep occur, or continue to occur, post-intervention. These findings are consistent with those presented in Table 15.4 which showed that the Bedtime Resistance subscale was the fastest to show improvement, with improvements in sleep anxiety and night wakings occurring later.

Parents' sense of competence

Changes in parents' feelings about themselves as parents (PSOC-Satisfaction¹¹⁴) and their perceived efficacy as a parent (PSOC-Efficacy¹¹⁵) were explored. The difference in scores on the Efficacy subscale between pre-intervention and all post-intervention time points was statistically significant. The means and standard deviations are displayed in Table 15.6 and show that scores increased on the PSOC-Efficacy subscale at each consecutive time point.¹¹⁶ Statistically, improvements were maintained, but did not further increase, at each

¹¹⁴ The Satisfaction subscale (9 items) of the Parenting Sense of Competence Scale (PSOC) is an affective dimension, measuring the extent to which parents are satisfied with their role as a parent, capturing parental frustration, anxiety and motivation. Scores can range from 9-54.

¹¹⁵ The Efficacy subscale (7 items) of the PSOC measures the extent to which parents feel they are managing the role of being a parent. It captures parents' perceptions of their competence, problem-solving ability and capability in the parenting role. Scores can range from 7-42.

¹¹⁶ An increase in scores on the Parenting Sense of Competence Scale represents increased confidence.

subsequent measurement point (12 and 24 weeks post-intervention).¹¹⁷ Whilst scores on the Satisfaction subscale had also improved post-intervention, this was not statistically significant, see Table 15.6, and Figure 15.5.

Figure 15.6 Mean PSOC-Satisfaction and PSOC-Efficacy Scores: Pre-intervention – 24 week follow-up

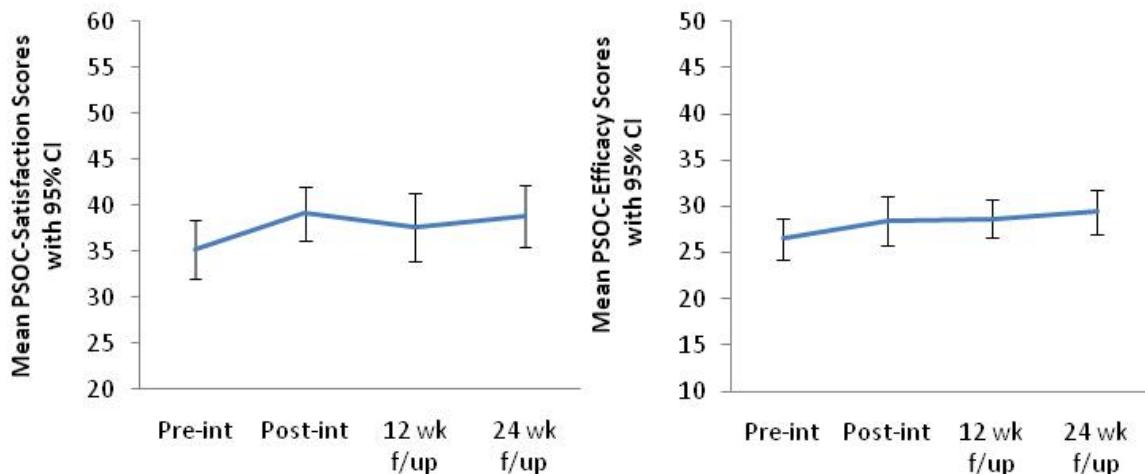


Table 15.6 Parents' sense of competence: Pre-intervention to 24 week follow-up

	Pre-intervention			Post-intervention			12 week f/up			24 week f/up			Repeated Measures ANOVA
	N	M	SD	N	M	SD	N	M	SD	N	M	SD	
PSOC-Satisfaction	22	35.18	7.13	15	39.13	5.22	15	37.67	6.72	18	38.78	6.76	$F(3)=2.075, p=.120$
PSOC-Efficacy	23	26.48	5.13	15	28.47	4.97	15	28.67	3.70	18	29.39	4.80	$F(3)=9.112, p<.001$

The scale of improvement in parents' sense of competence

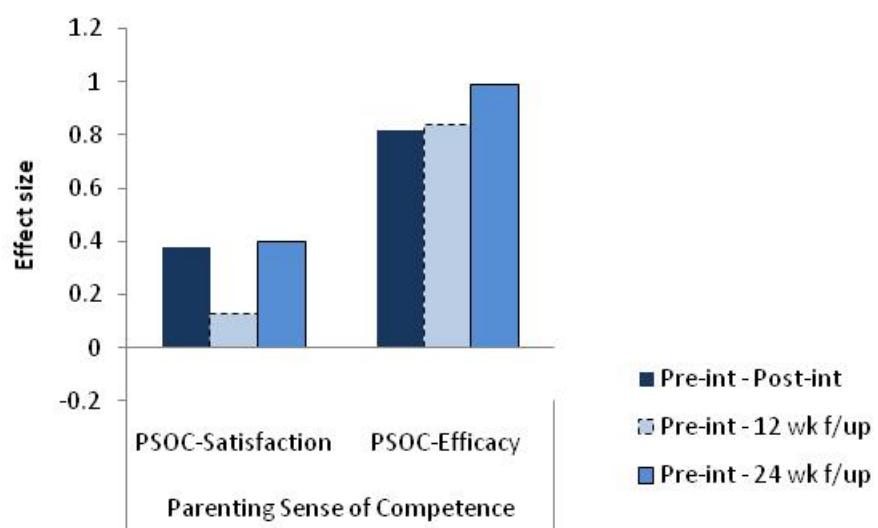
Effect size statistics for the changes in scores on measures of Parents' Sense of Competence are shown in Table 15.7.

¹¹⁷ A Bonferroni adjustment accounted for multiple comparisons.

Table 15.7 Effect sizes for changes in scores on the Parents' Sense of Competence measure

	Effect sizes from pre-intervention		
	Post-intervention	12 weeks post-intervention	24 weeks post-intervention
PSOC-Satisfaction	.38	.13	.40
PSOC-Efficacy	.82	.84	.99

The effect sizes for the parents' sense of efficacy are large and maintained to, at least, 24 weeks post-intervention. The size of improvement in parents' sense of satisfaction was smaller and more variable. Interestingly, the improved sense of satisfaction found immediately post-intervention was not found at 12 week follow-up ($d^2=0.13$), but was regained at 24 weeks follow-up ($d^2=0.4$, See Figure 15.6).

Figure 15.7 Effect sizes for changes in scores on the PSOC-Satisfaction and PSOC-Efficacy subscales

The proportion of parents reporting improvements in their sense of parenting competence

Once again, reliable change statistics were used to present the proportion of parents where 'true' changes in parents' sense of efficacy as parents and their satisfaction with the parenting role competence were observed, see Table 15.8.

Post-intervention, reliable improvement on the PSOC-Satisfaction scale was found for just under a third of parents (28.6%) whilst two-thirds of parents (66.7%) demonstrated reliable improvement for their feelings of parental efficacy. By 24 weeks post-intervention, over three-quarters of parents (75%) reported reliable improvement in their sense of parenting efficacy and the proportion of parents reporting reliable improvements in their feelings of parental satisfaction had increased to over 40 per cent.

Table 15.8 The proportion of parents improved parenting sense of competence: Reliable Change statistics

	Parenting Sense of Competency	
	Satisfaction	Efficacy
Post-intervention		
Reliably improved	4 (28.6%)	10 (66.7%)
No reliable change	9 (64.3%)	5 (33.3%)
Reliable deterioration	1 (7.1%)	0
12 weeks follow-up		
Reliably improved	4 (28.6%)	8 (53.3%)
No reliable change	9 (64.3%)	7 (46.7%)
Reliable deterioration	1 (7.1%)	0
24 weeks follow-up		
Reliably improved	7 (41.2%)	14 (77.8%)
No reliable change	9 (52.9%)	3 (16.7%)
Reliable deterioration	1 (5.9%)	1 (5.6%)

15.3 Costs

This section presents the costs data. The small sample size achieved during our investigation into sleep management interventions means that analysis at a group level on the impact of the child's sleep problems on parents; and their and their children's use of services which relate to the presence of sleep difficulties cannot be carried out. However, we are able to report data on the costs of each delivery of the intervention included in this study. We also present a "costed case study" to illustrate the impact, at an individual case level, of the intervention on parent and child outcomes and, where relevant, use of other services, see Figure 15.8.

The costs of delivering the intervention

This group-delivered intervention is facilitated by at least two CAMHS LD team members and up to four team members were present at the four courses that were included in the study. Staff time accounted for the main part of the cost, and this included time setting-up the group, planning the sessions and travelling, as well as delivering the intervention and debriefing.

The cost per session varied depending on the number, profession and the Agenda for Change salary band for each facilitator. The most expensive session cost £493 and the least expensive was £287. The variation in the number of participants at each session (between two and eight) means that the *cost per person per session* ranged from between £41 and £212. In terms of the *costs of delivering the intervention*, this ranged from £1,470 to £1,840 per intervention (mean = £1,700).

The *cost per person for the intervention* therefore also varied, depending on the number of facilitators (between two and four), the number of parents at each session, and the number of sessions each parent attended. Thus the mean cost for parents attending this course was £272, but the range was between £46 (just one session attended) and £641. This high cost figure being was for a parent who attended all four sessions of a programme led by three of four CALD team members and attended by only four participants.

Figure 15.8 Intervention G “costed case study”

Before the intervention

Rosie is 12 years old and lives with her parents. She has a diagnosis of Down's syndrome and metabolic condition. Mother attended the intervention as it was difficult for both parents to get away from work. Mother works part-time and although had not taken any time off work because of Rosie's sleep problems, she feels it has affected her health. She had not contacted anyone about these impacts however. The family get 36 days of short-breaks per year.

Supports

Rosie attends school five days a week, split between a mainstream primary school and a special school. She has a statement of special education needs and has not missed any school days or been excluded. She receives support for her health problems from the GP, specialist doctors and community nurse but also speech and language therapy and social worker support. By the Time 3 interview Rosie had moved to secondary school but still attended the special school part-time. We know she still received help for her health conditions but have fewer details about the level of support provided.

Services and costs three months prior to interview

Support	Pre-intervention		Follow-up interview	
	No. contacts	£ cost	No. contacts	£ cost
Outpatient/ Specialist Dr	3 contacts	£447	3 contacts	£447
GP	4 contacts	£128	9 contacts	£288
Prescriptions	None	£0	10	£390
Community nurse (30 minutes)	3 contacts	£135	Yes (est. 1)	£45
S&L therapy (60 minutes)	12 contacts	£444	Yes (est. 1)	£37
Social worker (30 minutes)	1 contact	£74	Yes (est. 1)	£74
CAMHS worker (30 minutes)	None	£0	Yes (est. 1)	£35
Total		£1228		£1316

Intervention

Mother had no specific goals for her daughter when starting the group intervention. She found she learnt from both facilitators and other group members: “you bounce ideas off each other and ... go away and try something else”. She de-cluttered Rosie's bedroom, and learnt new strategies to let Rosie know when it was bed-time and for when she wakes at night, such as encouraging Rosie to use a whiteboard to note things that were worrying her. In these ways, the intervention helped find strategies to get Rosie to look after herself by

identifying the problems and the reasons behind them.

On average, the four-session group intervention costs £270 per person to provide. At the end of the intervention Mother felt pretty confident that things would continue to improve despite every-day hiccups such as minor health problems and Rosie's concerns about her own health.

Outcome

By the Time 3 research interview, Mother was still working and felt that Rosie's sleep problems had still not affected work days or usual activities, and no longer affected her health. At the interview, some 22 weeks after the intervention, she said it had made her feel more confident and decisive in managing Rosie's behaviour. There were also wider benefits. She had made friends with other parents of children at the school and intends to attend the follow-up meeting.

15.4 Summary of the findings

- Progress in attaining goals for improved sleep behaviour and standardised measures of parent-report child sleep behaviour and parents' sense of competence were used to assess the effectiveness of the intervention. There was no comparator group to compare the outcomes which means that increased caution is needed when interpreting the findings.
- A significant improvement in goal attainment ratings was found at all time points post-intervention. Only two parents did not report an improvement in all their goals set.
- During the study period improvements were found on the Total Sleep Disturbance Score and Bedtime Resistance, Sleep Anxiety and Night Wakings subscales (as measured by the Children's Sleep Habits Questionnaire).
- Clinical significance indicators (effect size) suggest that the most significant improvements occurred with respect to improvements in bedtime resistance. Changes in sleep anxiety and night wakings were small or even negative initially, but grew steadily over time. This may represent initial resistance from the child when new sleep strategies are implemented and things 'getting worse before they get better'.
- The evidence regarding the impact on parents' sense of competence (measured by the Parenting Sense of Competency Scale) is also promising. Both subscales showed improvement post-intervention and the improvement in parents' sense of efficacy recorded post-intervention was statistically significant. This improvement was further illustrated as being clinically meaningful through large effect sizes which were maintained at 24 week follow-up. The majority of parents also showed reliable improvement on this subscale.
- The variation in the number of participants at each session (between two and eight) means that the cost per person per session ranged from between £41 and £212.
- The costs of delivering the intervention (4 sessions) ranged from £1,470 to £1,840 per intervention (mean = £1,700). A maximum of eight parents attended each delivery of the intervention.

Conclusions

- This investigation was an exploratory piece of work. No comparator group was available and the sample size was small. The quality of the evidence is, therefore, relatively weak. Importantly, it is not possible to ascribe observed changes in parent

and child outcomes to the intervention and only tentative and limited conclusions can be drawn.

- However, the investigation has yielded sufficient evidence to suggest that this sleep management programme appears to be a promising intervention in terms of improving children's sleep and parents' sense of competence. It should be subject to further evaluation. Any evaluation should include longer-term follow-up and a comparator group.

Chapter 16

Intervention H: A Sleep Management Workshop for Parents of Disabled Children

In this chapter we report findings from an exploratory study investigating the effectiveness of a one day workshop for parents with children aged 2-19, who have additional needs and are experiencing difficulties with their sleep.

Main findings

- This was an exploratory study; no control/comparator group was available. Interpretation of the findings in terms of effectiveness is therefore cautious and limited.
- At the beginning of the workshop parents identified up to three sleep-related goals. A significant improvement in goal attainment ratings was found at 12 and 24 week follow-up.
- Positive movements in scores on some, but not all, measures of sleep disturbance were recorded over the study period. Unlike other sleep management interventions we investigated, there is no evidence of the intervention having any lasting impact on parents' sense of competence.
- The costs of delivering a workshop were estimated at £612, with a cost per workshop participant of £46.30.

16.1 Overview of the intervention

Sleep Solutions 'Time2Sleep' Workshop	
Aims	To support families of children with sleep difficulties through raising awareness of good sleep practice and basic strategies to support parents in establishing new routines.
Target population	Parents of children with additional needs and practitioners. Other families may also attend if places are available.
Age range	2 to 19 years.
Structure & approach	<p>A single day workshop (~4.5 hours). Maximum number of participants=20. Manual sets out the structure and content of the workshop and contains handouts and other teaching materials. Predominantly didactic teaching with some group discussion/group-based learning activities.</p> <p>The workshop aims to cover many common sleep issues that children may face, the impact of sleep problems on the family, to increase background understanding of sleep and introduce simple cognitive behavioural therapy techniques to manage sleep problems. Participants receive a 'Delegate Resource Pack' of useful material.</p>

16.2 Overview of the investigation

Design	Exploratory, before and after study. Outcomes measured at the start of the workshop, and 12 and 24 weeks after attending the workshop. Outcome measures administered: pre-intervention; post-intervention; 12 weeks follow-up; 24 weeks follow-up (IG only). Rating of achievement towards parent-set goals: baseline (week 7 of programme; post intervention; 12 & 24 week follow-up).
Outcome s	<ul style="list-style-type: none"> Parent-set child sleep goal(s). Standardised measure of Parenting Sense of Competence (PSOC; Johnston and Mash, 1989) <ul style="list-style-type: none"> PSOC-Satisfaction subscale (satisfaction with the parenting role) PSOC-Efficacy subscale (feeling of efficacy as a parent) Standardised measures of sleep problems (Children's Sleep Habits Questionnaire (CHSQ), (Owens, 2000) <ul style="list-style-type: none"> Total Sleep Disturbance Score Bedtime Resistance subscale Sleep Anxiety subscale Night Wakings subscale
Sample	
Children	n=25
Age of child (<i>Mean (SD)</i>)	7 yrs (3.30)
Male (%)	16 (64%)
Description of child's additional needs	ASC (9, 36%), Learning disability (4, 16%), physical/sensory disability (4,16%) LD & PD/SD (3, 12%), ASC other (5, 20%)
Parents	n=26
Mother (%)	24 (92.3%)
Two parent household (%)	21 (80.8%)
Higher Education (%)	12 (46.2%)
White British (%)	25 (96.2%)
Response rates:	69% (12 wk f-up); 62% (24 wk f-up).
Intervention integrity	99%.

16.3 The evidence of effectiveness

Parent-set sleep goals

At the beginning of the workshop parents¹¹⁸ set up to three sleep-related goals for their child. For example 'self-settles within 30 minutes of going to bed, 50% of the time', 'For my son to be able to go to bed with no anxiety'. Mean goal attainment ratings¹¹⁹ improved significantly¹²⁰ following the intervention, see Table 16.1 ($F(2)=26.292$, $p<.001$).

Table 16.1 Mean goal attainment rating: Pre-intervention – 24 weeks follow-up

	Pre-intervention			12 week follow-up			24 week follow-up			ANOVA
	N	M	SD	N	M	SD	N	M	SD	
All main parents	51	2.47	1.50	36	5.19	2.92	36	5.92	2.72	$F(2)=26.292$ $p<.001$

N=number of goal scores available; M=mean goal attainment rating; SD=standard deviation.

Further analysis revealed that the mean goal attainment rating had significantly improved at each measurement point compared to the pre-intervention rating¹²¹ (see Figure 16.2). Comparisons carried out between follow-up time points showed that whilst improvement was maintained, no further significant improvements were made.¹²²

Looking now at the direction of change for each parent-set sleep goal. At 12 week follow-up attainment ratings had improved for 65 per cent of goals, see Table 16.2. By 24 weeks post-intervention, an improvement in goal attainment rating was found for over 85 per cent of the goals compared to pre-intervention ratings. Only two (3.4%) of the goal attainment ratings were lower at this time point compared to pre-intervention ratings. Improvements continued post-intervention with goal attainment ratings improving for nearly half of goals rated between 12 and 24 week follow-up.

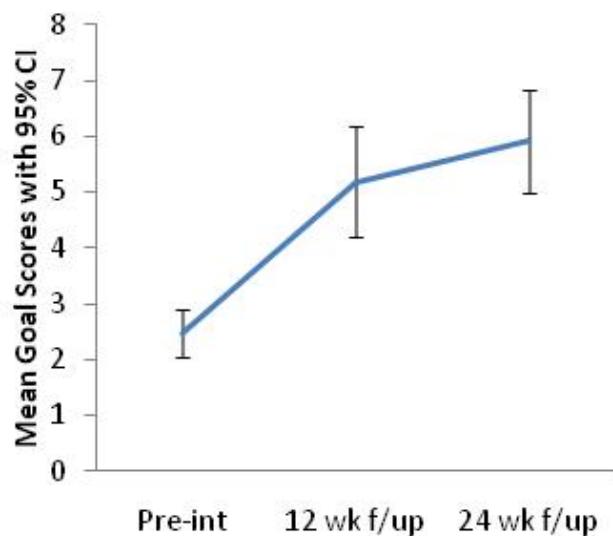
¹¹⁸ For these analyses, sleep goals collected from a father who had accompanied the mother were excluded so that the same goals for a child were not double counted.

¹¹⁹ A 10 point rating scale was used to indicate the extent to which a goal has been achieved: 1=very far from this goal; 10=I have achieved my goal.

¹²⁰ The parent's ID code was entered as a between-subjects factor into the ANOVA as some parents had given more than one goal.

¹²¹ 12 week follow-up: $F(1)=34.814$, $p<.001$, 24 week follow-up: $F(1)=78.225$, $p<.001$. Bonferroni adjustments were made for multiple comparisons.

¹²² 12 – 24 week follow-up: $F(1)=2.328$, $p=.147$.

Figure 16.3 Mean goal attainment ratings: Pre-intervention – 24 week follow-up**Table 16.2 Direction of change for parents who set sleep goals for their child**

	Pre-intervention - 12 week follow-up (n=31)	Pre-intervention – 24 week follow-up (n=30)	12-24 week follow-up (n=29)
Improved	20 (64.5%)	26 (86.7%)	14 (48.3%)
No change	6 (19.4%)	2 (6.7%)	10 (34.5%)
Deteriorated	5 (16.1%)	2 (6.7%)	5 (17.2%)

Parent-reported sleep problems

Changes in parent-reported sleep problems

Mean scores for the CSHQ Total Sleep Disturbance Score and the Bedtime Resistance¹²³ and Sleep Anxiety¹²⁴ subscales improved at 12 and 24 week follow-up. These changes were not statistically significant (See Table 16.3). As can be seen in Figure 16.3 movement for the Night Wakings¹²⁵ subscale is negligible.

¹²³ Examples of items on the Bedtime Resistance sub-scale are: “Goes to bed at same time” (reverse score); “Falls asleep in other’s bed”.

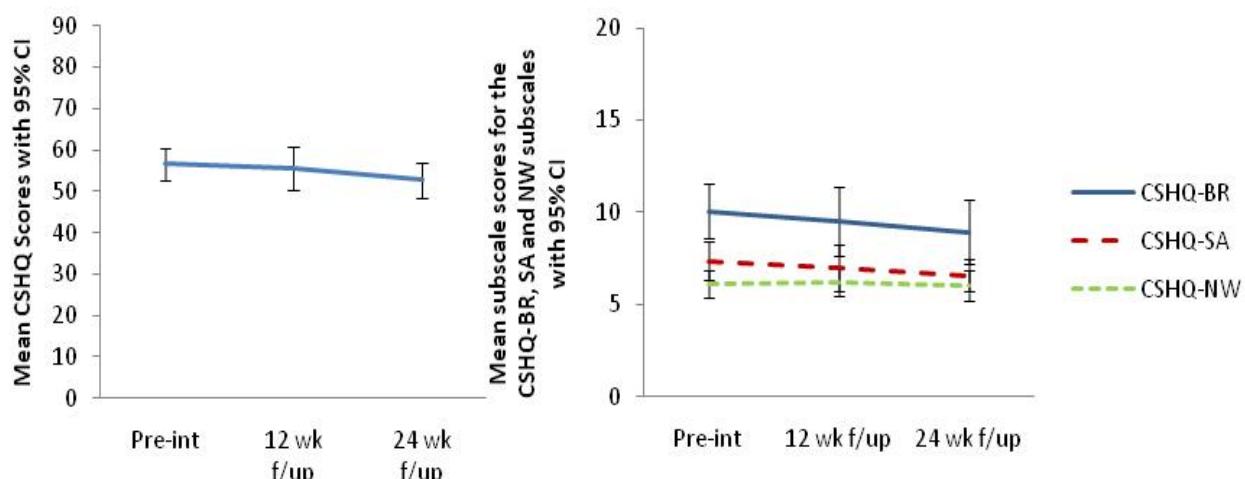
¹²⁴ Examples of items on Sleep Anxiety sub-scale are: “Needs parent in room to sleep”; “Afraid of sleeping alone.”

¹²⁵ Examples of items on the Night Wakings subscale are: “Moves to other’s bed in night”; “Awakes more than once during night”.

Table 16.3 Sleep outcomes

	Pre-intervention			12 week follow-up			24 week follow-up			Repeated Measures ANOVA
	N	M	SD	N	M	SD	N	M	SD	
CSHQ	24	56.58	9.50	18	55.56	10.76	16	52.69	8.25	$F(2)=.634, p=.538$
SCHQ-BR	24	10.04	3.51	17	9.53	3.66	15	8.93	3.17	$F(1.30)=.940, p=.371^G$
SCHQ-SA	24	7.38	2.48	18	7.00	2.59	15	6.60	1.68	$F(2)=.606, p=.553$
CSHQ-NW	22	6.09	1.66	17	6.24	1.48	14	6.00	1.41	$F(2)=3.11, p=.063$

^G Greenhouse Geisser adjustment to account for violation of assumption of sphericity

Figure 16.4 Mean Total Sleep Disturbance and Subscale Scores: Pre-intervention – 24 week follow-up

The size and direction of change in parent-reported sleep problems

Effect size statistics¹²⁶ explored the size (and direction) of changes in parent-reported sleep problems across the study period, see Table 16.4.

The size and direction of change in parent-reported sleep problems

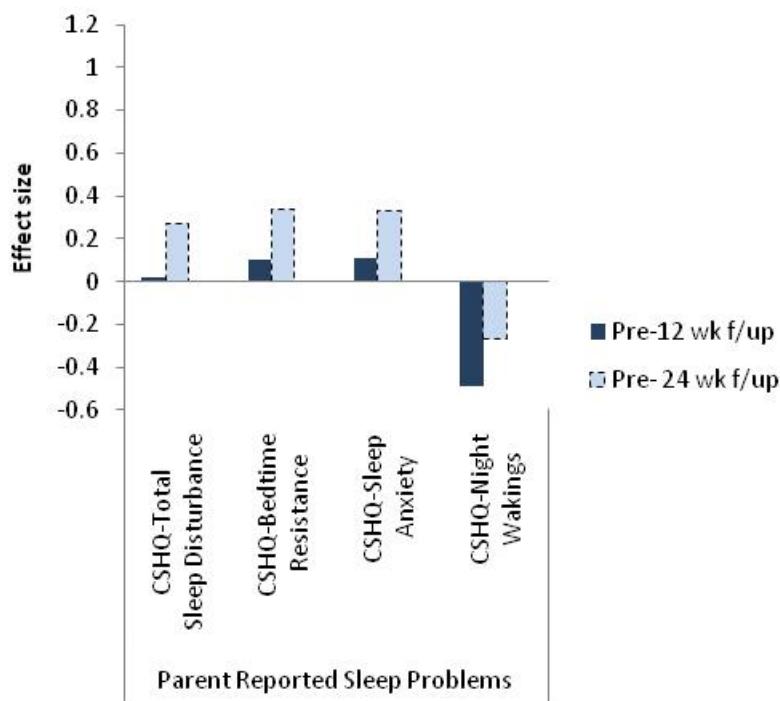
Effect size statistics¹²⁷ explored the size (and direction) of changes in parent-reported sleep problems across the study period, see Table 16.4.

¹²⁶ The effect size statistic quantifies the difference between two sets of data or between two groups. 0.2 is defined as a 'small' effect size, 0.5 as a 'medium' effect size, and 0.8 as 'large' effect size. Effect sizes are reported by the abbreviation: d^2 . In this study effect sizes were calculated within each sample (e.g. those who had attended a parent group) the effect size between two time – points being calculated. Effect size is calculated by dividing the difference between the means by the pooled standard deviation (Cohen's $d = (MT1 - MTx)/SD$).

Table 16.4 Effect sizes for changes in scores on sleep problem measure (CSHQ)

	Effect sizes from pre-intervention		
	12 weeks post-intervention		24 weeks post-intervention
Total Sleep Disturbance	0.02		0.27
Bedtime Resistance	0.10		0.34
Sleep Anxiety	0.11		0.33
Night Wakings	-.49		-.27

At 12 week follow-up effect sizes are very small, but positive for the Total Sleep Disturbance Scale, Bedtime Resistance Subscale and Sleep Anxiety Subscale (see Figure 16.4). By 24 week follow-up these increase to small-medium effect sizes. For night wakings there is a medium *negative* effect at 12 week follow-up which remains negative, although not as large at 24 week follow-up. It is not uncommon when implementing a new sleep programme that the parent will meet some resistance and things may get worse before they get better.

Figure 16.5 Effect sizes for changes in scores on the Total Sleep Disturbance Score and the Bedtime Resistance, Sleep Anxiety and Night Wakings subscales

¹²⁷ The effect size statistic quantifies the difference between two sets of data or between two groups. 0.2 is defined as a 'small' effect size, 0.5 as a 'medium' effect size, and 0.8 as 'large' effect size. Effect sizes are reported by the abbreviation: d^2 . In this study effect sizes were calculated within each sample (e.g. those who had attended a parent group) the effect size between two time – points being calculated. Effect size is calculated by dividing the difference between the means by the pooled standard deviation (Cohen's $d = (MT1 - MTx)/SD$).

The proportion of children with improved sleep

Sleep outcome scores for each child were then examined in order to determine whether any changes in scores could be regarded as 'true' changes, as opposed to spurious changes caused by inadequacies in the measure being used. The statistic used is known as the Reliable Change Index.¹²⁸ This is an important indicator of the clinical, as opposed to statistical, significance of any observed changes associated with an intervention.

Table 16.5 sets out the proportion of children who, according to parent-report sleep outcomes, had experienced a reliable change in their sleep at post-intervention, and then at 12 and 24 week follow-up.

**Table 16.5 The proportion of children with improved sleep at each time point:
Reliable Change statistics**

	Sleep problem area (measured by the CSHQ)			
	Total sleep disturbance	Bedtime Resistance	Sleep Anxiety	Night Wakings
12 weeks follow-up				
Reliably improved	3 (16.7%)	7 (41.2%)	4 (22.2%)	2 (13.3%)
No reliable change	10 (55.6%)	7 (41.2%)	10 (55.6%)	4 (26.7%)
Reliable deterioration	5 (27.8%)	3 (17.6%)	4 (22.2%)	9 (60%)
24 weeks follow-up				
Reliably improved	5 (31.3%)	8 (53.3%)	5 (33.3%)	2 (14.3%)
No reliable change	9 (56.3%)	6 (40%)	8 (53.3%)	5 (35.7%)
Reliable deterioration	2 (12.5%)	1 (6.7%)	2 (13.3%)	7 (50%)

Looking at specific types of sleep problem, the size proportion of parents showing reliable change differed. Whilst overall, less than a fifth of parents (n=3, 16.7%) had reliably improved on the Total Sleep Disturbance measure 12 weeks after attending the workshop, over forty percent (n=7) showed reliable improvement for the Bedtime Resistance Subscale. Conversely, only two parents (13%) showed reliable improvement with regards to Night Wakings, but nine (60%) showed reliable deterioration.

By 24 weeks after the workshop, there has been further improvement for both the Total Sleep Disturbance Scale and the Bedtime Resistance and Sleep Anxiety Subscales (See Table 16.5). Over half of parents are now reporting reliable improvement on the Bedtime Resistance Subscale and fewer are reporting Reliable Deterioration across the Total Score and three subscales. Again the picture is less positive for Night Wakings, with half of all parents still reporting reliable deterioration on this subscale.

¹²⁸ A reliable change was defined as those where a score of >1.96 on the Reliable Change Index was achieved (Hawley, 1995; Jacobson & Truax, 1991). The reliable change index (RCI) for each case was calculated by dividing the difference between the Time 1 and 2 scores by the standard error of measurement (SEmeas) [RCI = Mt1 – Mt2/Sdiff]. Sdiff will be obtained by calculating the square route of double the standard error squared (Sdiff = $\sqrt{2}(\text{SE})^2$).

Parents' sense of competence

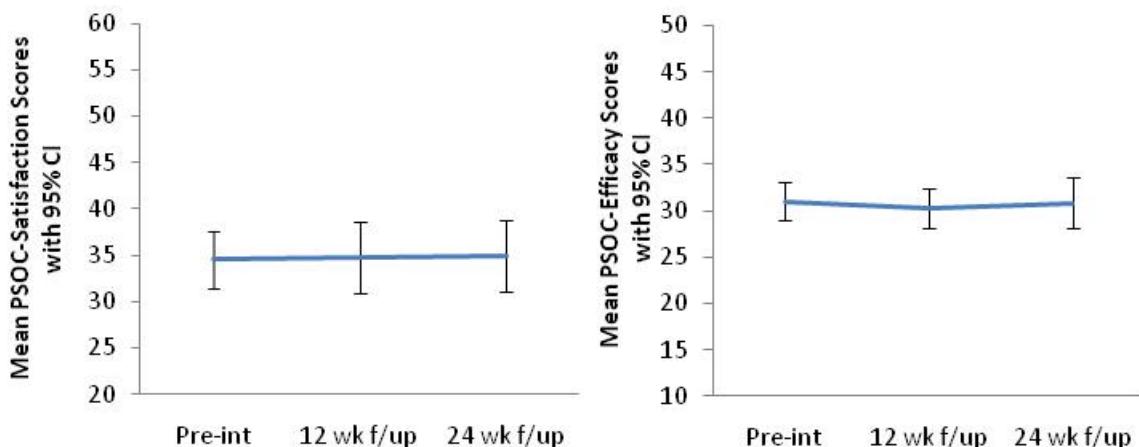
Changes in parents' feelings about themselves as parents (PSOC-Satisfaction¹²⁹) and their perceived efficacy as a parent (PSOC-Efficacy¹³⁰) were explored. Table 16.6 and Figure 16.5 suggest that there was little change in parents' feelings of satisfaction or efficacy after attending the workshop.

Table 16.6 Parents' sense of competence: Pre-intervention to 24 week follow-up

	Pre-intervention			12 week follow-up			24 week follow-up			Repeated Measures ANOVA
	N	M	SD	N	M	SD	N	M	SD	
PSOC-Efficacy	25	31.04	4.95	18	30.27	4.46	16	30.87	5.07	$F(2)=1.793, p=.185$
PSOC-Satisfaction	25	34.52	7.45	18	34.72	7.87	16	34.94	7.33	$F(2)=.264, p=.770$

G-Greenhouse-Geisser adjustment as ANOVA violated assumption of sphericity

Figure 16.6 Mean PSOC-Satisfaction and PSOC-Efficacy Scores: Pre-intervention – 24 week follow-up



The scale of improvement in parents' sense of competence

Effect size statistics for the changes in scores on the measure Parenting Sense of Competence are shown in Table 16.7.

¹²⁹ The Satisfaction subscale (9 items) of the Parenting Sense of Competence Scale (PSOC) is an affective dimension, measuring the extent to which parents are satisfied with their role as a parent, capturing parental frustration, anxiety and motivation. Scores can range from 9-54.

¹³⁰ The Efficacy subscale (7 items) of the PSOC measures the extent to which parents feel they are managing the role of being a parent. It captures parents' perceptions of their competence, problem-solving ability and capability in the parenting role. Scores can range from 7-42.

Table 16.7 Effect sizes for changes in scores on the Parents' Sense of Competence measure

	Effect sizes from pre-intervention	
	12 weeks follow-up	24 weeks follow-up
PSOC-Satisfaction	0.11	0.01
PSOC-Efficacy	-0.15	-0.21

Effect sizes have been reversed so that a positive effect size reflects a *positive* change.

Consistent with the findings reported in Table 16.6 effect sizes were negligible. Furthermore, there was a negative effect size for PSOC-Efficacy which increased at 24 week follow-up.

The proportion of parents reporting improvements in their sense of parenting competence

Once again, reliable change statistics were used to present the proportion of parents where 'true' changes in parents' sense of efficacy as parents and their satisfaction with the parenting role competence were observed, see Table 16.8.

There appears to be very little movement post intervention with parents appearing just as likely (If not more so for the PSOC-Efficacy subscale) to show reliable deterioration as reliable improvement at follow-up.

Table 16.8 The proportion of parents improved parenting sense of competence: Reliable Change statistics

	Parenting Sense of Competency	
	Satisfaction	Efficacy
12 week follow-up		
Reliably improved	4 (22.2%)	2 (11.1%)
No reliable change	12 (66.7%)	11 (61.1%)
Reliable deterioration	2 (11.1%)	5 (27.8%)
24 week follow-up		
Reliably improved	3 (18.8%)	1 (6.3%)
No reliable change	10 (62.5%)	11 (68.8%)
Reliable deterioration	3 (18.8%)	4 (25%)

16.3 Costs

This section presents the costs data. The small sample size achieved means that analysis at a group level on the impact of the child's sleep problems on parents; and their and their children's use of services which relate to the presence of sleep difficulties cannot be carried out. It also proved very difficult to obtain data needed to calculate the costs of delivering the workshops. An estimated cost is, however, provided. As with the other sleep interventions, we also present a "costed case study" to illustrate the impact, at an individual case level, of the intervention on parent and child outcomes and, where relevant, use of other services, see Figure 16.7.

The data available suggest there was only one practitioner facilitating each workshop for between six and nineteen participants. Delivering the intervention absorbs five hours of their time, but we have no information on time spent recruiting for the group (for example, distributing leaflets, setting-up, maintaining the waiting list, contacting potential participants), preparing the session, getting the room ready and tidying it after the session, or any of the other activities around delivering the intervention. Nor do we know what grade of staff are required to deliver the intervention or what materials (refreshments, flip-charts and the like) are required during the workshop.

Given the paucity of data we have based our estimate of costs on the fees charged for this intervention by a voluntary sector organisation that runs workshops nationally; £85 per professional (www.scope.org.uk). The average number of professionals attending the eleven workshops included in this study was 7.2. Assuming that the total fees paid for professional attenders cover the costs of the workshop, it would cost £612 to deliver the workshop. On average, six parents attended each workshop. With an average of 13.2 participants in total, the cost per workshop participant would be £46.30.

Figure 16.7 Intervention H “costed case study”

Before the intervention

Sally is an 11-year old girl who is a wheel-chair user and has cerebral palsy (right-side hemiplegia) and global developmental delay. She lives with her Mother who attended the workshop after taking her daughter to school. Mother felt she “needed to do something … it was like musical beds”. Her goal was to get Sally to sleep in her own bed.

Supports

We have no information on the supports and services used by either Sally or her Mother.

Intervention

Mother rang up as soon as the workshop was announced but could not get a place for four or five months. She liked the group format because she group could share experiences and tips with other parents. She found that the trainer did not “tell us everything” but got those attending to discuss things in smaller groups of two or three participants. These would cover issues such as what to avoid before bedtime and why, what the bedroom environment should be like, etc. Mother reported that she felt as though she was not the only one facing sleep problems and that other parents had similar (and worse) problems.

Mother reported that the workshop put her in the right frame of mind to address child's sleep problems rather than letting Sally do, more or less, what she wanted. She has removed TV and music from Sally's bedroom to provide a calmer environment and put a bed-time routine in place which includes reading to her and dimmed lighting. Mother has stopped talking to Sally as she waits for her to settle and when checking her at night (to turn her over, replace covers, etc.); Sally's father finds this more difficult.

Outcome

Mother was interviewed 11 weeks after the intervention and felt things had improved quite a lot. They still have to sit with Sally until she settles but usually this now takes only an hour, and Sally has not been in her parents' bed since the workshop. Sally wakes less often at night; from once an hour prior to the workshop to just once or twice during the night. Mother used to keep a mattress on Sally's floor and sleep on this when Sally was waking frequently but this has now been moved to another room.

The trainer said parents could email her if needed further help and suggested they keep a sleep diary if they wanted further support from a professional. By the Time 3 data collection, Mother felt her goal had been achieved and that family life had much improved. Sally's parents could now spend time together in the evening which helped their relationship.

16.4 Summary of the findings

- Progress in attaining goals for improved sleep behaviour and standardised measures of parent-report sleep behaviour and parents' sense of competence were used to assess the effectiveness of the intervention. There was no comparator group to compare the outcomes meaning increased caution is needed when interpreting the findings.
- At the beginning of the workshop parents identified up to three sleep-related goals. A significant improvement in goal attainment ratings was found at both follow-up time points post-intervention.
- During the study period slight improvements were found on the Total Sleep Disturbance Score and the Bedtime Resistance and Sleep Anxiety subscales (as measured by the Children's Sleep Habits Questionnaire and demonstrated through the mean scores and effect sizes). There was a negative effect at follow-up for the Night Wakings subscale. Improvement appeared to take time, effect sizes being greatest at 24 week follow-up. The negative effect for Night Wakings may be indicative of initial resistance from children as parents implement the new sleep strategies.
- The evidence regarding the impact on parents' sense of competence (measured by the Parenting Sense of Competency Scale) was negligible
- We have estimated that it costs £612 to deliver the workshop, with a cost per workshop participant of £46.30.

Conclusions

This investigation was an exploratory piece of work. No comparator group was available and the sample size was small. The quality of the evidence is, therefore, relatively weak. Importantly, it is not possible to ascribe observed changes in parent and child outcomes to the intervention and only tentative and limited conclusions can be drawn. Whilst there was little change following the intervention on the measure of parenting competence, evidence from the goal attainment ratings and the improvements on the Children's Sleep Habits Questionnaire suggest that the workshop may be successful for some parents who come along to the workshop to gain advice to work on specific sleep problems. Parents needing to gain confidence in their parenting strategies or those with children with very complex sleep problems may need this support to be supplemented with a more intensive and tailored intervention.

Chapter 17

The Outcomes of Parent-Training Programmes for Sleep: Parents' Views

17.1 Introduction

In this chapter, we report the findings from the individual and focus group interviews with parents on the outcomes they achieved through participating in a sleep programme. Despite the considerable variation between the sleep programmes with regard to their length, format and style, the themes emerging from parents' accounts in the qualitative analysis were largely consistent.

17.2 Types of sleep programme outcomes

A key outcome of the sleep interventions was to achieve a positive change in the child's sleep. We therefore began our analysis by categorising each parent as either as having achieved an improvement¹³¹ in their child's sleep or not.

What emerged from this process was that the majority of parents (28/35 of those interviewed, see also Chapters 15-17) had achieved quantifiable progress towards achieving at least one of the goals they had set for their child's sleep. Sometimes this progress was quite significant, even to the extent of fully resolving the child's sleep problem. For other families, the progress or improvement was less marked, but still positive changes had been observed.

The 'non-improvers' (a much smaller group overall), however, were not a homogeneous group. Instead, two sub-groups emerged. First, a group of parents who whilst not observing any positive changes in their child's sleep still reported positive outcomes, particularly for themselves, following participation in a sleep programme. Second, a group of parents where the lack of improvements in their child's sleep appeared to be due to the difficulties they had with the approach to managing sleep problems taken by the sleep programmes.

In the remainder of this chapter, we draw on the accounts of these various 'outcome' groups where relevant and appropriate.

17.3 Parents' views on the contribution of the sleep programme to improved sleep outcomes

All the parents who reported some improvement in their child's sleep thought that the sleep programme had contributed to this outcome. This contribution comprised a set of separate, but linked and broadly chronological, sub-outcomes for parents which had played a part in achieving the improvement:

- affirmation of parents' existing knowledge and behaviour
- positive changes in parents' knowledge, understanding and attitudes

¹³¹ Here 'improvement' was defined as an improved attainment rating on one or more parent-set sleep goals at 12 weeks post-intervention.

- changes in parents' behaviour
- improvements in parental well-being.

Interestingly, among parents where no quantifiable improvement in the child's sleep had been observed,¹³² some reported positive outcomes in these areas too. This was particularly the case for parents where physical or physiological factors (for example, pain, seizures) had been identified or confirmed by the sleep practitioner as the primary cause of sleep problems. In these instances the sleep practitioner took appropriate action to address these issues.

Affirmation of parents' existing knowledge and behaviour

Faced with the complexities of sleep problems and a disabled child, parents found it reassuring to have confirmation from the experts running their sleep programme that at least some of what they had already put in place was 'right' and should continue. Examples included parents who had a good bedtime routine in place, or – as in the following case – had created a calm environment in the child's bedroom:

It was nice to know I'd done that right really.

[80 (Mother) Programme F]

Such reassurance gave parents the confidence to carry on with these good practice strategies, as one parent explained:

I needed that reassurance ... "You are doing everything right, just persevere". I needed that, like somebody to tell me, "Yes, you are doing right" ... cos sometimes I thought well I must be doing something wrong.

[78 (Mother) Programme F]

Some of the parents who did not report positive changes in their child's sleep arising from a sleep programme described the experience of having their current sleep management strategies confirmed as being correct by a sleep practitioner to be very pleasing and reassuring.

Positive changes in parents' knowledge, understanding and attitudes

Parents spoke about a variety of ways in which new knowledge and understanding in relation to sleep had been beneficial. The broad dimensions of this learning were:

- an awareness that other families have sleep problems
- theoretical and practical learning about children and sleep in general (including strategies for promoting good sleep)
- clarifying links between the child's condition and sleep problems.

While parents in the one-to-one programmes (E, F) were reliant on their sleep practitioner for new information, those in the group-based and workshop interventions (G, H) reported learning from both the group facilitators and other parents. The acquisition of this new knowledge and understanding appeared to be crucial. It was enmeshed within parents' accounts of positive changes in their attitude towards their child's sleep problem. Taken together, these changes in understanding and attitude paved the way for the new or adjusted parent behaviours which proved key to improving the child's sleep.

Even amongst those parents who did not observe quantifiable improvements in their child's sleep following a sleep programme, positive gains in knowledge, understanding and their

¹³² That is, no change on sleep goal attainment ratings at 12 weeks post-intervention.

attitudes towards the child's sleep problem were sometimes reported. Some of these parents felt that the programme had boosted their confidence sufficiently that they planned, in the future, to implement some of their learning.

An awareness that other families have sleep problems

Many parents spoke about the personal impact of the programme in making them aware that they were not the only family with sleep problems. No longer perceiving their situation as unique reassured parents that their problems had not arisen through their own 'failure' as parents. This, in turn, helped them to feel more confident that they were capable of making positive change.

Parents in the group-delivered programmes (G and H) talked about the value of being with their peers:

It makes you more confident just because you know in that group that there are other people going through exactly what you're going through. It's just knowing that there are other people out there in the same boat as you.

[94 (Mother) Programme G]

... being able to talk to the other parents and know that you're not alone, that you're not being a bad parent, that everyone's having the same difficulties or again, you know, different difficulties.

[97 (Mother) Programme H]

Parents in one-to-one programmes, although not in direct contact with other parents, could still benefit from the experiences of their sleep practitioner:

At times I was just thinking, "Well, why me?", you know, "Why? Why?". And she's reassured me, "You're not the only person, I've seen families in a lot worse positions". And basically made me see I'm not the only one going through this.

[78 (Mother) Programme F]

For some parents attending a group programme, the opportunity to listen to each other's vivid personal stories led them to revise (always in a positive direction) their perception of the severity of their own situation. For example, one father (Programme G) said he had found it "weirdly comforting" to hear about the worse problems of other parents.

Some of the things I heard at the workshop, I was thinking: "Gosh, I thought I'd got it bad".

[102 (Mother) Programme H]

Theoretical and practical learning about children and sleep

As a result of new learning about sleep, a few parents realised that the consequences of their child's sleep problem were not as severe as they had thought. In turn, their attitude to the problem changed. For example, a mother whose daughter had trouble settling to sleep, felt less anxious after finding out that she was still getting sufficient sleep for her age.

If she's not asleep on the dot of half past eight or nine o'clock ... as long as she's relaxed and she's not distressed and I know that she will fall asleep ... then I think I'm a lot calmer with her.

[97 (Mother) Programme H]

For other parents, gaining what one mother called a better "*theoretical understanding*" [99 (Mother) Programme H] of sleep was valuable for rethinking a problem. An example given

by this parent was that she had realised that the reason her child seemed like a “coiled spring” [99] in the evening could be due to over-tiredness, which was the opposite of what she had previously thought. Parents also found it helpful for their understanding to have situations explained from the child’s point of view, for example:

I understand a lot more now where he comes from and why he's waking up every night and things.

[78 (Mother) Programme F]

She [workshop facilitator] explained it all really well from a child's point of view ... if a light's on in your bedroom, you can just ignore it, it's not particularly exciting or whatever, but [for] a child, it's the most fascinating thing in the universe, it's distracting them from going to sleep, you know, and stuff like that.

[103 (Mother) Programme H]

Learning about the importance and components of a good bedtime routine emerged as an important outcome area for many parents. For some, this was new knowledge, while others realised that their existing routine was not as good as they had thought. Parents in the longer-term programmes (E, F and G) had the opportunity to complete a sleep diary and several commented on its value for pinpointing where they needed to make changes.

It did kind of hit home to me where it was going wrong. I quite enjoyed doing that [the sleep diary] because it gave me something to reflect back on, you know.

[80 (Mother) Programme F]

Reviewing a sleep diary could also clarify for parents which aspects of their child’s sleep needed their attention and which did not. For example, one mother from Programme E (whose most difficult problem was her child not sleeping in his own bed) learned from sharing the sleep diary with her sleep practitioner that her son’s overall quantity and quality of sleep was satisfactory, so she should focus her efforts on being more strict about her son being in his own room.

Clarifying links between the child's condition and sleep problems

This was an important area for clarification with many parents feeling unsure how far they could apply any general sleep strategies. Parents found that the sleep programme helped parents to understand – and accept – the ways in which their child’s condition might always affect his or her sleep, along with what might still be possible to achieve to improve their sleep.

A child's sleep pattern is a learned behaviour and can be re-learned.

[73 (Mother) Programme E]

Parents reported that this learning had helped them to feel more in control of their situation. Continuing the example above, while the child’s condition would always make him prone to night wakenings, the parent felt that work with the sleep practitioner had put her and her partner “back on track”, no longer letting their son’s disability “fog” what they could do to improve matters [73 (Mother) Programme E].

Importantly, confirming a link between their child’s condition and sleep problems helped parents to free themselves from parenting norms associated with sleep. Parents from the Programme G focus group in particular (all of whom had a child with autism) talked about how the programme had helped to reassure them in this respect:

I think sometimes you need someone to tell you that it's okay not to be achieving what other children achieve, you know. All the literature you read, based on obviously mainstream children ... children without these problems, say, "Oh, you shouldn't be doing this and that" and so really they [the programme facilitators] just confirmed that it was okay because they're different ... so it's okay for them to do different things and come on more slowly.

[90 (Mother), Programme G, focus group]

I'm not a bad parent; I've just had a different child to deal with.

[81 (Mother) Programme G, focus group]

Being reassured that there were no definitively right or wrong answers for tackling sleep problems - especially for 'non-mainstream' children - parents felt that their attitude to the problem had changed. For example, they had stopped worrying about their child's unconventional sleep habits. The following conversation at a focus group demonstrates this well:

I think it's a case of us not being as stressed now 'cos you're given permission ... it doesn't have to be as you would expect a child to be. Just because his bedtime routine or his bedroom is chaos, that's cool. It doesn't matter. It's not important ...

[87, Mother]

... Yeah, I would agree with that. I can't even describe the devastation he does in his bedroom and then, at some point, he must pull his mattress off the bed and put it over the top of the devastation and go to sleep. I know before that course I would have been so stressed: "What a terrible mum I am letting him sleep like that!" Now, I think, "He's asleep!" ...

[91, Mother]

... I've learnt it's okay. If they want to sleep on the floor, they can.

[81, Mother]

Inadequacies in the educational element of the programme

Parents who reported no improvements in their child's sleep following their participation in a sleep programme often attributed this to advice on sleep management given by the programme not being appropriate to their child's needs and abilities.

Positive changes in parents' behaviour

It was clear from parents' accounts that attending the sleep programme had, in itself, provided an impetus to take action by increasing their resolve. Interestingly, the parents who drew attention specifically to this outcome had attended Programme H, which was the shortest (one-day) intervention.

For these parents, taking a day to look at sleep had enabled them to:

- stand back from the "rollercoaster" of everyday life, "just trying to get by day by day" [99, Mother]
- think about the value of sleep strategies; start to reflect on their current practice, looking afresh at possible solutions
- and boost their confidence to take action:

It got everyone thinking about well, okay, we often say, don't we, that we've tried everything that we can, but maybe just need to take a step back and a fresh look and, and see what might work and have another go.

[96 (Mother) Programme H]

It changed sort of the frame of mind and how confident I was about it and everything.

[102 (Mother) Programme H]

Across all four programmes many examples were given by parents of how they had changed their behaviour as a result of attending a sleep programme, and with at least some success.

There were two key areas of activity:

- setting up or improving their child's bedtime routine
- handling night wakenings.

Across both areas, learning to persevere was cited as important (since progress could be slow), as was support from others involved in the child.

Setting up or improving the bedtime routine

Some parents reported having learned about the importance of bedtime routine from the programme, while others learned ways of improving their existing routine. Successful changes included: having a set time for starting the routine; following a sequence of bedtime activities which the child understood and knew led towards going to bed; and replacing stimulating activities (such as television) with quieter ones (reading, drawing) before bedtime.

Parents reported that the sleep practitioners had given them personalised advice on strategies to tackle their sticking points. For example, parents from Programmes E and G cited having received successful advice on explaining the steps in a bedtime routine to their child in ways that they could understand. For example, using very simple language, extending the child's existing PECS system to cover bedtime, or – in one case – using an egg timer to indicate bedtime, which had been “brilliant” [Parent 94 (Mother) Programme G].

Parents in longer-term programmes (E, F, and G) spoke about the value of ongoing support to help parents persevere with new or changed routines.

I did kind of need to keep sticking to it [new sleep strategy]. I think sometimes I'd kind of kept him up that little bit later so he'd sleep that little bit longer, you know. So I think it kind of hit home to me that I needed to just, you know, keep going with it and stick to a routine in order to get somewhere really. It was just general things like: “... after his milk, do a bath, story ...”; it was, you know, common sense things. But, for me, it was just trying to fit that in around him and his problems.

[80 (Mother) Programme F]

Even where parents felt they had already been doing most things 'right' in their bedtime routine, the sleep programme had been valuable for reminding them to be consistent. For example one father felt that the programme had made him stricter about reinforcing the family's pre-existing rule: “10pm lights out, no excuses” [92 (Father), Programme G].

However sticking with the routine could be difficult. For example, one parent whose partner worked outside the home, said that while they were seeing progress it took a lot of effort some evenings to manage to squeeze in all that needed to be done before the target

bedtime. Another parent mentioned that it could be tempting some evenings to give up on the routine “*for an easy life*” [75 (Mother) Programme E]. However perseverance was acknowledged as important, since it took time for children to get the message “*slowly but surely*” [89 (Mother) Programme G].

Sticking with an improved bedtime routine was achieving positive results for many families, sometimes dramatic:

I used to dread bedtimes, get anxious, but now it's no bother at all ... he runs up to bed.

[74 (Mother) Programme E]

Although not necessarily solving the child's sleep problems entirely (for example, where the routine did not work every night or formed only a part of the child's sleep problem), a good bedtime routine was nevertheless still seen as a key plank in a sleep strategy. As one parent commented: “*it's when they have a nice settled routine at night it seems to be a lot better*”. [97 (Mother) Programme H].

Another parent drew attention to the benefits of a good bedtime routine for all three children in the family, despite only one child having sleep problems. All were enjoying quiet activities in their bedrooms after bathtime and the parent judged that “*it's helped all three to wind down*” [96 (Mother) Programme H].

Adapting the bedroom environment

Several parents (across all four programmes) who reported some improvements in their child's sleep had made changes to their child's bedroom environment, often in tandem with improving the bedtime routine. Changes included: redecorating the room to make it more appealing to the child; removing toys, TVs and other potential stimulators/distractions; altering lighting or heating levels; and reducing where possible noises elsewhere in the house where it was thought these could be disturbing the child.

Handling night wakenings

Many parents had set goals relating to night wakenings. Difficulties experienced by parents were children being noisy and apparently distressed when they woke during the night, unable to self-settle and sometimes leaving their own room to seek out their parents. These behaviours were not only detrimental to the child (lack of sleep and the dangers inherent in moving around the house unsupervised) but could also mean that the whole family suffered disturbed sleep.

Before embarking on a sleep programme, parents said they had tended to intervene early, going into the child's bedroom to attempt to soothe him or her to aid re-settling, a strategy which had not been effective. As one parent said, she and her husband were “*absolutely exhausted*” [75 (Mother) Programme E].

Parents who reported improvements with regard to night wakenings said that the sleep programme had taught them to handle this situation differently. An important aspect of their learning had been to perceive their child's sobs or screams as possibly a desire for attention, rather than genuine distress. Parents therefore tried to harden their resolve not to go automatically into their child's room. This had not always been easy, especially for parents who felt it seemed they were “*being horrible*” [76 (Mother) programme E] and/or said they felt sorry for their child owing to their wider problems:

I think I'd just kind of give in a little bit more because of his condition and things.

[80 (Mother) Programme F]

Other successful strategies mentioned for reducing night wakenings or lessening their impact were ensuring the child did not sleep during the day and keeping interaction minimal if the parent did need to go into their bedroom during the night.

Instead of talking to him ... we've just ignored him, kind of thing, and made ourselves boring so there's no entertainment [for him] in getting out of the bed.
[103 (Mother) Programme H]

Parents had also put into place strategies for helping their child to self-settle. In cases where the child would leave their room, sometimes boundaries needed to be reinforced by physical means, for example propping a chair against the child's bedroom door.

Implementing such strategies did work for these parents although, as one parent noted, it took "time, effort & patience" [76 (Mother) Programme E]. As with implementing a new or changed bedtime routine, parents in longer-term programmes valued the support available to help them to persevere with changed behaviours. In Programme G, the group sessions enabled peer and facilitator support, while in one-to-one settings parents reported benefitting from the regular contact with their sleep practitioner. Several parents also mentioned that keeping a sleep diary had helped to keep them motivated by revealing progress over time, however small, as in this example:

*... so you felt like you were achieving something and you weren't awake all night
... and when you start realising it's not as bad, it starts improving quicker.*
[81 (Mother) Programme G, focus group]

A successful outcome was beneficial not just for the child, but the rest of the household:

She's not wandering about the house any more, and that's what we did want. I mean I've literally, for the last ten years, slept with an ear to the ground because, you know, she comes wandering down the stairs and falls, or she comes wandering round the house picking things up that she shouldn't be or doing something that she shouldn't be: it's a real worry, you know. So she, she's pretty much staying in her own bedroom environment, which is good for her and good for everyone.
[96 (Mother) Programme H]

As their child's sleep problems began to improve, parents reported improvements in their own well-being through getting better sleep themselves. In turn this enabled parents to think more clearly about responding further to their child's sleep-related needs.

The following excerpt portrays this well:

I was rocking him to sleep right up until midnight and then he'd go asleep for an hour and then that was it. ... And obviously because of the lack of sleep we were having, it wasn't doing us any good health-wise. So I just wasn't really much good to, to anybody really. Obviously now that I'm being a little bit more [consistent] and because he's had that little bit more sleep now, I can now kind of tune in to doing that now [implement a routine]. Whereas before I was just too exhausted to even think about a routine really. Now I feel that little bit more better in myself, I can focus on what he needs more now. I know a lot of it [sleep strategy] is common sense. But sometimes I think, when you're not in that frame of mind, common sense doesn't really come into it ... when you're so tired that you, you can't think straight you just don't think about them things until it's said to you ... and then you think "Oh god, yeah, why didn't I do that, you know?".
[80 (Mother) Programme F]

The importance of consistency across primary carers

Parents reported it was important that, when implementing new approaches to managing bedtime or night wakenings, others involved with the child were willing to follow a consistent approach, or otherwise act in a way which supported their goals. Most often this was a partner, whether or not s/he had been able to attend the programme, since they were present at bedtime and often shared bedtime responsibilities. A typical comment was made by this mother about her partner:

He goes along with the routine and we work together really to try to solve any problems.

[80 (Mother) Programme F]

Sometimes a partner needed encouragement to change their behaviour. For example one mother described her partner as “*like a big kid sometimes*” [74 (Mother) Programme E] so she had “*trained*” him not to play with their son in the evenings when calm time was needed. In another family, a father from Programme G who had been separated from his wife for several years (their son splitting his time between both parents) explained how he had taken care to update his former partner about each session, and that both had adopted a consistent approach with a new bedtime routine and completed a sleep diary.

In families where the child sometimes stayed with a grandparent, a consistent approach to bedtime routine in the different settings where the child slept was seen as important.

Improvements in parental well-being

In the previous sections we have included parents' observations on improvements in their own well-being where these were closely linked to the positive outcomes in their child's sleep. It is clear that improvements in their own well-being could be a powerful driver for parents in changing their behaviour.

The sleep programmes supported improved parental well-being in a number of areas:

- feeling more reassured about their parenting skills (in general and regarding some of their existing sleep strategies)
- reduced feelings of isolation
- a reduced perception of the scale of their problem (compared with other families)
- feeling stronger as a person, freed from parenting norms/judgement of others
- boosted with the confidence necessary to implement changed or new behaviours.

Once committed to new behaviours and starting to see some improvement in their child's sleep, parents reported feeling:

- less anxious, worried or stressed
- more calm, relaxed and 'in control'
- supported to persevere
- less tired
- positive about progress and the prospect of continued improvement.

Parents also reported other improvements in their own well-being, which were associated with the sense of emotional support more generally they had gained during (and sometimes also since) the programme. While less directly related to the positive outcomes in their child's sleep, such support was important nonetheless for a change for the better in parents' underlying state of mind. The existence of the programme itself was seen as a source of support. For example one mother who had been struggling with her child's sleep problems for sometime said that it been a relief to her simply that “*somebody was listening*” [75 (Mother) Programme E]. At the end of sleep programmes, given that progress was often

slow and/or not all problems were able to be addressed within the timescale, knowing that there was still a practitioner point of contact was cited as by some parents as important for their peace of mind.

Finally, it is important to note that some of the parents who did not experience improvements in their child's sleep nevertheless secured some enhancement in their own well-being through participating in a sleep programme. These improvements can be summarised as follows: reassurance about their parenting skills with regard to sleep strategies; optimism that it might be possible to tackle an underlying physical cause for the problem; greater acceptance of an intractable sleep problem; reduced feelings of isolation; a reduced perception of the scale of their problem (compared with other families); and a sense of confidence about coping in the future.

17.4 Parents' views on the contribution of factors other than the sleep programme to improved sleep outcomes

All the parents who experienced at least some improvement in their child's sleep attributed this, at least in part, to the sleep programme. In addition three other contributory factors were identified by parents: starting nursery or school; age-related development; or a medication. Since these factors were concurrent with changes being made from the sleep programme parents felt unable to ascribe weightings to their respective contributions.

Starting nursery or school

Some parents believed their child having started nursery or school had resulted in an improvement in their sleep. Several beneficial changes were mentioned. First, that their child was simply more tired at the end of the day. The consistent rhythm of the school day was also seen to support adopting greater structure in the evenings.

Age-related development

Several parents attributed the gradual improvement in their child's sleep problem since the programme at least in part to their child growing older. Aside from the associated development in the child's general understanding, specific examples included the child's growth in capacity to sit still and enjoy a bedtime story and, in terms of night wakenings, the ability to stay in their room and self-settle by doing a quiet activity. Such developments had not necessarily overcome the sleep problems completely – progress could still be slow – but helped parents to feel more optimistic that positive change would continue.

Medication

In addition to their learning from the programme, a few parents had decided to use medication to aid their child's sleep and reported it as effective.

17.5 Parents' views about factors hindering the achievement of improved sleep for their child

Despite all parents in the 'improvement' group having noted some positive change in their child's sleep problems, the extent of progress achieved was variable and the pace typically slow. This section therefore pools the accounts of all parents and reports the factors which parents perceive hinder the achievement of improvements in their child's sleep.¹³³

Parents cited a variety of factors which they felt blocked the extent to which they were likely either to fully meet their sleep-related goals, or do so consistently. These hindering factors were associated with:

- the child's condition
- parents' difficulties in changing their own behaviour
- changes and disruptions
- the home environment
- unmet needs for sleep information and advice.

The child's condition

Parents identified features of the child's condition which, they believed, limited sleep improvements or could mean progress was more fragile. This was particularly the case for children with ASC or children with on-going health needs.

Parents of children with ASC felt their child's heightened levels of anxiety, an inability to communicate, over-activity, and heightened sensitivity to noise were all factors which could impede the implementation of a sleep management strategy. Typically, parents were pragmatic about the limits posed by their child's difficulties.

I probably didn't go looking for a magic remedy because I honestly think she is who she is and that's how it's going to be.
[93 (Mother) Programme G]

An issue noted by parents attending the one-day workshop (Programme H) was that it had not been possible to address the way autism-specific issues might affect sleep management strategies.

Several parents spoke about sleep improvements going 'backwards' when their child was undergoing medical interventions or otherwise unwell for a while, when "everything goes out of the window" [75 (Mother) Programme E]. A spell of illness meant that a child's sleep could be more disturbed and an already anxious child could feel more stressed and so less able to self-settle. Where the child had learning difficulties, parents said that it was more difficult to offer reassurance than with other children the same age.

Parents' difficulties in changing their own behaviour

Parents encountered various difficulties in changing their behaviour – or sustaining change – to maximise progress with their child's sleep problems. At one extreme were a couple of parents who reported that they had refused to accept the advice given to them by their sleep practitioner. It was more common, however, that parents realised the need to change their current approach to managing their child's sleep but, nevertheless, found it difficult.

¹³³ There was a high level of consistency in parents' accounts, regardless of whether they had been categorised as 'improved' or 'not improved' (see Section 17.2).

First, the pace and complexity of everyday 'real life' for parents could make it difficult, to sustain their focus on the child's needs regarding sleep.

We have a busy life, some days are very hectic.
[99 (Mother) Programme H]

Second, parents said that on days when they felt especially tired it was more difficult to maintain optimum behaviours with regard to sleep, such as sticking to a good bedtime routine, responding in the best way to night wakenings, and/or filling in their sleep diary.

Third, some parents said they struggled to change their behaviour, especially in the face of strong resistance (distress) from the child. For example, one mother described her early work with a sleep practitioner as "*heart-wrenching*" as she tried to implement strategies for her son to sleep in his own room [76 (Mother) Programme E]. Two parents who had been advised to handle night wakenings by putting their children back to bed without talking to them both spoke about having taken a decision to follow this advice only up to what one termed the "*threshold*" [73 (Mother) Programme E] where they judged they needed to intervene, owing to the length or intensity of their child's crying.

A couple of parents who had reported no improvements in their child's sleep appeared to have been disheartened by a lack of progress. It is impossible to ascertain, however, whether this was due to inappropriate advice being given by the sleep practitioner and/or lack of consistency or perseverance on the part of the parent. In both instances parents had reverted to the previous sleep management practices.

Changes and disruptions

Temporary changes in daily routines or family circumstances also disrupted parents' ability and/or motivation to maintain good practice sleep routines. Parents found maintaining sleep routines during school holidays were particularly difficult, especially when they were away from their usual surroundings. Weekends, with the lack of school routines, presented this difficulty.

The home environment

Parents judged that aspects of the home environment placed limits on progress with their child's sleep in a variety of ways. This was particularly an issue where the child shared a bedroom with siblings. Here, where the child was prone to night wakenings and sleep advice had been not to intervene, parents said they sometimes felt unable to comply, as they had to take account of the need for sleep of other siblings if the child was crying.

17.6 Summary

This chapter has sought to capture parents' experiences of seeking to improve their child's sleep. The role played by the sleep programmes in achieving positive sleep outcomes is very clear and parents were able to give often quite detailed accounts of the way the various elements of the programme they received supported achieving positive outcomes. In addition to positive sleep outcomes, improved parental well-being also featured highly in parents' accounts. For some parents, this benefit off-set a lack of observable improvement in their child's sleep.

Interestingly, we did not discern large differences in the accounts of parents according to the type of intervention they had received. However, one area where the one-day workshop appeared to be less effective was in being able to address some parents particular concerns about how their child's sleep may be affected by their condition. This was particularly the

case for parents of children with ASC. Interestingly, the workshop attendees did not report a lack of on-going support as they changed their sleep management practices (a feature of the other sleep programmes). However, this would not have been something these parents were expecting from a one-off workshop and this might account for this rather surprising finding.

A minority of parents reported negative experiences of a sleep programme. It had not furnished them with the information they required, and/or they did not feel the advice and strategies being suggested to them were appropriate for their child.

One of the interesting themes emerging from parents' accounts is the sense that parents' feel de-skilled in managing their child's sleep because of the presence of a disability and/or complex health condition. As we note, addressing that lack of confidence appears to be key to subsequent progress. A second issue is the high level of anxiety (and exhaustion) parents experience when their child does not sleep 'normally' in a bed and/or requires little sleep. This can be a common experience for parents of children with ASC. Clearly the sleep programmes were effective in helping parents to accept and adjust to their child's different sleep and also gave parents' permission to adopt sleep management practices appropriate and effective for children with ASC.

The barriers to improving a child's sleep are wide-ranging. Parents may be unable to implement sleep management strategies because, initially, the problem appears to deteriorate. The strategies may also run counter to their parenting beliefs and/or their interpretation of the situation. Implementing changes in bedtime routines or how night wakenings are managed can be very demanding on parents' emotional and physical resources. Progress can also be stymied by unanticipated or uncontrollable events or circumstances. It was also apparent from some parents' accounts that overcrowding was a significant barrier to achieving any progress with their child's sleep. However, despite these obstacles, this chapter has presented very clear evidence of parents successfully implementing sleep strategies and reaping the rewards of doing so.

Chapter 18

Practitioners' Views on the Effectiveness of Parent-Training Programmes: How, For Whom and in What Circumstances?

18.1 Introduction

A key aim of any evaluation is to understand why an intervention is effective, for whom and in what circumstances. In this chapter, we report practitioners' perspectives on the answers to these questions.

We have chosen to synthesise the accounts of practitioners delivering both the sleep and behaviour interventions. An initial analysis of the data revealed a large degree of commonality, such that to report the data separately would result in high levels of repetition. However, where appropriate, care has been taken to identify when intervention-specific features (for example, ASC specific, sleep intervention) need to be taken into account.

The approach taken in this chapter has been to focus on describing, from practitioners' perspectives, 'what works' and also, what gets in the way of an intervention working. Six sets of factors have been identified:

- the features of the intervention
- the provision of post-intervention support
- the family context
- parent-centred factors
- condition-centred factors
- the child's personality.

These will be explored and described in turn.

Programme outcomes

To start, it is worth quickly revisiting the outcomes which the programme authors had in mind as they developed the interventions under investigation in this study.

The overall purpose of the programmes is to support parents of children with ASCs post-diagnosis (programmes A and C), or parents with disabilities more generally who were experiencing difficulties with managing their child's behaviour (B and D) or their child's sleep (programmes D, E, F and G), see Figure 18.1.

Figure 18.1 Programme aims

Programme	Aims
Behaviour management	
A	To increase understanding of children with ASC, to empower parents to address specific behaviours and to support their child's behavioural development.
B	To empower parents to confidently manage their child.
C	To increase understanding of ASCs and what is behind behaviours, to provide strategies to manage difficult behaviours, to signpost to relevant local ASC resources, and to meet with other local parent/carers.
D	To enable parents to understand and manage their child's behaviour in the context of additional needs, using functional analysis, communication and behavioural approaches. To encourage parental confidence and emotional well-being.
Sleep management	
E	To support parents to address their child's sleep problems.
F	To help families to improve their child's sleep.
G	To help parents manage their children's sleep difficulties.
H	To support families of children with sleep difficulties through raising awareness of good sleep practice and basic strategies to support parents in establishing new routines.

However, whilst improvements in a child's sleep or behaviour, achieved through changed parenting practices, are primary aims, practitioners' accounts of the desired outcomes of these interventions add some important details, and a touch of realism, to these broad brush aims.

First, it is important to reiterate that each of these programmes seeks to empower parents to better manage the difficulties they are facing. In all of these interventions parents are perceived as active actors rather than passive recipients. This process of empowerment, it is hoped, leads to improved parenting confidence or self-efficacy. Sometimes this is the key, and most realistic, outcome.

It's not even the fact that all the children that we visit have ended up sleeping all night, that's not the case. But I still think the families have benefited from the support and even just having the confidence to continue and know that they're doing the right things around bedtime. Even if they're not getting a good night's sleep every night, they're on the right track and they're doing the right thing ... So I think if it gives them the confidence to just keep on going, then that reduces their stress.

[E2]

It's lovely if the children's behaviour does change as well, but sometimes I do think that the children haven't changed very much and it's actually the parents who have changed – it's their management of their stress levels and their ability to cope. Cos I think we've got to accept that some of these children are very

difficult and it would be naïve to think we could really change them an awful lot, especially some of the children with strong autistic traits. [C1]

Second, sometimes the key area of change lies in parents' perceptions of their child's sleep or behaviour as opposed to a quantifiable change in the sleep or behaviour itself. This changed perception could arise from contextualising their difficulties within the accounts of others (see Chapters 6 and 13); parents' understanding of their role in how their child behaves; and/or from understanding more about their child's condition, particularly if their child has ASC. A changed perception was seen as a primary outcome in situations where, realistically, the child's behaviour is unlikely to change significantly. This last point is particularly relevant for parents of children with ASC.

It's quite possible that the change you get is not that the behaviour changes but that what people see as challenging or unmanageable changes. So the behaviour stays the same but it ceases to be seen as a challenging behaviour in the sense that you, you can't see how it's managed or you don't feel able to manage it.

[B3]

But these problems are really severe and significant and they're not going to go away, there's not a cure. So we do expect people to continue to have some behaviour difficulties, and we do hope that they'll have a few more strategies to put in place.

[D2]

18.2 The features of the interventions perceived to effect change

This section reports practitioners' beliefs about the features or aspects of the intervention they delivered which were associated with improved parent and child outcomes.

The following generic features supporting effectiveness were identified from practitioners' accounts and now described:

- the educational aspects of the intervention
- the family-partnership approach
- the group effect
- working with both parents
- flexibility within the programme
- practitioner knowledge and skills.

In addition, we report the perceived impact of two additional features of the one-to-one sleep interventions: an initial assessment, including home visits; and implementation support.

The educational aspects of the programme

All the programmes drew upon behavioural theory and behaviour modification principles to improve parents' understanding of their child's problem behaviours (including sleep¹³⁴) in order to develop an effective strategy to modify that behaviour. Parents attending the ASC-specific programmes (A and C) additionally learnt about ASC and its impact on behaviour, parents receiving sleep interventions received background, generic information about sleep.

¹³⁴ From this point forward the phrase 'problem behaviour' refers to both daytime behaviour and night-time, or sleep, behaviours. It is used collectively and can refer to a single, difficult-to-manage behaviour or a number of behaviour problems.

Importantly, as well as teaching parents the principles of behavioural approaches to sleep and/or behaviour management, practitioners also 'translated' this theoretical knowledge into specific and practical strategies and advice.

The outcomes of these new bodies of knowledge were therefore: improved knowledge and understanding and an improved or wider repertoire of parenting skills and strategies.

We give them a toolkit. We give them the skills and the strategies to be able to look at what the problem is, break the problem down, and then look for the realistic and practical solutions that they can put in place.

[G1]

Unsurprisingly, practitioners identified the educational aspects of the programmes as a key factor in supporting positive outcomes. Importantly, however, they all recognised that increased parental knowledge and understanding was achieved because the teaching approaches used were effective.

Effective teaching approaches or tools identified by practitioners included:

- experiential exercises
- visual learning techniques (for example, a DVD made by young people with ASC; video-footage of good and poor behaviour management techniques)
- hands-on experience with real parenting tools (for example, a behavioural analysis chart, a communication tool)
- using 'real life' examples
- the use of everyday analogies (for example, the Iceberg principle, the FIRE wheel)
- 'homework'.

We do the exercise where we bombard parents with lots of sensory stimuli and they say, "Gosh, I didn't realise how difficult it is to concentrate when you've got sensory overload!"

And when we do the exercise about play where parents are given play equipment but then are told: "You don't have imagination, you don't have theory of mind", they themselves experience how difficult it is to play, and then they've said, "Well, the only thing you can do is line things up or start fiddling with things!"¹³⁵

[A2]

We learnt that visual approaches were best for everybody. Seeing it happen takes away all the complexities of language. Just watch this for two minutes and you, you'll get the story. So having that visual audience, you know, was one of the key points.

[B2]

'Homework' or 'home practice'

We explore 'homework' or 'home practice' in a little more detail now as there were some differences between interventions in the way it was emphasised and used.

'Homework' or 'home practice'¹³⁶ was recommended to parents by all the interventions (with the obvious exception of the one-day workshop) to help embed new knowledge and/or practice newly acquired skills.

¹³⁵ Typical ASC behaviours.

¹³⁶ We simply use the term homework from this point forward.

Homework to embed new knowledge might involve reading (though this was, perhaps, regarded as the least important form of homework), doing some observational work, keeping a diary of the child's behaviour.

I think it's what parents put into the course by coming for eleven weeks ... I think that is enough for them. We don't actually push the reading, but parents are encouraged to just go away and throughout the week [observe] ... their child's behaviour ... I think that's enough.

[A2]

Homework which involved practising new skills or trying out new behaviour management strategies either followed input from the practitioners on a particular behavioural technique, or was with respect to a specific behaviour that the parent was struggling with.

I think they do gain from each week being able to go back [home] and look to see whether their child does this that or the other that you've been talking about. I think that probably consolidates the learning. ... And I think again that we felt the same thing with the behaviour stuff, cos the last four or five sessions are about sort of changing the behaviour and parents actually need to go away and try something.

[A4]

Putting into practice the stuff we've learnt in the group is essential for making any change, cos if they don't go away and do the things then they're not going to see any difference with their children's behaviour. So generally we get quite a lot of adherence to the home practice.

[D2]

Homework was not an essential requirement for receiving any of the behaviour management interventions, and views differed amongst these practitioners as to its importance.

We don't make [homework] a requirement, no. We just, you know, leave them with the information that they've got. I know that that's often a core bit in other parenting programmes, you know, for them to try something out and come back and report back on it. I suppose if we were going to do that it would cut into [the] beginning bit of the next session [and] I think we're squeezed enough with the time.

[C3]

In contrast, the one-to-one and group-based sleep interventions all required, or expected, parents to undertake 'homework' or 'home practice' including, in the case of the one-to-one sleep interventions, implementation of a sleep strategy.

The family-partnership approach

With the exception of the one-to-one sleep interventions, all the programmes overtly took a family-partnership approach to delivering the intervention. The Family Partnership Model (Davis *et al.*, 2002; Day, C. & Davis, H. 2009) advocates a collaborative approach to working with families in which parents' knowledge and experience is valued as much as professionals. The rationale for this approach is the need to develop and build parenting self-efficacy and to ensure that parenting interventions make effective but realistic suggestions to parents regarding the management of problem behaviours.

All the group-based parenting programmes highlighted their partnership approach to parent-training as a key factor in their success. Parents were valued as experts on their own

children and actively influenced and shaped the sessions, and they were supported in a 'positive', 'non-critical' way.

We're not doing very much at all apart from just helping parents to realise they can do it, they've all got the skills there, but it's just getting that confidence back again which I think it's really knocked [by their experiences].

[B1]

The key thing for us that we want to adopt in this sort of approach is ... one of facilitating, [it is] not a taught course, it's not come and learn the top ten tips but these top ten tips will emerge out of it.

[B2]

[The facilitators] are constantly valuing the parents and emphasising that the parents are the expert and not the professionals.

[A2]

Similarly, practitioners described how parents could be more responsive to the views and experience of other parents than they were to the practitioners delivering the programmes.

I can say, "Oh, I've been working with children in these situations for thirty years and my experience is this ..."; [... but] it doesn't have anything like the same impact as another parent saying, "I tried this and it worked really well, not every time but it worked really well a lot of the time". That's got vastly more impact: there's no two ways about that.

[B3]

I think hearing other people's difficulties, and the strategies that they've used to overcome those difficulties is really helpful

[G1]

The group effect

Six of the interventions in this study were delivered through group-mode. We therefore have very rich data on the powerful impact 'the group effect' can have on the effectiveness of an intervention.

For these interventions, the 'group' was seen to support intervention effectiveness by achieving the following:

- increasing openness and honesty
- 'normalising' the problem behaviour.

These features of 'the group' were seen to have a positive impact on parental outcomes, specifically, their perceptions of themselves as parents, their perceptions of their child's problem behaviour and their perceived levels of social and emotional support. Practitioners believed that these group processes could serve to 'boost' parents to such an extent that they felt able to actively engage in doing something about their child's problem behaviour.

'The group' supporting openness and honesty

Practitioners observed that parents appeared to find it less 'shameful' to share details of their child's problem behaviours in a group with other parents experiencing similar difficulties, than to talk about these directly to a professional in a one-to-one situation. Obviously, the more detailed a picture the practitioner has of a problem behaviour, the more effective they can be in their work with that parent.

Parents have said that they haven't really felt comfortable enough to be able to share some of the behaviour that, at times, they're almost ashamed to tell people about, some of the behaviours that the children present. And so to be with other parents [makes them] feel comfortable enough or feel listened to well enough, they're prepared to actually share very personal things.

[A2]

'The group' normalising the problem behaviour

Another powerful effect of the group was to, in a sense, 'normalise' the problem behaviour. This was noted by all the practitioners working in a group mode, including those delivering the one-day workshops.

Practitioners had observed that meeting other parents experiencing similar behaviour or sleep issues helped parents to realise that they were 'not alone' or 'the only one'; this, in turn, helped reduce parents' sense of inadequacy and social isolation.

I think what also helps parents enormously is [the realisation that] I'm not the only one having this problem.

[G1]

Now, to be in a group where there is confirmation that you're not the only one experiencing these difficulties: that cannot be underestimated.

[C1]

Lots of parents say that they thought it was only them going through this difficult time. So it actually helps them emotionally to see that other parents are going through similar things, and it's not down to their parenting.

[H2]

Group composition

Among the practitioners we interviewed, there was a range of views regarding the way that the size and/or composition of the group may affect effectiveness.

Thus, some practitioners believed it was better to match group members as far as possible in terms of the child's age and disability and parents' abilities in order to maximise their learning from each other and to maximise the 'group effect' discussed above. Certainly working with a group where one parent was very different to the rest of the group seemed to present particular difficulties and practitioners were conscious that these parents may not have benefitted from participating in the programme.

I'm not sure how useful it was for [an unaccompanied father]. His child was the only one with significant learning difficulties in the group. So I think he felt that he was in a group with predominantly mums, with children in mainstream school whose problems were insignificant compared to the magnitude of his difficulties. ... So looking at parental characteristics or child characteristics beforehand and matching them might have been a bit better.

[C3]

I think the more homogeneous group the better really, yeah. I've had one group when one parent, who had a child who had very significant learning difficulties, was quite upset by being among a group with everybody else. They, they all had children who were cognitively very able.

[C4]

Working with a group where there was a wide range of children's ages was also seen as potentially problematic – benefitting some but not others.

Sometimes the ones who have younger children say it's nice to know about what they're going to be like when they're older, and the transition issues and the sexuality and all that kind of stuff. But then for another, for one parent it, it was quite upsetting to realise that their child wasn't going to grow up into being not autistic ... and listening to some of the issues that the parents of the older children have.

[C4]

Regarding the size of the group, practitioners believed there were advantages to both small and large groups. Small groups could be easier to facilitate and ensure the full engagement of all parents but, in terms of the family partnership approach, the pool of parental expertise was more limited. Practitioners also noted that with large groups, there is a risk that the teaching approach becomes more didactic, which is counter to what is perceived to be the most effective way of working.

Working with both parents

Some programmes positively encouraged, where appropriate, the direct involvement of both parents and/or other primary carers (such as grandparents). The practitioners who developed these programmes firmly believed it increased the potential effectiveness of the intervention. This was for two key reasons.

First, the programme was viewed by a number of practitioners as a neutral and supportive context in which parents could discuss parenting beliefs and practices.

It's quite a safe and secure environment for parents to sort of both come away with the right messages. So it doesn't end up one feeling that they're empowered and the other one is in catch up.

[B2]

By having both parents there, they can not only learn from each other but learn from you, and be in a safe place to learn it and help each other. It [involving both parents] just really opens it up and it says, "It's OK what you think, and it's OK what you think", because that is hugely important.

[H1]

Second, and in turn, it increased the likelihood of united and consistent parenting.

It's important to get [mum and dad] together so that they have a shared understanding of why it's important to be consistent and to make decisions together as parents, and the best way of doing that is to have them both there and understand the same basic information.

[C3]

If the system [around the child] is able to understand the child, they will be able to understand their behaviour better and therefore manage their behaviour where the child is living. With other family members it's important that they all share that understanding because otherwise the consistency might not be there.

[A5]

Those who did not routinely deliver the intervention to both parents, and/or where this was not possible, noted that this could present difficulties and, indeed, create new problems.

A lot of the time you'll be seeing one parent. It's one of the things that we can get difficulties with if they disagree or, you know, if they're trying to put [a new sleep strategy in place]. It creates more stress in the relationship and things like that.

[F1]

Grandparents

The practitioners we interviewed also noted that grandparents could also be a barrier to positive outcomes either by reducing parents' sense of competence or by a lack of consistency in behaviour management approaches. Interestingly, a number of practitioners, in an aside, noted the need for grandparent-specific programmes: this was particularly the case of grandparents of children with ASC.

[It is really important to include grandparents] in terms of if you think of the support mechanisms we have around childcare generally, the knowledge and information we get we quite often get from our parents, etc, etc. If your own mother cannot understand the disability, and sometimes it's a generational thing, you know, "And didn't have it in my day, he's just a naughty boy," if you can unlock and you can get the light to come on in that grandmother, you're opening up a whole new support avenue for that family, which is really, really important.

[C1]

[Parenting confidence] is often knocked by their own parents as well, and they're telling them things like, you know, I never had these problems with you, so a lot of parents will bring along their own parents to get that sort of backup as well.

[B1]

Flexibility within the programme

A further factor highlighted by some practitioners as supporting programme effectiveness was that the delivery of a programme could, and should, be tailored to different groups of parents. Thus whilst the core elements remained (for example, behaviour theory approaches to managing problem behaviour), there was flexibility within the core structure to respond to the needs of each parent and/or group.

[The programme] has been quite organic in terms of trying to change and adapt to meet people's needs.

[C1]

I say that I think that the most important thing is we listen to what parents want and what they're asking of us and that sometimes, one of the best approaches when you're doing that, is to move on to something slightly different.

[A1]

Practitioner knowledge and skills

Practitioners believed that their skills and knowledge were essential to the effectiveness of the programme they delivered. A certain level of professional qualification and experience, sometimes alongside specific training, is required to deliver all these programmes (see Chapters 3 and 4).

Where the intervention was being delivered to parents of children with ASC, expertise with these conditions was felt to be very important. Those delivering sleep interventions needed to also be knowledgeable about the possible physical and physiological causes of sleep disturbance.

I think they've got to have a great deal of experience of working with families with children with disabilities in a professional role. So they need to have an enormous amount of knowledge about different conditions, syndromes, because you'll get all these acronyms thrown at you during the training, and if you don't know what you're talking about, it makes you look highly unprofessional. So you've got to have enormous knowledge around the physical needs.

[H2]

Working within the 'family partnership' model

Practitioners acknowledged that it could be difficult to adjust to working within the 'family partnership' approach which contrasts strongly with the traditional 'expert model'.

We're asking [facilitators] to shift the way that they work and to go with what the group brings

[A1]

It's up to them what they do with [the information I give them] because you don't want to tell them what to do. I'd say that's one of the major things as a facilitator that you are very conscious of not giving any solutions. So we gave what's in the programme but when they are brainstorming their issues, or sometimes, you know, directly asking for solutions ... you just have to delay, delay as much as possible, and if possible just not to give them the solution but get them ... encourage them to get the solution [for themselves].

[G2]

Working with groups

The core and generic skills associated with group facilitation were, naturally, identified by practitioners during the interviews. This included effective skills in managing groups and group dynamics, listening skills, the ability to engage everyone actively in the group and a positive working relationship with co-facilitators.

Well I'm sure how you actually run [the group] is important, and the ability of the people running the group. It's kind of a difficult one to quantify when you're doing it, but I'm sure it makes a difference. It does in running any group really. You need to kind of actively engage with parents, for them to feel that they've got space to talk and that they're listened to and all of those things. So yeah, that definitely has an impact on the effectiveness of the group.

[A4]

It is about getting to know your facilitator and being relaxed with each other and being sure that you, you worked similarly.

[B1]

In addition, interviewees identified the importance of being able to rapidly respond to the experiences and examples being generated by a group discussion, for example, in order to reinforce learning about basic behavioural principles and/or the features of autism.

The facilitators ... whatever experience a parent shares ... they use that to pull out ... the topics of the autism ... to link it to the theory of autism

[A2]

Practitioners believed that having facilitators from different professional backgrounds was beneficial:

I actually think it works ... really well if you had someone from Children's Services, CAMHS, Health, and Education.
[A2]

There are different skills that we bring but [the facilitator from education] has got much more hands on experience of children ... [while as a psychologist] ... I've got more experience of the emotional issues that arise in families when you have to come to terms with the fact you've got a child with a disability and obviously over the years we've shared skills a lot more.

[B1]

The use of parents as co-facilitators

One of the interventions used parents as co-facilitators. These practitioners noted how this provided added value because of the unique connection this facilitator had with the parents in the group. There was a natural empathy between them and the facilitator was able to draw on and share her own experiences of raising a disabled child.

But it was wonderful to have a parent cos they could actually say I know exactly what you mean ... and [were] happy talking about their own experiences, they did that as well and could really be part of [the group].

[D1]

On-going learning from delivery

Practitioners commonly described how the approach and skills they brought to a programme evolved and developed in response to their experiences delivering it. Whilst the 'hard copy' of the manual may not change, there was a sense of a refinement to skills and an accumulation of experiences which practitioners brought to every new delivery of the programme.

I think now we're much better at getting people into small groups: we match people who have got similar difficulties together: that's something that's really evolved. And we've got better at including everybody and giving everybody a chance to speak.

[D1]

We always say that the materials that we use just constantly evolve. So on paper it may look fairly similar to what we started off with, but what we do is we tend to weave in all the personal stories that we've heard, the strategies that we've heard, new resources that we've found.

[H2]

The one-to-one sleep interventions

The one-to-one sleep interventions did not only differ from the other interventions in terms of mode of delivery, they also had two additional features which practitioners believed were key to positive outcomes:

- a detailed initial assessment, including home visit
- implementation support.

And then I would do a home visit, and with all the families I would need to do at least one initial home visit and that would be to look at the sleep diary and discuss that with parent or parents to really often have a look at the sleeping environment ... the child's bedroom.

[E2]

Implementation support

The one-to-one sleep interventions were unique in that they provided regular, individual and on-going support to parents implementing a sleep management strategy. Practitioners delivering a sleep intervention in this way believed this was essential to successful outcomes.

I think the fact that they know someone is going to be coming back to ask how they're doing ... It is such a difficult thing, if you're not getting sleep yourself. Just to have someone who is there going, "I know this is hard, but you're doing so well!", and "Just remember what your goal is and just remember, you know, what that is". And just having someone to talk through those issues ... acknowledging that it's hard to keep your focus there. I think that is very helpful for families.

[E1]

Delivering implementation support by telephone

Some families receiving Programme E received implementation support over the phone rather than through home visits. Early experience of this alternative approach was positive:

The [specialist health visitor] has been really pleased that often the phone contact has meant has been as effective as a visit. That's not the case with all families, but from being in a situation where we had thought you really need [to do] home visits, [the specialist health visitor] would now say, for certain families ... who she knows she can get hold of and are engaging well ... that actually the phone support worked really well.

[E1]

18.3 The provision of post-intervention support

The issue of post-intervention support to ensure positive outcomes are maintained, increased or generalised was discussed with practitioners. There was broad agreement amongst practitioners about the need for parents to receive ongoing support to help them to maintain positive outcomes in the longer term. However, practice varied across programmes in terms of post-intervention support. Those practitioners offering a repeat programme and those able to provide additional one-to-one support believed that the post-intervention support they delivered impacted positively on parents and children's outcomes.

The option to repeat the programme

In principle, all of the group-based behaviour management programmes allowed parents to repeat the programme if they so desired, particularly if they had had to drop-out of a group due to unforeseen circumstances or because they were not ready to engage with the programme the first time round.

However, the option to repeat the programme was only routinely offered by programme B. Practitioners believed this had become an important way of parents maintaining the positive outcomes associated with this intervention.

Over the years that there have been certain re-attenders ... [for whom] I think it was more about developing their confidence as people, as individuals, and listening to everything we were saying and, and almost applying it to themselves than their children's. So it really, I guess for them, was about a parenting class and a confidence building class and, and they gained a lot from that, so they

came regularly. Others dip in and out and have used it exactly as we've said, to come back for a top-up. Like [parent X] ... [who has] bouts where she thinks she's losing the plot again and thinks she needs to sort of have her confidence boosted, to be told that she is doing a good job and, and, so there's that sort of side to it as well.

[B2]

Post-intervention one-to-one monitoring and support

Parents who remained active cases with a service once a programme was complete were typically able to access further help with their child's sleep or behaviour should they require it. Thus, the two individually delivered sleep interventions, being delivered out of a child development centre and neighbourhood early years centre had on-going contact with parents and were able to monitor progress with the child's sleep and, where necessary, re-introduce specific sleep intervention work with the family. This post-intervention monitoring and input was typically seen as essential to maintaining improvements in the child's sleep:

What you'll sometimes find is that you've had a period of improvement and then something has happened ... like the child's been ill, been in hospital, a new baby's been born ... something's happened and you can see them, them slipping back into the difficulties they've had. In which case [specialist health visitor] would be able to go out and just provide some support again just to bring those back on line. Or sometimes the families themselves will just be in contact and say "Oh we're, we're starting to struggle again". And, and often it [intervening] works much quicker because they really know what they're doing and it was just they just needed that extra bit of [a nudge].

[E1]

If they're still within the catchment of the children's centre of their age I think it is pretty much said, "Yes, come back if you've got any problems".

[F1]

Accessing additional one-to-one work from the service delivering the programme

It was not routine practice to refer families directly on for one-to-one work though occasionally this did happen on the basis of what practitioners had observed during the delivery of a programme. Where this did happen, practitioners noted that the programme provided a very useful foundation on which to build the individual work.

I have found it a useful to refer back to [the programme] when I've been working with people on a one-to-one basis. For example, "Do you remember when we talked about mind blindness? You know, when challenging behaviour comes up, it's because of your child not being able to appreciate other people have had thoughts and feelings". So I have found [pre-attendance on the programme] very useful in those situations.

[A2]

On-going post-programme support

Two services had made arrangements for low level on-going support which parents could access post-intervention. Both services run behaviour and/or sleep interventions routinely and on a relatively frequent basis and have developed a monthly drop-in service where parents can access advice and support from practitioners involved in delivering the parenting programme. The investment made to set up and run these services supports the view that at least some parents may require on-going support to maintain the positive outcomes arising from a parent-training-programme.

One of the things that we've put in place now ... [is a] support morning once a month. So anybody who's been on a workshop or on a sleep programme or just wants to know about us, can come along on this morning and talk to us. So if they've been on a workshop six months ago and they think right, I've had enough now but I can't quite remember what they were on about, they can come along and just talk to us and it can re-boost their confidence or whatever. Or they can come along and say, "Look, I tried that and I tried that and, yeah, things have improved but [now] I'm a bit stuck".

[H1]

Three-month follow-up sessions

Two programmes (C and D) routinely ran a follow-up session. In the case of the other programmes (A and G) this was more of an *ad hoc* arrangement depending on interest from the group. Interestingly, all pitched these meetings at around three month post-intervention. None of the programmes had sought to achieve any formal input and the overall impression was that practitioners were led by the needs and preferences of those who attended. However, a common theme emerging from practitioner accounts was the poor attendance at these follow-up sessions.

Views on why attendance was poor were broadly similar and related to parents having been interested in meeting up again when the group was disbanding, but by the time the follow-up session came around this interest had waned since parents had 'moved on'.

We, we don't necessarily put that three month follow-up in place because we expect everyone to come back or because we think it's necessary. I think what we think is that when you get to the end of the ten weeks it feels like an, an extra safety net for people, like a psychological safety net, and also a way for us to be in, stay in touch with them in case difficulties do get worse or whatever.

[D2]

18.4 The impact of the family context on intervention effectiveness

Competing demands on parents' time and energy

All the practitioners recognised that the everyday pressures of family life made it difficult for parents to find the time to reflect on their learning, to put it into practice and to remain consistent in their parenting approach. Other children, work commitments outside the home, illnesses, bereavement and other life events were among the many things that practitioners said affected the extent to which a parent-training programme could impact on parent and child outcomes.

I think for many parents it's the, the busyness of their lifestyle, with having a child who presents or demands so much time and attention that parents have said sometimes that actually make the time to sit down with the 'Fire Chart' and to, to use it sometimes gets, well often gets crowded out.

[A2]

It is worth noting that some practitioners believed that, given the physical and emotional demands of everyday life for many parents, delivering the programme in the evening was not ideal.

What I would say about that is families would prefer to do a daytime one and we would prefer them to do a daytime intervention. Not just because it is harder to get practitioners to deliver in the evening, it's also about [parents] capacity to

absorb the information in the evening. If you think this is nearly a three hour session now, we've increased the time that we deliver it and we start at quarter past six and finish at about quarter past nine. And if you've done a day's work on top of that or if you've been with young children during all day and then having to do this, your capacity to absorb that information is not as great as the daytime one.

[C1]

Significant or disruptive events

Practitioners also gave examples of highly engaged parents who, following a significant event in their lives which distracts their attention or diverts their energies, had lost the momentum of change.

And so you might have that people are very committed or that they are interested and then the child becomes unwell and then that's not a good time, and then you, you sort of lose that impetus, or something else happens in the family or, you know, just, just multiple things really.

[E1]

Even more minor changes in families' lives were seen to, potentially, disrupt progress with sleep problems (for example, seasonal daylight changes, British Summer Time clock changes, going on holiday and changes in routine (for example, school holidays)).

The time of year and seasonal changes in light affects our children a lot ... the nights either getting lighter or darker affects the kids.

[G2]

Things like Christmas is an absolute nightmare for a lot of our families who have got a child with special needs, cos they don't like the disruption to routine. So Christmas, family holidays, all those kind of things when life's not running just as it should be ... that can be incredibly challenging for the parents. So I think sometimes the sleep problems can slip back and if [pre-invention] they have been co-sleeping with the child, it can be easier to co-sleep than to carry on with the sleep programme that we've put into place, or with the ideas that they've come up with at the workshop.

[H2]

The domestic environment

Finally, and particularly with respect to the sleep interventions, overcrowded housing with inadequate sound insulation or a lack of a suitable bed for the child were obstacles that the programmes found difficult to surmount in terms of achieving improvements in the child's sleep. Indeed, during the interviews a number practitioners gave examples of where an intervention had been suspended until housing and/or equipment difficulties had been resolved.

Families who are in social housing: you're lucky if you've got a three-bedroomed house. So if you've got children with disabilities or children that have got behaviour issues in the middle of the night, and you're trying [to manage them], and you've got other children sharing ... I think that's one of the huge things. That is definitely an issue. You can still do some behavioural stuff around how you respond to a child in the middle of the night and things like that, but it is a lot more difficult.

[F1]

If a child is making a noise overnight and you get complaints from neighbours, and then sometimes the family's been under pressure that they're being reported that their child is crying at night. With a family who maybe is quite concerned about how they're judged by professionals or neighbours, they can feel: "I can't possibly let my child cry overnight", and will try all sorts of ways to pacify them that actually are making the sleep problems more difficult. So there's a lot, lot of [housing] hurdles really to be overcome.

[E1]

[For one family] the bed wasn't appropriate. There was one kid in a cot and she just needed to have a better designed bed ... for a kid that's got ... complex learning disabilities and physical difficulties. That was such a major thing just to get the bed right. ... And that's very expensive and has to be designed according to that child.

[G2]

18.5 Parent-centred factors perceived to impacting on effectiveness

Parents' resilience and mental health

A number of practitioners observed that individual differences in resilience had a bearing on the potential impact on a programme on parent and child outcomes. Some parents, they observed, were better able to deal with the ordinary and the extraordinary stresses of life, and so had a greater capacity to remain consistent and stick with the sleep or behaviour management strategies.

Issues around mental health, even at the 'softer' end of the mental health continuum, were also seen to have the potential to significantly impact on parents' abilities to implement and maintain new parenting approaches. All these programmes require parents to respond in an active way to the input they receive through the programme. For some parents this is demanding in itself. In addition, changes to parenting approaches may lead, initially, to a deterioration in behaviour. Thus embarking on a parent-training programme from a position of emotional vulnerability or weakness is unlikely to yield positive outcomes.

So, you know, I think ... it's a bit like dieting. I think you've got to be extremely positive and at your best to diet. You know, if you're feeling a bit fat and down, you know, you never do it do you?

[G3]

Yeah, life, real life gets in the way. And sometimes if parents are, are feeling low themselves, it's easier to slip back into bad habits.

[H2]

Willingness to engage with the programme approach

In terms of group-delivered interventions, parents' willingness to engage with the programme approach was seen as another key factor influencing outcomes. Specifically, the willingness to engage and share with the group was seen to be very important. However, practitioners acknowledged this could be very difficult for parents. In addition, in order to make progress, parents sometimes had to be prepared to relinquish long-held parenting beliefs and practices.

... sometimes around just television in the room ... that's almost a stock requirement now and it's quite a thing to try and persuade people that really it isn't a basic requirement. Bottles overnight again is ... a very common practice in this area for quite long periods.

[E1]

Acceptance of the child's diagnosis

Practitioners delivering programmes to parents of children with ASC had observed that parents who were still in the process of coming to terms with their child's diagnosis were more likely to find it difficult to change the way they parented their child. A possible reason for this was, practitioners believed, because these parents were not emotionally 'ready' to assimilate the fact that their child's perceptions and experiences of the world were very different to theirs.

Well we've noticed that those parents or families who have been struggling more [with] accepting the diagnosis are the ones that would struggle more in implementing behavioural strategies ... somehow they don't really see that link that actually it's the behaviour, you know, you need to understand the behaviour to manage it.

[A5]

Parents' level of understanding

At one level, and aside from the presence of learning disabilities *per se*, practitioners observed that some parents were more able to understand and assimilate the theoretical concepts and behavioural principles than others. This inevitably, practitioners believed, had a bearing on intervention effectiveness.

Obviously some parents are more able than other parents and pick the ideas up a lot quicker than other parents do. We keep going over it, I still think at the end of it some parents have a much better idea of what you've discussed than other parents do.

[A4]

There will always be some parents who just don't get it.

[C3]

Some practitioners delivering group-based interventions, on noticing a parent was having difficulties assimilating information, tried to provide extra support after or between sessions. Others said they would have liked to have the capacity to do this.

Two groups of parents were, however, particularly identified as being at risk for a lack of understanding of the fundamental concepts underlying the programmes: parents with English as a second language and parents with learning disabilities.

Parents with English as a second language

Practitioners with experience of delivering a programme to parents who do not use English as their first language noted that one of the difficulties encountered was that analogies they had developed to support parents' learning and understanding did not work for these parents.

Cos we've had some where English isn't their first language so might be struggling with some of the concepts ... being aware about some of the language you use, some of those things that we might take for granted ... we might not kind of use some of those metaphors and things really.

[A3]

Parents with learning disabilities

Parents with learning disabilities were a clear group who, practitioners found, struggled to grasp the theoretical concepts behind behavioural approaches to managing sleep and behaviour problems. This lack of understanding subsequently compromised a parent's ability to critically use their new knowledge and to generalise it.

Yeah, I mean it's still quite difficult with parents who have limited abilities themselves, they will be less able to generalise and understand what applies to one child mightn't apply to another.

[B1]

Indeed, one practitioner questioned the appropriateness of a group-delivered programme for parents with learning disabilities.

I think for those parents [with learning disabilities], the answer would be much more about them having support in their own home environment and being able to watch somebody do it, literally watch them manage their child and, and deal with it, and then almost say "Right, your turn, you try". Because they're not necessarily internalising the concepts.

[B2]

Parents' access to informal support

In light of the often overwhelming demands on parents referred to above coupled with the demands of the parent-training programme, it is perhaps unsurprising that practitioners believed that those parents in couple relationships or with a supportive extended family generally found it easier to implement their learning and 'stick with' the programme. Indeed, one programme facilitator went as far as to say she would have no hesitation about advising a single parent without the support of an extended family that the programme might not be a realistic option at this point of time.

If [parents] are not supported, you know, it's all very well learning about all these theories and things you can do, but then if they've got a large family or haven't got supportive husband or partner ... [and] other stresses are going on ... they've just got to function, you know, that functioning's going to come first.

[C2]

If you've got a chance to go home and talk about it with somebody else then you're more likely to be going over it and using the principles and getting support when it's difficult, and it's just widening the chance I think that you're going to have success.

[D1]

18.6 Condition-centred factors

Complex reasons underlying the sleep or behaviour problem

Some practitioners believed that group-delivered interventions were not effective nor, indeed, appropriate where behaviour problems were complex and/or the reasons underlying the behaviour problems were difficult to ascertain.

... most complex behaviour might need more complex understanding and maybe even more sort of individual work. ... You know, you really need to go and meet the child and see his environment and do a bit more work on that assessment there before you can get a good [behaviour management] plan.

[A6]

It is important to note, however, that these programmes were not originally developed to meet the needs of families dealing with complex or challenging behaviour. It may be that, in the absence of any other available support, families are being directed to these programmes. Certainly, they are being used as a 'stop gap' whilst parents are on waiting lists. In these instances, there can be longer-term benefits for parents as it can mean they enter one-to-one work with well developed understanding of behaviour theory etc. (see also earlier section on post-intervention support).

The child has severe learning disabilities

Some of the practitioners using the autism specific-programmes felt the programmes were less suited to those with severe learning disabilities, which was often associated with more complex and challenging behaviour. This was a reflection of the fact these programmes had originally been developed for children with high functioning autism and Asperger syndrome. Adapting the programme, particularly the input on communication, was felt necessary.

However, as noted earlier in this chapter, a strength of these programmes was that the programme could be adapted and tailored for different groups of parents and amended in light of feedback from parents.

We're now getting more and more families with children with severe learning disabilities and their needs are slightly different in some contexts and, again, we've tried to identify that, so we've run some learning disability specific programmes to try and identify where we need to change and adapt the programme. ... So we've done that, to an extent, so we now think the programme is more user friendly for all of those families,

[C1]

In light of earlier comments regarding the composition of groups, it is worth noting that some services chose to run separate groups for parents of children with Aspergers and for parents of children with ASC and learning disabilities.

On-going acute or complex health needs

Practitioners reported that parents of children with on-going acute or complex health needs typically found it more difficult to adhere to a sleep management strategy because they had real fears about the health and safety of their child during the night.

I think the biggest impact is if the child's got significant health issues ... if the child's got epilepsy or ... on oxygen in the night or they've got things where their parent just feels they have to attend to them in the night or they're even in fear of whether ... something's going to happen to them in the night, you know, those sort of things, I think that makes it very, very hard to deal with really. Just

differences of how that condition can affect the child's sleep but also how the parent feels that they have to respond to the child, you've just kind of got two things going on there.

[F1]

18.7 The child's personality

Lastly, it was noted that a child's personality could have a bearing on the success or otherwise of an intervention. Specifically, the speed at which parents were able to observe positive changes in their child's problem behaviour(s) may vary according to the child's personality.

It's not just the fact that the child may or may not have a developmental problem, sometimes it's just the personality of the child. Some children are, you know, more compliant and others are not.

[E1]

18.8 Summary

This chapter sets out the factors which practitioners believe moderate or mediate the effectiveness of parent-delivered sleep and behaviour problem interventions. The length of this chapter captures the complexity of this issue and highlights the significant barriers that can exist to achieving positive outcomes for parents wishing to learn to better manage their child's sleep or behaviour problems. At the same time, however, practitioners were also able to identify factors which support the achievement of positive outcomes for parents and their children. Some of the factors described can either operate as barriers or facilitators to positive outcomes, depending on how a factor is manifest; for example, child's personality, the domestic environment, parental resilience and mental health; parental level of understanding and so on. Figure 18.2 sets out an overview of the factors identified as impacting on the effectiveness of parent-training programmes.

Figure 18.2 Factors identified by practitioners which support or hinder positive outcomes from parent training programmes

The features of the intervention <ul style="list-style-type: none">• the educational aspects of the intervention• the family-partnership approach• the group effect• working with both parents• flexibility within the programme• practitioner knowledge and skills
The provision of post-intervention support
The family context <ul style="list-style-type: none">• competing demands on parents' time and energy• significant or disruptive events• the domestic environment
Parent-centred factors <ul style="list-style-type: none">• Resilience and mental health• Willingness to engage with the programme approach• Acceptance of the child's diagnosis• Level of understanding• Access to informal support
Condition-centred factors <ul style="list-style-type: none">• Complex reasons underlying the sleep or behaviour problem• Severe learning disabilities• Acute or on-going complex health needs
The child's personality

It is important to note that some of the barriers and facilitators to effectiveness set out above are outside of the control of practitioners delivering these interventions and, indeed, the families themselves. In the absence of any other forms of appropriate parenting support it is understandable that sometimes these programmes will be delivered in less than optimal circumstances. However, as noted earlier, in spite of these difficulties, the features of the programmes themselves and parents'/families' willingness to engage with an intervention do mean that positive outcomes are achieved.

The approach encapsulated by the majority of these interventions: group-delivery, interactive and engaging teaching, and adopting a family partnership approach appear, from practitioners' accounts to be key contributors to the potential effectiveness of the programme. In addition, and aligned with the notion of family partnership, is the need to respond to the specific needs of particular groups and/or group members.

Two of the sleep interventions adopt a different approach, choosing one-to-one work with parents. It certainly seems that intervening with children's sleep is a more complex task, even though the behaviour itself might be more 'contained' than daytime behaviours. The

domestic environment and family support are, practitioners believe, important factors in terms of achieving positive outcomes. The very high demands a sleep intervention can make on parents' physical and emotional resources do suggest that one-to-one work would, for some families, be a highly appropriate approach. The use of telephone calls to provide implementation support is an interesting development which we have been able to explore in a preliminary way in this study (see Chapter 16) and about which practitioners (with experience of the mode of delivery) seem optimistic.

One of the issues which is clearly of concern to practitioners involved in delivering these interventions is the provision of post-intervention support. Without this, improvements achieved by the programme may not be maintained, extended or generalised. At the same time, the way in which to deliver that support is vexing: either because practitioners are unclear about how to deliver that support or do not have the resources to do so. The settings where on-going support has proved easiest to deliver is where the programme is delivered by a service in on-going contact with parents.

Chapter 19

Discussion

This report has described the findings from a programme of work which has evaluated exemplars of 'known best practice' with regard to helping parents of disabled children better manage their child's sleep or behaviour problems.

Four behaviour support parent-training programmes and four sleep support interventions have been investigated. We have presented the quantitative evidence on the effectiveness of each of these interventions and, where possible, evidence on costs and cost effectiveness (though this was severely limited by achieved sample sizes). In addition, qualitative evidence has been presented. Here the analysis took a broader approach, considering the views of parents and practitioners as collective groups, thereby extracting a broader understanding of the experiences of services users and practitioners. This has allowed us to generate recommendations or implications for practice which have as wide as possible application.

In Chapter 1 we reported that the existing evidence base on the effectiveness of parent-training¹³⁷ interventions for parents of disabled children was weak and sparse and, we would suggest, reflected the level of provision of such support in the UK. This contrasted with a substantial literature on the effectiveness of parent-training interventions for parents of non-disabled children that has been born out of the development, testing and implementation of a number of now internationally well-established programmes such as *Triple P*, *Incredible Years* and *Strengthening Families*. The appropriateness and suitability of these programmes for parents of disabled children, in terms of the therapeutic content, their effectiveness and parents' experiences of receiving a mainstream intervention, has been questioned. In recent years some programmes have responded to this by creating and publishing a modified version for use with parents of disabled children.

One of the difficulties with providing a parent-training programme to parents of disabled children is that they are a small minority in a much larger population. Thus there is a risk of them being overlooked by mainstream parenting activities at a local level. At the same time, specialist disability services have typically focussed on supporting families through the provision of family support services such as short-breaks, multi-agency key-working and information services, and increasing the inclusion and participation of disabled children and young people in mainstream or community activities.

Yet, there is sound evidence that disabled children, and particularly children with learning disabilities and autistic spectrum conditions (ASC), are much more likely to exhibit sleep or day-time behaviour problems than their non-disabled peers. In addition, these problems are likely to persist and increase in severity. The impacts on the children and their families are wide-ranging and, potentially, significant.

Early in this programme of work we conducted a mapping exercise in which social care, paediatric and education services were invited to report parent-training programmes or interventions being delivered to parents of disabled children. A number of promising interventions were identified and the best and most well-established were selected for participating in this research. All these interventions had been developed from scratch by

¹³⁷ We use this term to infer any intervention or programme where parents are supported by practitioners to change their parenting approaches and/or strategies in order to effect change in their children's day- or night-time behaviours.

practitioners who had found that generic parenting programmes did not fit the bill when it came to providing parenting support to parents of disabled children.

The evidence we have gathered on their effectiveness, while varying in its robustness, is that these are promising interventions that can, for some parents at least, yield positive benefits to them and their disabled child in the short- and medium-term, see Figures 19.1a and 19.1b below. There is also preliminary evidence, emerging from a couple of programmes, that these programmes have the potential to be cost-effective.

Methods and the quality of the evidence

The research team responded to the inadequacies of the existing evidence-base by designing a suite of investigations which, where possible, used a controlled trial design. In addition, 12 and 24 week follow-ups were included in the protocol. Finally, a qualitative element sought to capture stakeholders' experiences of these programmes. These features mean that this research has an important contribution to make to current understanding of the best ways to support parents of disabled children.

Some of the interventions we researched were being delivered in areas of high levels of deprivation, with many parents describing demanding, complex, and sometime chaotic, lives. We are, therefore, very satisfied with the high degree of retention to the research, including at 12 and 24 week follow-up. Post-intervention data was collected for at least 50 per cent of the sample (50%-92% across all interventions; average=81% behaviour interventions; 71% sleep interventions). At 24 week follow-up, the average retention rate to the research was just under 60 per cent (42%-77%). In addition, we are pleased that we were able to recruit families from minority ethnic groups and parents with English as a second (or third) language to both the quantitative and qualitative elements of project. The numbers of parents from these groups recruited to the research reflected the typical demographics of parents accessing the interventions. The time (and linguistic) demands which completing the research instrument placed on parents makes this particularly satisfying.

This research was conducted on interventions being delivered as part of routine practice and, perhaps inevitably, unanticipated events impacted on the research process. Two sleep interventions were particularly affected by this. Where a single practitioner is delivering the intervention, and/or its funding is 'fragile', continuity in delivery of the intervention becomes precarious. At the same time, however, the sample sizes achieved compare very well to those of published studies in this area (see McCaid and Sloper, 2008; Beresford, 2009). Until interventions such as these are being delivered on a more widespread basis sample size will continue to be a problem for research into their effectiveness. Routine outcomes monitoring (including over the medium- to long-term) by services delivering these interventions would help to ameliorate this. However, as we discuss in the final paragraph in this section, a parent-friendly outcome measure capturing their exposure to difficult to manage behaviour, and their confidence in dealing with it, is currently lacking. Practitioners have told us this is a barrier to them routinely collecting data on intervention outcomes.

Smaller than hoped for sample sizes for some interventions has meant that the costs work has not been as extensive as was anticipated. In addition, this has meant that particular investigations may not have been adequately powered to detect change. The interpretation of effectiveness findings has, therefore, been conservative.

Our investigations have reaffirmed the need for any research or outcomes monitoring activities to track intervention outcomes over a follow-up period. There are two main reasons for this. First, outcomes may not be fully achieved immediately post-intervention. Second, the maintenance of improved child and parent outcomes after the immediate post-intervention phase is a key concern.

A final methodological note, and touched on earlier, concerns the adequacy of the measures used, and the lack of a robust measure which captures parent-reported difficult to manage behaviours. We used the Child's Challenging Behaviours Scale for this purpose but it is limited to behaviours in the home and, we would suggest, the wording of some items is unnecessarily complex. We were constrained by a desire not to over-burden parents in terms of the length of the research instrument, but this meant that we were unable to measure other child or parent outcomes which we hypothesise would be affected by a parent-training interventions such as parental well-being, parental knowledge and, in the case of sleep interventions, day-time behaviours. Very few investigations have used both parent-set goals as well as standardised outcome measures. We believe using both was very valuable, with each capturing a different dimension of, or perspective on, intervention outcomes.

Key messages from the research

Each of the chapters reporting research findings concludes with a summary of the findings and the conclusions which can be drawn. These are not replicated here. However, there are some general conclusions or recommendations which are appropriate at this stage and, to support this we have provided an overview of the quantitative evidence on the effectiveness of the interventions, see Figures 19.1a and 19.1b.

The interventions we investigated were developed because practitioners identified a high level of unmet need for parenting support among the families they saw on a day to day basis. This was the consistent experience of professionals working in health, education and voluntary sector settings. Equally, they believed that disability-, and including ASC-specific, parent-training programmes were required to meet this need. Parents also consistently reported that the disability-specific nature of their intervention was one of the factors which encouraged their take-up to an intervention and, they believed, made it an effective. The sometimes very negative experiences of parents whose child was dissimilar to others in the group (in terms of severity of their condition) is, perhaps, an indication of how these parents would feel attending a mainstream parenting intervention. It is worth noting that we did not find that a negative experience of a group was associated with being from what are traditionally regarded as 'minority groups' (either, by ethnicity, language or, in the case of these interventions, gender).¹³⁸

For the behaviour interventions, the use of groups was a deliberate choice made for therapeutic reasons. However, both practitioners and parents acknowledge that, at the stage of take-up, the group-mode is a significant barrier. Parents had some creative but simple ideas in terms of how providing the right sort of information could help overcome this. However, it remains that not all parents like groups. Indeed, for some, they can be a negative experience. We would also draw attention to an issue, raised primarily by practitioners, regarding the suitability of group-based interventions for parents with mental health difficulties or learning disabilities. Thus, whilst the evidence on the effectiveness of group-delivered parenting interventions presented in this report is promising, we would suggest that only providing a group-based parent-training programme will mean that some parents, and perhaps amongst the most needy, will not be able to access the support they require. We would also note that childcare can be an obstacle to parents' with pre-school children accessing group-based support. However, the relative cost of providing this facility is extremely low against the entire cost of the intervention (see Chapter 10).

¹³⁸ Fathers are much less likely to be accessing parent-training interventions.

Figure 19.1a Overview of selected evidence on the effectiveness and costs of the group-delivered behaviour management interventions

Programme	Participants N	Trial arm	Post-intervention				12 week follow-up				24 week follow-up				Mean costs of delivery*						
			Behaviour outcomes		Parent outcomes		Behaviour outcomes		Parent outcomes		Behaviour outcomes		Parent outcomes								
			Goals (% improved)	ECBI-IS	ECBI-PS	CCBS	PSOC-SAT	PSOC-EFF	Goals (% improved)	ECBI-IS	ECBI-PS	CCBS	PSOC-SAT	PSOC-EFF	Goals (% improved)	ECBI-IS	ECBI-PS	CCBS	PSOC-SAT	PSOC-EFF	
A	62	IG ^{AS}	72	✓	✓	≡	✓	✓	87	✓	✓	✓	✓	✓	96	✓	✓	✓	✓	✓	£5,570 (£3,410-£8,325)
		IG ^{LD}			✓	✓	X	✓		=	✓	=	=	X		✓	✓	✓	✓	X	
		CG		=	=	=	X	=				✓	=	✓							
B	40	IG	73	✓	✓	✓	✓	✓	64	=	✓	✓	X	=							£3,635 (£2,385-£4,515)
		CG		=	=	=	=	=		=	=	X	=	✓							
C	68	IG		=	✓	✓	✓	=	91	=	✓	✓	✓	=	89	✓	✓	✓	✓	✓	£2,390 (£1,190-£3,460)
		CG		X	=	=	=	=		=	✓	=	✓	✓							
D	76	IG	79	✓	✓	✓	✓	✓	84	✓	✓	✓	✓	✓	92	=	=	✓	✓	✓	£3,570 (£2,975-£4,590)
		CG		=	X	=	X	=													

Key to table**Programme**

A: 11 wk, autism specific (< 19 yrs)
 B: 6 wk generic disability (3-11 yrs)
 C: 6 wk, autism specific (7-18 yrs)
 D: 10 wk generic disability (4-10 yrs)

Trial arm

IG = intervention group

CG = no-treatment comparator group

Effect size statistic

✓ : positive change in score
 (effect size > 0.2)

= : no change in score
 (effect size -0.19 to +0.19)

X : negative change in score

Outcomes

Goals = % parent-set goals with improved rating

ECBI = Eyberg Child Behaviour Inventory

IS=Intensity Scale (frequency of problem behaviours)

PS=Problem Scale (no. behaviours perceived as problem)

CCBS=Challenging Child Behaviour Scale

PSOC=Parenting Sense of Competence Scale

SAT=Satisfaction with parenting subscale

EFF= Sense of parenting efficacy subscale

AS=ASC no learning disabilities LD=ASC with learning disabilities	(effect size > - 0.2) *Costs of delivery affected by: number of sessions, number and grades of facilitators, number of parents attending and attendance rates.	
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Figure 19.1b Overview selected evidence on the effectiveness and costs of the sleep interventions

Programme	Intervention mode	Participants N	Trial arm	Post-intervention						12 week follow-up						24 week follow-up						Costs of delivery/intervention			
				Sleep Outcomes				Parent outcomes		Sleep outcomes				Parent outcomes		Sleep Outcomes				Parent outcomes					
				Goals (% improved)	CSHQ-Tot	CSHQ-BR	CSHQ-SA	CSHQ-NW	PSOC-SAT	PSOC-EFF	Goals (% improved)	CSHQ-Tot	CSHQ-BR	CSHQ-SA	CSHQ-NW	PSOC-SAT	PSOC-EFF	Goals (% improved)	CSHQ-Tot	CSHQ-BR	CSHQ-SA	CSHQ-NW	PSOC-SAT	PSOC-EFF	
E	1:1	13	HV	60	✓	=	✓	=	✓	=	80	✓	✓	✓	=	✓	✓							£290	
			TS	100	=	✓	✓	=	=	✓	100	✓	✓	✓	✓	=	✓							£165	
F	1:1	12		75	✓	✓	=	=	✓	✓	71	✓	✓	✓	✓	=	=							£195	
G	Gp	23		93	✓	✓	=	=	✓	✓	87	✓	✓	✓	✓	=	✓	78	✓	✓	✓	✓	✓	£1,470-£1700 (max. gp size=8)	
H	W/S	26									65	=	=	=	X	=	=	87	✓	✓	✓	X	=	X	£612/ workshop

Key to table

Programme	Effect size statistic	Outcomes
D: 1 to 1 intervention	✓ : positive change in score (effect size > 0.2)	Goals = % parent-set goals with improved rating CSHQ=Child Sleep Habits Questionnaire CSHQ- TOT= total score CSHQ-BR=bedtime resistance CSHQ-SA=sleep anxiety CSHQ-NW=night waking PSOC=Parenting Sense of Competence Scale
E: 1 to 1 intervention	= : no change in score (effect size -0.19 to +0.19)	
F: 4 session group intervention (Gp)		
G: One day workshop (W/S)	X : negative change in score	
Trial arm		
HV = home visit to support implementation of		

sleep strategy TS = telephone support to support implementation of sleep strategy	(effect size > - 0.2) *Costs of delivery affected by: intervention mode, number of sessions, number and grades of practitioners, (for groups: number of parents attending and attendance rates)	SAT=Satisfaction with parenting subscale EFF= Sense of parenting efficacy subscale
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A second key theme from parents' and professionals' accounts on barriers to take-up, and also intervention effectiveness, was the notion of 'parental readiness'. The ways in which trusted professionals can support parents to 'readiness' was flagged up, but more important is the view that parents may have to be repeatedly offered the chance to attend a parent-training intervention. Delivering these interventions in or through services with which parents are in routine contact (for example, schools, child development centres, early years services) would facilitate this process.

There is good evidence from this study that behaviour management interventions can benefit both parents and children, though maintaining improvements in child behaviour and/or parental sense of competence may be compromised after a few months, see Figure 19.1a. The parents' accounts of attending one of these programmes reveal the very high value placed on the group-delivery mode and the family-partnership approach. A sense of feeling more empowered as a parent emerges as a strong theme in many accounts (and is supported by our quantitative parent outcome measure). The sleep interventions we investigated were delivered through one-to-one work, a group and a one day workshop. For all these interventions the evidence on effectiveness is less robust: sample sizes are small and/or there is no comparator group. However, it is possible to conclude that each of these interventions definitely merit further attention. This should include exploring the relative effectiveness of the different delivery modes in terms of parent characteristics and/or sleep problem severity. Once again, parents' eloquently described feeling empowered to 'do something' about their child's sleep as a result of the intervention they received.

There was a clear sense in the data, therefore, that many parents come to these programmes feeling de-skilled. Indeed, evidence from parents' accounts suggests that this lowered sense of parenting confidence and competence needs to be addressed before we can expect parents to change how they parent. In addition, we would highlight the fact that this sense of being 'de-skilled' was, at least in part, fuelled by parents not being sure what behaviours are 'normal' given their child's condition, and what are 'learnt' problem behaviours which can be addressed by a change in the way they parented the child. This supports the argument for the need for disability-specific, and indeed condition-specific, parent-training interventions which are delivered by practitioners with a sufficient level of expertise in childhood disability and/or a particular condition. Certainly parents with the least positive experiences of these interventions commonly reported that this was due to the programme not being sufficiently tailored to their child's needs and abilities, or the facilitator lacking the necessary knowledge or expertise.

It is important to stress that, unlike much previous research (see McDaid and Sloper, 2008; Beresford, 2009), a wide range of parental educational attainment and socio-economic circumstances were represented. In two of the behaviour interventions and three of the sleep interventions, around two-thirds of parents had no or GCSE-level qualifications only, with paid employment levels following a similar pattern (see Appendix N and O). Our data suggests that parent-training programmes can be an effective intervention for these groups and, for behaviour interventions at least, intervention retention rates are high. However, as we discuss in more detail below, there is evidence that on-going or follow-up support would support maintaining positive outcomes any/or reinforcing the learning achieved throughout programme attendance.

Parents did not typically locate the barriers to achieving positive outcomes in the programmes *per se*. Rather, it was the considerable demands that implementing new learning and changes to their parenting made on their internal resources and resilience, especially in the context of the busy-ness of their everyday lives. The evidence parents provided on this issue was very powerful and practitioners should note that parents need to feel able to do what is being suggested to them. It would seem that implementing sleep strategies is more difficult, and more likely to breakdown, than implementing day-time

behaviour management strategies. On this note, it is important to highlight the preliminary evidence on telephone versus home-visit support which emerged from our investigation of one of the sleep interventions. Telephone support is more convenient for parents and practitioners and is less expensive to deliver. It can also provide support in a more immediate and reactive way. These are all reasons why this approach should be explored further. There is tentative evidence to suggest that practitioners' concerns, as opposed to parents', may be a greater barrier to using this mode to support parents when they are implementing new parenting approaches or strategies.

A supportive partner and/or close family was consistently mentioned by parents and practitioners as enabling positive change. Programmes varied in terms of the extent to which both parents were encouraged to attend and, for many parents, this is not practicable anyway. In which case, developing resources which parents can take home to 'train' other family members may be worth exploring as a way of overcoming this and/or a single session, at a suitable time of day.

Maintaining newly learnt parenting skills and strategies after completion of a parenting support intervention and/or generalising such skills and strategies to new or emerging troublesome behaviours are essential to positive outcomes in the longer term. We were only able to monitor outcomes to 6 months post-intervention. At this time point a number of different 'outcome trajectories' were observed, including: further improvement in outcomes (compared to earlier time points); a deterioration in scores on outcome measures (though not a return to pre-intervention scores); maintenance of improved outcomes recorded at post- or 12 week intervention; or, very unusually, a poorer outcome than was recorded pre-intervention. With respect to this last observed effect, this was only found for scores on measures of parenting competence as opposed to sleep or behaviour outcomes. In addition, during the 6 month follow-up period possible in this study, there was also evidence that parents may experience set-backs or deteriorations before further improvements in their child's sleep or day-time behaviour are secured. Intuitively such experiences would suggest themselves as times when parents may be particularly vulnerable to reverting to previous parenting practices. This, along with the mixed pattern of outcomes observed at 6 month follow-up, aligns with practitioners' beliefs that, for some families, follow-up support may be necessary.

In general, evidence on the long-term outcomes for parents of non-disabled children who have received a parenting intervention (for example, Lindsay et al., 2011; Gardner et al., 2006; Scott et al., 2001) paints a more positive picture than is suggested for parents of disabled children obtained by this study. A number of possible explanations suggest themselves. First, the heightened social isolation of parents of disabled children means they are less likely to be receiving on-going, low level informal parenting support from peers with children of a similar age. Second, the evidence from the qualitative research clearly demonstrated that the presence of disability appears to 'de-skill' parents and, as a consequence, parents are less confident in their abilities to discern behaviours which need 'to be managed' and those which are part and parcel of their child's condition. Parents can also feel de-skilled in the appropriate ways to manage a problem behaviour because of concerns about the child's condition/health. Third, the presence of learning disabilities and autistic spectrum conditions may demand parenting skills which are less intuitive and/or the management of a problem behaviour may require greater perseverance than is required to where there is no cognitive impairment. Finally, parents of children with learning disabilities or autistic spectrum conditions are more likely to have these conditions themselves (albeit in a mild form). It is interesting to note that the authors of one interventions believed that some parents need to attend an entire programme on more than one occasion before they fully assimilates and were able to implement the new parenting approaches being advocated. Parents with learning disabilities were identified as a group of parents who may require such a repeat of the intervention.

Not surprisingly, therefore, the provision of follow-up or on-going support is something that was a significant concern to practitioners, and for which most believed they had not yet achieved a satisfactory solution. Those more satisfied with the on-going support they provided were all based in services which parents routinely used and practitioners were therefore in regular (formal or informal) contact with them. This facilitated the speedy provision of additional support if a need for it emerged, and/or allowed parents to 'top up' or confirm their parenting approaches with a trusted professional, on a formal or informal basis. Sometimes it also was the means by which friendships between parents forged during a programme were maintained. What does not seem to work particularly well are single follow-up meetings organised about three months post-intervention where attendance is very low and there is a lack of clarity, amongst practitioners and parents, as to their purpose.

It is important to stress, however, that there needs to be further research into a number of issues including: the longer-term outcomes of these interventions; what prompts or stimulates the need for follow-up or on-going support; the parenting experiences of parents of disabled children of secondary-school age; the parent- and child-centred factors associated with the need for follow-up support; and the most effective ways of delivering such support.

The evidence on the costs of delivering the intervention is interesting. Staff costs and the size of the group are the main factors driving these costs and this is revealed in the wide range of costs of delivering the interventions – both between programmes and within an intervention depending on which service is delivering it. Clearly, cost effectiveness needs to remain a key element of future research. We would also suggest that further research which explores of intervention effectiveness in terms of practitioner-centred factors (professional role, seniority etc.) and group duration and group size (in the case of group-delivered interventions) would make an important contribution.

Concluding comments

Many parents of disabled children, especially those with learning disabilities or autistic spectrum conditions, will at some stage struggle to manage their child's day-time behaviour and/or sleep. For some, these problems will have a significant impact on parents' and children's well-being, and that of the wider family. Parenting support for this particular group of parents is far less well-established and evidence-based compared to generic, mainstream parent-training programmes.

This study has found that disability, and/or ASC specific, parent-training interventions can help, at least some, parents better manage their child's behaviour problems, with positive gains for both the parent and child being achieved in the short- to medium-term. The four interventions we investigated all produced promising findings. All these interventions are "manualised" and are therefore available to practitioners and services wishing to develop such services (see Appendix P). The evidence on the effectiveness of sleep parent-training interventions, though less robust, is promising. Again, all these interventions are "manualised" and available to other practitioners.

A final note

During the course of conducting this research we have encountered a high level of interest from practitioners, many of whom were seeking to provide parenting support to parents of disabled children. All were keen not to 're-invent' the wheel but, rather, to use a pre-existing intervention for which there is evidence of its effectiveness. We hope that this report proves to be a useful resource for such individuals as well as commissioners of services.

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