Research Report DFE-RR204a

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

Summary Report

Bryony Beresford[+], Lucy Stuttard[+], Susan Clarke[+], Jane Maddison[+] Jennifer Beecham[*]

[+]Social Policy Research Unit, University of York PSSRU, [*]University of Kent

Department for Education

Disclaimer

In May 2008 the Department commissioned the Centre for Excellence and Outcomes (C4EO) to undertake a study into early interventions for disabled children. The Social Policy Research Unit at the University of York, a member of the C4EO consortia, took the lead role in this project.

Introduction

This summary report provides an overview of the findings from 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 (Beresford, et al.,2012).

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). 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 reviews also noted, however, that good quality, robust evidence in the area is very limited and called for studies which adopted more rigorous designs including the use of comparator groups. In addition, the lack of research into parents' experiences of receiving such interventions was highlighted.

The second element of the project drew on the findings of these reviews. A suite of investigations explored the effectiveness, user and practitioner experiences of four behaviour management interventions and four sleep management interventions for parents of disabled children, some of which were specifically designed for parents of children with autistic spectrum conditions.

A full project report is available (Beresford, et al.,2012) alongside a volume of appendices and a research material annexe

https://www.education.gov.uk/publications/RSG/publicationDetail/Page1/DFE-RR181#downloadableparts.

Further outputs from the project, including executive summaries for commissioners, practitioners and parents will be produced shortly.

The purpose of this summary report is to provide the reader with an overview of the rationale and aims of the project, the interventions we investigated, methodology and the key findings. The report concludes by drawing out the key implications for practice. Appendices are used to provide more detailed information on each of the interventions we investigated including: an overview of the intervention; the costs of delivering the intervention; and specific details of the research methods and sample. Some headline evidence on effectiveness is also provided. Information on how to obtain the intervention manual and contact details of the intervention authors is also given.

Key findings

- Practitioners and parents desire disability and/or autism specific parenting support interventions.
- Parents' trust and confidence in the practitioner directing or referring the parent to an intervention is an important factor affecting the decision to attend a programme.
- Parental 'readiness' to address their child's sleep or behaviour problems affects take-up, on-going engagement and intervention outcomes.
- The benefits of such interventions are wide-ranging, with improved parent and child outcomes being described and observed.

- Overall, the evidence shows the interventions yielding, to a greater or lesser extent, positive outcomes both post-intervention and at later follow-up time points for parents and children.

- Strategies for providing on-going or 'top-up' support need to be developed and tested.

- Further work may need to be done on the existing interventions to make them more effective for parents of children with autism at the more severe end of the spectrum.

- The group-delivery mode, whilst a powerful tool, is not suitable (and has the potential to be harmful) for all parents. It can also be a barrier to take-up.

Overviews of each intervention, the design of the evaluation and a selection of some of the quantitative evidence on effectiveness and costs of delivery are provided in the appendices. It is important to note that comparison of findings between interventions should not be undertaken. The demographics of the samples across the interventions differ on key variables 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 intervention 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.

Background

Disabled children, and particularly those with learning disabilities and/or autistic spectrum conditions (ASC), are much more likely to have problems with their sleep or behaviour than non-disabled children. Previous research reports prevalence rates of sleep problems ranging from 34%-80% (Bartlett *et al*., 1985; Richdale and Prior, 1995; Quine, 2001), whilst the rates of behaviour problems are estimated to be three to four times higher in disabled children compared to their non-disabled peers (Baker *et al*., 2002; Volmar and Dykens, 2002; Baker *et al*., 2003; Emerson, 2003a). These problems are typically persistent and do not resolve themselves without intervention (Wiggs and Stores, 1996; Lancioni *et al*., 1999). Indeed, they can become more severe, or difficult to manage, with increasing age. Daytime behaviour problems can threaten children's safety and can interfere with, participation in school, community and social activities and/or accessing other support services (Abbott *et al*., 2000; Kahng and DeLeon, 2008).

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; Herrings *et al*., 2006; Whitaker and Read, 2006). Child sleep problems are associated with high levels of parental stress and irritability (Quine, 1991) and, importantly, increase the risk for, and the severity of, daytime behaviour problems (Wiggs and Stores, 1996a). Over the years a number of studies found parents reporting high levels of unmet need for skills to manage their child's sleep or day-time behaviour (Quine and Pahl, 1989; Beresford, 1995; Wiggs and Stores, 1996b; Chamba *et al*., 1999; Baker *et al*., 2003; Bromley *et al*., 2004).

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 parent-training interventions

Until the 1960s, 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.

"Parent-training interventions", which seek to change, or introduce new, parental behaviours and responses, have been shown to be highly effective among non-disabled children (for example, Campbell, 1995; Taylor, 1998; Barlow, 2000; Lindsay *et al*., 2011). Parent-training programmes (for example, Triple P, Incredible Years) are a key plank of parenting support policies in many developed countries including England (Lindsay *et al*., 2008). All these programmes have been developed for typically developing children and practitioners report finding the need to modify and adapt their content to respond to the particular needs of parents of disabled children (for example, McIntyre *et al*., 2008; Lindsay *et al*, 2011). In response to this the authors of some of these generic interventions have developed disability-specific modifications to their programmes (for example, Stepping Stones Triple P (Sanders, 2004)).

In England there is little evidence, however, that these modified programmes are being delivered to parents of disabled children (see final project report: Appendix B). However, a small number of practitioners (based in CAMHS, special education and the voluntary sector) have developed bespoke parent-training interventions for parents of disabled children, or specifically parents of children with autistic spectrum conditions. The authors have formalised these intervention into a 'manual' or intervention checklist allowing it to be delivered by other practitioners. This study has investigated the effectiveness, costs and experiences of delivering or receiving eight such interventions: four behaviour management programmes and four sleep management interventions.

Study aims

The aims of this study were, through a portfolio of effectiveness investigations and qualitative research, to:

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

Methodology

The interventions were selected following a national, voluntary, mapping exercise of practitioners working in health, education and voluntary sector. The interventions which represented best practice, and where sustained delivery was demonstrated, were selected for the study (Figure 1). Further information about each intervention are provided in the appendices to this summary report (see also Chapters 3 and 4, Appendices C and P of the main report).

Figure 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. (See Appendix A.)
Programme B	A 6 week group-delivered programme for parents of disabled children. Seeks to empower parents to confidently manage their child. (See Appendix B.)
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. (See Appendix C.)
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. (See Appendix D.)
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. (See Appendix E.)
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. (See Appendix F.)
Programme G	A 4 session (over 5 weeks) group-delivered programme. Seeks to help parents better manage their child' sleep difficulties and better understand their child's sleep problems within the context of their disability. (See Appendix G.)
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. (See Appendix H.)

The design of the evaluations

The quantitative element

The aim was, for each intervention, to use a controlled trial design to investigate the effectiveness of a behaviour- or sleep-focused parent training programme in terms of child (behaviour or sleep problems) and parent (parenting sense of competence) outcomes. Comparator groups were to be either being a waiting list or 'no intervention' control group, or different modes of delivering the intervention. The strength of this type of design is that it can potentially demonstrate not only that if the intervention is given, the improved outcome occurs, but that if the intervention is not given, then the outcome does not occur. Outcomes were to be measured pre-intervention, post-intervention and at one or more follow-up intervals (12 week (three months), 24 week (six months)).

The outcome measures used were:

- 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.

The study was conducted on interventions being delivered in service settings and, for that reason, a number of challenges were encountered, particularly in executing the quantitative aspects of the study. Here it was sometimes necessary to deviate from the preferred design. The final design of the quantitative element of each evaluation is set out in Figure 2.

Figure 2 The quantitative element of the evaluations

	COMPARATOR GROUP	**SAMPLE SIZE (PRE-INTERVENTION)**	
Behaviour parent-training programmes			
		Intervention group	Comparator group
Programme A	Waiting list control	41	21
Programme B	No intervention convenience community sample	20	20
Programme C	Waiting list control	35	33
Programme D	Waiting list control (pre- and post-intervention time points only[1])	48	28
Sleep parent-training programmes			
Programme E	Treatment arms: home visit vs. 'phone support	Home visit=6 'Phone support=7	
Programme F	No comparator group	12	
Programme G	No comparator group	23	
Programme H	No comparator group	26	

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

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

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.

The qualitative element

Parents’ experiences of receiving the intervention, and their experiences of implementing and generalising newly learnt skills and strategies were explored through interviews with subsamples of parents receiving each intervention. Parents were purposively sampled to the qualitative element to ensure equal representation of all the interventions and factors such as intervention outcomes, gender, child’s disability, educational attainment, ethnicity and language were represented. 103 parents were interviewed (65 parents had received a behaviour intervention; 38 parents had received a sleep intervention)

Practitioners delivering the interventions were interviewed regarding their experiences of delivering the intervention, its perceived effectiveness, strengths and weaknesses. Thirty-nine practitioners were interviewed (behaviour interventions n=24; sleep interventions n=15).

The costs component

Descriptive information was collected from each service including: 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. Parents completed a short version of the Client Service Receipt Inventory (CSRI) (Beecham and Knapp, 2001).

Findings

Practitioners had developed and/or delivered the interventions under investigation because they recognised high levels of unmet need among parents of disabled children for help with better managing their child’s daytime- or sleep-behaviour. All believed that disability and/or autism specific programmes were required and that generic parent-training programmes were not appropriate. This view was based on their experiences of trying to use such programmes with parents of disabled children. The need for autism-specific parent-training programmes was particularly emphasised because of the close association between how autistic children perceive and experience the world and their behaviour. In addition, parents and practitioners agreed that the divergence of needs and experiences of parents of disabled children compared to other parents meant that generic parent-training programmes could be positively unhelpful and serve to increase parents’ sense of incompetence and social isolation. Chapter 5 of the main report reports these issues in more depth.

Take-up of sleep or behaviour management support

Parents' 'readiness' to address their child's sleep or behaviour problem was a key factor driving parents' decision to take-up the offer of sleep or behaviour management support. Five elements to readiness emerged from parents and practitioners accounts:

- 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 to making those changes.

Practitioners who have on-going contact with a parent, and whom parents trust, can support movement towards a state of readiness.

Behaviour management parent-training programmes tend to be delivered through groups and this mode was recognised as a common barrier to take-up. Strategies to minimise the newness of the experience were seen as important such as: using a familiar venue, known facilitators, one-to-one meetings with a facilitator in advance of the programme, and taster sessions. Providing information which allays parents' concerns was also essential. Key concerns about joining a group were: being judged as a poor parent; speaking up in the group about personal things; having to do things in the group which made them feel uncomfortable. Photographs of facilitators or a previous group 'in progress' were valued sources of information, as was information about what the parent could expect to learn or gain from the programme.

Parents and practitioners both noted that the group mode will not suit all parents and that alternative modes of delivering these sorts of interventions should be available. Childcare and other domestic responsibilities and employment are other key barriers to parents' accessing group-delivered interventions.

A more detailed exploration of the parent-reported factors affecting take-up of behaviour and sleep management interventions can be found in Chapters 6 and 13 of the main report. Practitioners' views on this topic are contained in Chapter 5.

On-going attendance or engagement with the intervention

There was a high degree of concordance between parents and practitioners views of the factors which supported, or acted as barriers to, on-going engagement with a parent-training programme. The predominant factors were:

- unanticipated events and situations
- the experience of positive outcomes (predominantly cited by professionals)
- the practitioners' empathy and skills (mentioned by parents only)
- a growing sense of empowerment and confidence
- the management of missed sessions or appointments

There were two ways unanticipated events or an escalation of a difficult or demanding situation resulted in parents not completing an intervention. Either it meant practical barriers (time, childcare issues) prevented parents attending, or it meant parents no longer had the personal resources (i.e. motivation, commitment, physical or emotional energy) to continue to commit to the programme. This latter issue reflects the fact the parent-training interventions, by their nature, make demands on parents including evaluating and changing their parenting practices.

Practice in how missed sessions or appointments were managed could be a little haphazard and was, perhaps, an area which generated the most criticism from parents attending group delivered interventions. Practitioners described how it could be difficult to discern how proactive to be in working to continue to engage parents. It could also be very time-consuming.

Finally, in terms of group delivered interventions, whether or not a parent found the group a significant source of emotional and social support was a key factor determining on-going attendance. The majority of parents shift from, at the outset, being anxious about joining a group to the group being one the main factors supporting their engagement and attendance. This positive experience is generated from parents learning that their problems and difficulties are not unique and receiving emotional support from others with similar experiences. On the other hand, failing to identify with the rest of group was equally powerful in contributing to a negative, and even harmful, experience.

Cultural and language issues in group interventions

The interviews with parents from minority groups (in this case, minority ethnic groups and fathers) who had attended a group-delivered programme revealed generally positive experiences (see Chapter 6 of the main report for a fuller discussion). Practitioners were more cautious, especially about using interpreters in group delivered interventions although one service felt they had done this successfully (see Chapter 5 of the main report).

Evidence on the effectiveness of the interventions

Quantitative and qualitative data on the outcomes of the interventions and their effectiveness was collected. In this summary report it is only possible to provide ‘headline’ findings and key emerging issues. In the main report, analysis of the quantitative data on outcomes is presented in a series of chapters, one for each intervention (Chapters 7 to 10 (behaviour management interventions); Chapters 14 to 16 (sleep management interventions)).

Parent-identified outcomes

The qualitative interviews provided rich data on the outcomes of attending a parent-training intervention (see Chapter 12 and 17 of the main report). Parents identified positive outcomes in a number of areas arising from receiving sleep or behaviour management support:

- a greater understanding of behavioural principles of managing problem day-time or night-time behaviours
- acquisition of new skills and strategies to manage problem day-time or night-time behaviours
- improvements in their child’s day-time behaviour or sleep.
- improvements in their own well-being, particularly improved sense of parenting competence and confidence.

In addition, and particularly pertinent of parents of children with autistic spectrum conditions, parents described attaining a greater understanding of their child’s condition and how to communicate with them. Parents receiving a sleep management intervention also typically described having a better general understanding of sleep. Parents attending group-delivered interventions also identified positive outcomes associated with a reduced sense of social isolation and feelings of being emotionally supported. Evidence from the accounts of parents receiving a sleep intervention were particularly powerful in demonstrating that empowering and increasing parents’ confidence is often needed before behavioural in parenting practices can be embarked on and achieved.

The quantitative evidence on intervention effectiveness

Overall, the quantitative data on effectiveness, using standardised psychometric measures of parents’ sense of competence and sleep or daytime behaviour, shows that these interventions have a positive impact. The robustness of that evidence is, however, variable due to differences in the research design which was achieved and sample size. Tables 1 and 2 (overleaf) present overviews of findings on effectiveness of the behaviour and sleep interventions respectively using an indicator of clinical significance known as effect size. In this research effect size statistics were used to measure of the size of difference between pre-intervention scores on the outcome measures and scores at other time points. The purpose of presenting evidence on the interventions together is not to encourage comparison between interventions. As noted earlier, this is not possible and should not be undertaken. Rather, our intention is to demonstrate the consistency of findings regarding the positive impact of interventions which support parents to better manage their child's sleep or behaviour problem.

The behaviour management interventions

Robust investigations into the effectiveness of two autism-specific interventions (Programmes A and C) were conducted as part of this study (see Chapters 7 and 9 of the main report). At six month follow-up, improvements in 90% of parent-set child behaviour goals set at the beginning of the intervention was recorded. Changes in scores on standardised measures of child behaviour compared to 'no-intervention' comparator groups suggest that these interventions result in positive changes in child behaviour and that, for at least some parents, these interventions result in positive outcomes. There is some evidence to suggest that parents of children with autism and learning difficulties may not benefit as much from these interventions. However, alternative explanations for our findings may be that the potential for improvement in child behaviour among this group is less, and/or improvements take longer to achieve than other groups due to the level of cognitive impairment. Attendance at these programmes was also associated with positive improvements in parents' sense of competence as parents. Again, parents of children with autism and learning difficulties are less likely to experience this positive effect. This could be related to these parents being more likely to experience fewer or smaller changes in their child's behaviour compared to others attending the programme. At six months follow-up improvements in some, but not all, areas of parent-reported child behaviour and parents' sense of competence had been maintained.

Two disability specific behaviour management interventions were also studied (see Chapters 8 and 10 of the main report). The smaller than ideal sample size for one of these investigations (Programme B) means that findings comparing intervention and control group outcomes should be interpreted cautiously. However, it is useful to note that at post-intervention, 87% of parent-set goals had improved from their previous rating. Regarding Programme D, there is robust evidence that this is an effective intervention for at least some parents of disabled children. At six month follow-up, improvements in 90% of parent-set child behaviour goals set at the beginning of the intervention was recorded. Generally, improvements in parent-reported child behaviour and parents' sense of competence observed post-intervention was maintained at 12 week follow-up, but gains in child behaviour outcomes appeared to be declining at six-month follow-up.

The sleep management interventions

The sleep management interventions studied were more diverse, and the investigations more preliminary. This reflects the under-development of these services in England which necessarily impacts on recruitment, sample size and the availability of waiting list control groups. One-to-one interventions (see main report Chapter 14), a group delivered sleep management programme (see main report Chapter 15), and a one-day workshop (see main report Chapter 16) were examined. Importantly, there are no 'no-treatment' control groups for any of these investigations. Thus we cannot be certain that the outcomes reported below can be ascribed to the intervention.

Changes in the attainment ratings on parent-set sleep goals were typically in a positive direction over the period of the study. At 12 week follow-up, an average of 84% of parents receiving one-to-one support reported positive progress towards achieving their goals for their child's sleep. Equally, for the group-delivered intervention progress was recorded in achieving 87% of parent-set sleep goals, though dropping slightly to 78% at 24 week follow-up. Goal attainment ratings for two thirds of goals set by parents attending the one-day workshop had improved at 12 week follow-up, with this figure rising to 87% at 24 week follow-up. Positive changes on at least some standardised measures of sleep and parents' sense of competence were also observed for all these interventions. Two particular features of these interventions should be particularly highlighted. First, the study findings would support further investigation into the effectiveness of delivering one-to-one support as parents implement sleep strategies using telephone calls as opposed to home visits. Second, the use of groups to deliver sleep management training is relatively novel but the evidence from this study is that this approach merits continued development and further investigation.

The issue of supporting the maintenance improved child behaviour and parents' sense of competence was a key theme emerging from the interviews with practitioners. They acknowledged that this was an area which needed for further attention and that, for some families, low level or 'top-up' support was needed following attendance at a parent-training programme.

Factors impacting on outcomes

There was close agreement between parents and practitioners on the factors which support or hinder effectiveness (see Chapters 12, 17 and 18 of the main report). These included:

- Accessible and effective educational elements which increase parental knowledge and understanding;
  - however, the group mode may not be an effective setting to deliver this information to parents with learning difficulties, language or literacy problems.
  - some parents appear to struggle more with generalising behavioural theory and behavioural approaches to managing new and emerging problem behaviours.
- The skills and knowledge of the facilitators;
  - the disability and/or autism specific knowledge and expertise was identified by parents and practitioners as being an essential component of the interventions alongside the disability/autism specific 'content' of the intervention.
  - facilitator skills are essential to generating the therapeutic 'added-value' associated with group-delivered interventions.
- An intervention approach which empowers parents;
  - however, some parents may not have the mental, emotional or physical resources to be active partners in an intervention. Some parents may require more support than others to bring about changes in their parenting.
    - It would seem that intervening with sleep problems is more likely to require this level of support.
    - Parents experiencing multiple demands but with low access to support and other resources may require a higher level of support.
  - a minority of parents expect, and want, a more prescriptive approach
- A wide range of contextual factors can support or jeopardise individual outcomes including:
  - life events, over-crowded housing
  - unsupportive or uncooperative family members can significantly hinder consistent parenting practices and undermine a parent's efforts to change the family's approach to managing sleep or behaviour problems.

Table 1: Overview of selected evidence on the effectiveness of behaviour interventions

Programme	Participants N	Trial arm	**Post-intervention**						**12 week follow-up**						**24 week follow-up**					
			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	**√**	**√**	**√**	**√**	**√**
		IG^{LD}	-		**√**	**√**	**X**	**√**		**=**	**√**	**=**	**=**	**X**		**√**	**√**	**√**	**√**	**X**
		CG	-	**=**	**=**	**=**	**X**	**=**				**√**	**=**	**√**						
B	40	IG	73	**√**	**√**	**√**	**√**	**√**	64	**=**	**√**	**√**	**X**	**=**						
		CG		**=**		**=**	**=**	**=**		**=**	**=**	**x**	**=**	**√**						
C	68	IG	-	**=**	**√**	**√**	**√**	**=**	91	**=**	**√**	**√**	**√**	**=**	89	**√**	**√**	**√**	**√**	**√**
		CG	-	**X**	**=**	**=**	**=**	**=**		**=**	**√**	**=**	**√**	**√**						
D	76	IG	79	**√**	**√**	**√**	**√**	**√**	84	**√**	**√**	**√**	**√**	**√**	92	**=**	**=**	**√**	**√**	**√**
		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 AS=ASC no learning disabilities LD=ASC with learning disabilities	**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 (effect size > - 0.2)	**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

Table 2: Overview selected evidence of the effectiveness of the sleep interventions

Programme	Participants N	Trial arm	Post-intervention							12 week follow-up							24 week follow-up						
			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	CHSQ-NW	PSOC-SAT	PSOC-EFF
D	13	HV	60	**√**	**=**	**√**	**=**	**√**	**=**	80	**√**	**√**	**√**	**=**	**√**	**√**							
		TS	100	**=**	**√**	**√**	**=**	**=**	**√**	100	**√**	**√**	**√**	**√**	**=**	**√**							
E	12		75	**√**	**√**	**=**	**=**	**√**	**√**	71	**√**	**√**	**√**	**√**	**=**	**=**							
F	23		93	**√**	**√**	**=**	**=**	**√**	**√**	87	**√**	**√**	**√**	**√**	**=**	√	78	**√**	**√**	**√**	**√**	**√**	**√**
G	26									65	**=**	**=**	**=**	**X**	**=**	**=**	87	**√**	**√**	**√**	**X**	**=**	**X**

Key to table

Programme	**Effect size statistic**	**Outcomes**
D: 1 to 1 intervention E: 1 to 1 intervention F: 4 session group intervention G: One day workshop **Trial arm** HV = home visit to support implementation of sleep strategy TS = telephone support to support implementation of sleep strategy	**√ :** positive change in score (effect size > 0.2) **= :** no change in score (effect size -0.19 to +0.19) **X** : negative 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 SAT=Satisfaction with parenting subscale EFF= Sense of parenting efficacy subscale

Conclusions and Implications

The evidence that many parents of disabled children are likely to need help with managing their child's behaviour or sleep is well-established. However, parents and practitioners do not believe generic or mainstream parenting programmes are appropriate or effective. As a result parenting support for these families seems to have fallen between the two stools of parenting support policies and activities, and specialist family support services for parents of disabled children.

The overall finding from this study is that there are disability- and autism-specific interventions to help parents better manage their child's sleep or behaviour problems currently being delivered in England, albeit in a relatively small scale way, that are effective ways of providing 'early intervention' parenting support to at least some parents of disabled children.

In terms of the behaviour-management interventions, commissioners and practitioners should be encouraged to deliver these interventions, where there is at least some evidence on effectiveness, rather than 're-inventing the wheel' and, at a local level, developing and delivering new, untested interventions. As delivery of these interventions becomes more widespread it will be possible to conduct further, research into their effectiveness and explore more closely demographic, child- and disability-centred factors which may impact on effectiveness.

The limitations of the research design and sample size means the evidence base on the effectiveness of the sleep-management interventions is less secure and the conclusions drawn have been more circumspect. However, we would argue that there is sufficient evidence to support the continued delivery of these interventions. Again, increased and more wide-spread delivery of these interventions will provide important opportunities for more robust testing of their effectiveness.

It is important to stress, however, that none of these interventions should be regarded as the sole solution to early intervention parenting support for parents of disabled children. As we discuss below, a range of modes of delivery is necessary in order to accommodate parents' different needs, abilities and circumstances.

When designing these evaluations a compromise had to be reached between the burden on research participants and supporting high response rates versus collecting data on a wide range of outcomes. As a result we were not able to explore whether the sleep interventions investigated had any impact on the child's day-time behaviour. However, evidence from previous research shows a clear association between the two. This would suggest that any parenting support strategy for parents of disabled children needs to incorporate support to manage both day-time and sleep behaviour problems.

The interventions we investigated were typically being delivered through multi-agency partnerships between CAMHS, children's/education services and/or the voluntary sector. Programmes delivered by services or agencies in routine contact with families have the advantage of being able to work with families to support their 'readiness' to receive such interventions, to most easily manage missed sessions or appointments, and to provide on-going support.

A dominant model across the interventions was the notion of the family partnership approach (David and Day, 2010) which empowers parents to generate and implement their own solutions whilst being positively guided by the knowledge and experience of appropriately skilled facilitators. Parents and practitioners identified this element of the interventions as a key factor contributing to both on-going engagement with the programme and positive outcomes, particularly parents' increased sense of competence. It seems addressing this lack of parenting confidence is key to achieving positive outcomes in terms of the child's sleep or behaviour and should, therefore, be a core element to any intervention.

All the behaviour management interventions we investigated were delivered in group mode. This was, in itself, a very powerful therapeutic environment. At the same time, it was very clear that a small minority of parents did not find the group mode a positive experience and it may result in negative outcomes – particularly in terms of parents' sense of competence. Practitioners were also very clear that some parents, particularly those with learning difficulties or mental health problems, may not benefit from a group-delivered intervention. In addition, using groups to deliver interventions may be a barrier to take-up. It is crucial, therefore, that groups are one of a number of parenting support interventions which parents of disabled children can access. The evidence from the sleep interventions we investigated which included one-to-one, group and workshop delivery modes usefully highlighted the advantages and disadvantages of these different modes.

The evidence on outcomes at 24 week follow-up is mixed. Sometimes, greatest improvements on outcome measures were recorded at this time point. This may reflect the fact that some day or night problem behaviours take longer to resolve than others and/or were more severe at the outset. Continually improving scores may also be a reflection of parents generalising the skills and strategies learnt during the intervention to other problem behaviours and/or a growing confidence in their abilities as a parent. We have not, within the scope of this study, been able to explore this issue more fully. It does, however, warrant more research attention. Equally, it is important to highlight the evidence which suggests that, sometimes, positive gains observed immediately post-intervention and/or 12 week follow-up were not maintained at 24 week follow-up. We can hypothesise that a number of factors are potentially at play here. First, the lack of on-going support leads to parents returning to previous parenting practices. Second, parents fail to generalise the skills and strategies they have learnt when faced with new or emerging behaviours.

Certainly the accounts of parents and practitioners point to the need for parenting support interventions to incorporate longer-term support strategies. This might either be in terms of low level, informal support; easy access back to practitioner advice/support or some sort of regular 'top-up'. Whatever developments take place with regard to this need to be monitored or evaluated as this is an area where there is no evidence on 'what works'.

Informing future practice and commissioning decisions regarding parenting support for parents of disabled children: key messages from the research

- Preventive or early intervention support to parents of disabled children which helps them to manage their child's sleep or behaviour needs to be 'disability- (or autism-) specific'.

- Disability-specific sleep and behaviour interventions have been developed and are being routinely delivered (albeit in a relatively limited way) by health, mental health, education and social care practitioners.

- The evidence regarding the effectiveness of the four behaviour management interventions we investigated is sufficiently robust to recommend the use of these interventions and to caution against investing in the development of new interventions/programmes.

- All the behaviour support interventions investigated were group-delivered. This can be a powerful and effective mode of delivery; however, it is not suitable for all parents, nor will all parents find this an acceptable mode of delivery. A 'menu' of parenting support options is therefore required.

- Sleep support to parents of disabled children appears to be less available but much needed by parents. Individual, group-delivered and single day-workshops are all approaches which have been developed by practitioners to provide early intervention/preventive support. Preliminary evidence from this programme of work suggests these approaches have the potential to be effective interventions.

- As with behaviour support, the specific needs and situation of the parent, and the severity of the sleep problem, are factors which will determine the suitability of delivery mode.

- Practitioners need to pay careful attention to the mechanisms by which parents will be referred to, or will access, such interventions. The use of ‘trusted professionals’ is recommended. Preliminary work with parents so that they feel ‘ready’ to address their child’s sleep or behaviour problem may be required.

- Parents respond very positively to interventions (and practitioners) which value their own expertise and knowledge and which provides opportunities for them, individually or as a group, to identify and develop their own solutions.

- It was only possible to investigate intervention outcomes to 6 months post-intervention, and there was some evidence of loss of earlier positive child and parent outcomes at that time point. Finding an effective and appropriate way to provide follow-up or ‘top-up’ support was identified as a key challenge by practitioners and is clearly an important consideration for the future delivery and refinement of these programmes.

- Finally, adolescent-specific parenting support interventions were not investigated by this programme of research. There is, however, strong evidence from the wider body of research for the need for such support. Our systematic review of evidence (Beresford, 2009) did not identify any research on adolescent-specific interventions suggesting there is a pressing need for research in this area and, perhaps, the need for such interventions to be developed.

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Appendices

Appendix A: Intervention A - overview of the investigation and key findings

ASCEND (Autistic Spectrum Conditions – Enhancing Nurture and Development) *An 11 week, group delivered parent-training programme for parents of children with Autistic Spectrum Conditions (ASC) (Intervention details overleaf)*			
Mean costs of delivering the intervention		£5,750	
Research design	Controlled trial: intervention (IG) & waiting list control (CG) groups. Outcomes measured pre- & post-intervention; 12 & 24 week follow-up (IG only). Intervention integrity=90%. IG & CG generally well matched at baseline. IG recruited from 5 deliveries of ASCEND.		
Sample	IG= 41; CG=21. Retention rates: post-intervention=77%; 12 wk f/up=74%; 24 week f/up=51%.		
EVIDENCE ON EFFECTIVENESS[2]			
	Post-intervention	**12 week follow-up**	**24 week follow-up**
PARENT-SET GOALS (% improved)	72%	87%	96%
	Effect size statistic[3]		
PARENTING SENSE OF COMPETENCE: Satisfaction subscale *(Satisfaction with the parenting role)*			
IG-ASC only	0.3	0.52	0.63
IG- ASC & learning difficulties	-0.23	0.08	0.32
CG	*-0.22*	*0.01*	--
PARENTING SENSE OF COMPETENCE: Efficacy subscale *(Feelings of efficacy as a parent)*			
IG-ASC only	0.59	0.52	0.37
IG- ASC & learning difficulties	0.44	-0.33	-0.20
CG	*0.17*	*0.26*	--
EYBERG CHILD BEHAVIOUR INVENTORY: Intensity scale *(Frequency of disruptive behaviours)*			
IG-ASC only	0.45	0.28	0.41
IG- ASC & learning difficulties	0.18	0.11	0.21
CG	*-0.05*	--	--
EYBERG CHILD BEHAVIOUR INVENTORY: Problem Scale *(No. behaviours perceived as a problem)*			
IG-ASC only	0.48	0.29	0.56
IG- ASC & learning difficulties	0.21	0.41	0.22
CG	*0.10*	--	--
CHALLENGING CHILD BEHAVIOUR SCALE			
IG-ASC only	0.11	0.41	0.54
IG- ASC & learning difficulties	0.28	0.11	0.32
CG	*0.07*	*0.41*	--

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[2] Intervention effectiveness was examined using tests to measure the statistical significance of changes in scores on outcome measures (ANCOVA), and tests of clinical significance (i.e. reliable change, effect size, movement around clinical cut-off points). Full reports of these analyses are presented in the project report. Here we present effect size data only.

[3] The effect size statistic quantifies the difference between scores taken at two time points. 0.2 is defined as a ‘small’ effect size, 0.5 as a medium effect size, and 0.8 as a ‘large’ effect size. Effect size is calculated by dividing the difference between the means by the pooled standard deviation. A negative effect size indicates deterioration.

ASCEND (Autism Spectrum Conditions – Enhancing Nurture and Development) **INTERVENTION OVERVIEW**	
Aims	To increase understanding of children with ASC, to empower parents to address specific behaviours and to support their child's behavioural development.
Mode	Group (up to 20 participants per programme). Intervention authors believe most successful when run for the parents of eight to ten children.
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. 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.
Homework	Session handouts provided. Optional homework exercises to reinforce learning.
Facilitators	Qualified therapists, including child psychiatrists, clinical psychologists, community psychiatric nurses etc. with experience of working with families of children with ASCs. The number of facilitators per session depends upon the group size. The sessions exploring individual problems and strategies work best with one individual facilitator per child represented. The course can be run using the manual by suitably qualified professionals. However, the authors are happy to contacted about running training courses for professionals interested in starting their own ASCEND programmes.
Follow-up	Ad hoc follow-up workshops/informal social reunion meeting may be arranged.
Manual details	Wright, B. & Williams, C. 2007. *Intervention and Support for Parents and Carers of Children on the Autism Spectrum: A Resource for Trainers*. London: Jessica Kingsley Publishers.
Contact for further information	Dr Chris Williams, Consultant Child Clinical Psychologist, CAMHS (Lime Trees), 31, Shipton Rd, York. YO30 5RF. Tel: 01904 726610
Associated Publications	Williams, C. & Wright, B. 2004. *How to live with Autism and Asperger Syndrome: Practical strategies for Parents and Professionals*, London, UK, Jessica Kingsley Publishers. Pillay, M., Alderson Day, B., Wright, B., Williams, C. & Urwin, B. 2011. Autism Spectrum Conditions - Enhancing Nurture and Development (ASCEND): An evaluation of intervention support groups for parents. *Clinical Child Psychology and Psychiatry*, 16, 5-20.

Appendix B: Intervention B - overview of the investigation and key findings

Confident Parenting *A 6 week, group delivered parent-training programme for parents of disabled children. (Intervention details overleaf)*		
Mean costs of delivering the intervention	£3,635	
Research design	Controlled trial: intervention (IG) & no-intervention comparator (CG) groups. Outcomes measured pre- & post-intervention; 12 week follow-up. IG & CG well matched at baseline apart from IG reporting child behaviour more problematic and fewer education qualifications[4]. IG recruited from 6 deliveries of Confident Parenting.	
Sample	IG= 20; CG=20. Retention rates: post.=90%; 12 wk f/up=80%.	
EVIDENCE ON EFFECTIVENESS[5]		
	Post-intervention	**12 week follow-up**
PARENT-SET GOALS (% improved)	73%	64%
	Effect size statistic[6]	
PARENTING SENSE OF COMPETENCE: Satisfaction subscale *(Satisfaction with the parenting role)*		
IG	0.2	-0.33
CG	*0.1*	*0.04*
PARENTING SENSE OF COMPETENCE: Efficacy subscale *(Feelings of efficacy as a parent)*		
IG-ASC only	0.44	-0.05
CG	*0.13*	*0.20*
EYBERG CHILD BEHAVIOUR INVENTORY: Intensity scale *(Frequency of disruptive behaviours)*		
IG	0.25	0.10
CG	*-0.05*	*0.04*
EYBERG CHILD BEHAVIOUR INVENTORY: Problem Scale *(No. behaviours perceived as a problem)*		
IG	0.30	0.24
CG	*0.27*	*0.03*
CHALLENGING CHILD BEHAVIOUR SCALE		
IG	0.33	0.21
CG	*-0.01*	*-0.30*

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[4] These factors were subsequently entered as co-variates in analyses to measure effectiveness.

[5] Intervention effectiveness was examined using tests to measure the statistical significance of changes in scores on outcome measures (ANCOVA), and tests of clinical significance (i.e. reliable change, effect size, movement around clinical cut-off points). Full reports of these analyses are presented in the project report. Here we present effect size data only.

[6] The effect size statistic quantifies the difference between scores taken at two time points. 0.2 is defined as a ‘small’ effect size, 0.5 as a medium effect size, and 0.8 as a ‘large’ effect size. Effect size is calculated by dividing the difference between the means by the pooled standard deviation. A negative effect size indicates deterioration.

Confident Parenting INTERVENTION OVERVIEW	
Aims	To empower parents to confidently manage their child.
Mode	Group. Intervention authors note that it is difficult to manage a group of more than 8 families or 12 participants.
Target population	Parents of primary-school aged disabled children (3-11 years), including ASC, learning and complex disabilities. Other family members and family friends can also attend.
Age range	Pre-school and primary school aged children.
Structure & approach	6, weekly 2 hour sessions. No prescribed format. A facilitator's handbook sets out the approach and core elements which should be addressed during the programme. These include: parental feelings; parenting skills and strategies; communication; developing the child's skills; working together with other family members. 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. One or two additional 'parent pampering' session(s) (for example, relaxation techniques, aromatherapy) may be delivered at the end of course.
Homework	Handouts including 'top tips' and summary of themes/advice discussed each week. Homework tasks are not assigned though parents are encouraged to consider and modify a parenting/behaviour area each week.
Facilitators	Three facilitators, two of whom with requisite skills and experience (for example, clinical psychologists, special needs teachers).
Follow-up	No routine follow up session is delivered. However, in the site where this research was located, parents are able to re-attend the programme.
Manual details	Hames, A., Rollings, C. & Janes, E. 2009. Confident Parenting. A guide for group facilitators, HEADS. http://www.headstraining.co.uk
Contact for further information	HEADS Office, Hadrian School, Bertam Crescent, Newcastle upon Tyne. NE15 6PY. Tel: 0191272 4440. admin@hadrian.newcastle.sch.uk
Associated Publications	Hames, A. & Rollings, C. 2009. A group for the parents and carers of children with severe learning difficulties and challenging behaviour. *Educational and Child Psychology*, 26, 47-54.

Appendix C: Intervention C: Overview of the investigation and key findings

CYGNET Parenting Support Programme *A 6 week, group delivered parent-training programme for parents of children with Autistic Spectrum Conditions (ASC). (Intervention details overleaf.)*			
Mean costs of delivering the intervention	£2,390		
Research design	Controlled trial: intervention (IG) & waiting list control (CG) groups. Outcomes measured pre- & post-intervention; 12 & 24 week follow-up (IG only). Intervention integrity=97%. IG & CG well matched at baseline. IG recruited from 7 deliveries of CYGNET.		
Sample	IG= 35; CG=33. Retention rates: post-intervention=82%; 12 wk f/up=76%; 24 week f/up=77%.		
EVIDENCE ON EFFECTIVENESS[7]			
	Post-intervention	**12 week follow-up**	**24 week follow-up**
PARENT-SET GOALS (% improved)	--	91%	89%
	Effect size statistic[8]		
PARENTING SENSE OF COMPETENCE: Satisfaction subscale *(Satisfaction with the parenting role)*			
IG	0.33	0.55	0.48
CG	*-0.18*	*0.20*	--
PARENTING SENSE OF COMPETENCE: Efficacy subscale *(Feelings of efficacy as a parent)*			
IG	0.18	0.14	0.59
CG	*0.11*	*0.41*	--
EYBERG CHILD BEHAVIOUR INVENTORY: Intensity scale *(Frequency of disruptive behaviours)*			
IG	0.02	0.18	0.24
CG	*-0.20*	*0.07*	--
EYBERG CHILD BEHAVIOUR INVENTORY: Problem Scale *(No. behaviours perceived as a problem)*			
IG	0.52	0.77	0.80
CG	*-0.06*	*0.28*	--
CHALLENGING CHILD BEHAVIOUR SCALE			
IG	0.20	0.32	0.20
CG	*-0.15*	*-0.04*	--

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[7] Intervention effectiveness was examined using tests to measure the statistical significance of changes in scores on outcome measures (ANCOVA), and tests of clinical significance (i.e. reliable change, effect size, movement around clinical cut-off points). Full reports of these analyses are presented in the project report. Here we present effect size data only.

[8] The effect size statistic quantifies the difference between scores taken at two time points. 0.2 is defined as a 'small' effect size, 0.5 as a medium effect size, and 0.8 as a 'large' effect size. Effect size is calculated by dividing the difference between the means by the pooled standard deviation. A negative effect size indicates deterioration.

CYGNET Parenting Support Programme INTERVENTION OVERVIEW	
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	Group. Intervention authors recommended that there are no more than 12 parents/carers attending a group.
Target population	Parents of children with Autism Spectrum Conditions (ASCs). Other family members may attend.
Age range	7-18 years
Structure & approach	6, weekly 2 ½-hour sessions. 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.
Homework	Session handouts provided. Optional homework exercises to reinforce learning.
Facilitators	Two to three facilitators per group working in field of autism. Can be drawn from range of professional groups including clinical psychology, education and the voluntary sector and parents. Lead facilitators are required to attend training in the approach.
Follow-up	No formal follow-up. Parents are invited to an informal social reunion three months after completing the programme.
Manual details	*The Cygnet Parenting Support Programme: 2010. Trainer's notes with handouts and evaluation sheets.* Barnardo's. http://www.barnardos.org.uk/yk_cygnet-parents_carers_support_programme.htm
Contact for further information	Andy Morris (Cygnet Training Coordinator), Cygnet Parenting Support Service, Queens Road, Bradford. BD8 7BS Tel: 01274 481183. Email: andy.morris@barnardos.org.uk
Associated Publications	Raghavan, R. 2008. *Cygnet Autistic Spectrum Training Programme for Parents: Evaluation Report*. Northumbria University. Barnardo's 2006 - 2010*. Barnardo's Cygnet Service (2006-2010) Evaluation Reports*. Barnardo's, Queen's Road, Bradford. Robson, K. 2010. *Birmingham CAMHS Cygnet Evaluation*. Birmingham CAMHS.

Appendix D: Intervention D - overview of the investigation and key findings

Riding the Rapids: Living with autism or disability
A 10 week, group delivered parent-training programme for parents of children
with Autistic Spectrum Conditions (ASC) and other disabilities. (Intervention details overleaf)

Mean costs of delivering the intervention	£3570
Research design	Controlled trial: intervention (IG) & waiting list control (CG) groups. Outcomes measured pre- & post-intervention; 12 & 24 week follow-up (both IG only). Intervention integrity=97%. IG & CG well matched at baseline. IG recruited from 8 deliveries of *Riding the Rapids*.
Sample	IG= 48; CG=28. Retention rates: post-intervention=75%; 12 wk f/up=67%; 24 week f/up=53%.

EVIDENCE ON EFFECTIVENESS[9]

	Post-intervention	**12 week follow-up**	**24 week follow-up**
PARENT-SET GOALS (% improved)	79%	84%	92%
	Effect size statistic[10]		
PARENTING SENSE OF COMPETENCE: Satisfaction subscale *(Satisfaction with the parenting role)*			
IG	0.59	0.54	0.50
CG	*-0.42*	--	--
PARENTING SENSE OF COMPETENCE: Efficacy subscale *(Feelings of efficacy as a parent)*			
IG	0.64	0.51	0.29
CG	*0.04*	--	--
EYBERG CHILD BEHAVIOUR INVENTORY: Intensity scale *(Frequency of disruptive behaviours)*			
IG	0.27	0.37	-0.06
CG	*-0.19*	--	--
EYBERG CHILD BEHAVIOUR INVENTORY: Problem Scale *(No. behaviours perceived as a problem)*			
IG	0.67	0.35	0.15
CG	*-0.23*	--	--
CHALLENGING CHILD BEHAVIOUR SCALE			
IG	0.39	0.48	0.53
CG	*-0.01*	--	--

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[9] Intervention effectiveness was examined using tests to measure the statistical significance of changes in scores on outcome measures (ANCOVA), and tests of clinical significance (i.e. reliable change, effect size, movement around clinical cut-off points). Full reports of these analyses are presented in the project report. Here we present effect size data only.

[10] The effect size statistic quantifies the difference between scores taken at two time points. 0.2 is defined as a 'small' effect size, 0.5 as a medium effect size, and 0.8 as a 'large' effect size. Effect size is calculated by dividing the difference between the means by the pooled standard deviation. A negative effect size indicates deterioration.

Riding the Rapids: Living with autism or disability **INTERVENTION OVERVIEW**	
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	Group. Intervention authors suggest up to 12 adults / group.
Target population	Parents of children with ASC and/or learning and/or physical disabilities. Open to both parents. Intervention authors report the intervention was designed to be accessible to parents from low SES backgrounds and BME groups.
Age range	Children aged 4 – 10 years.
Structure & approach	10, weekly 2 hour sessions. 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.
Homework	Parents receive handouts at each session. Parents are encouraged to complete homework tasks between sessions to reinforce learning.
Facilitators	Lead facilitators are currently clinical psychologists. Co facilitators have included LD nurses, teaching staff or parent of a disabled child.
Follow-up	Parents are invited to an informal social reunion three months after completing the programme.
Manual details	In print. Please contact authors (see below)
Contact for further information	Jo Bromley, Consultant Clinical Psychologist, Service Lead for Clinical Psychology Service for Children with Disabilities, Carol Kendrick Centre Stratus House, Southmoor Road, Wythenshawe, Manchester. M23 9XD. Tel: 0161 902 3400. Email: jo.bromley@cmft.nhs.uk
Associated Publications	Todd, S., Bromley, J., Ioannou, K., Harrison, J., Mellor, C., Taylor, E. & Crabtree, E. 2010. Using Group-Based Parent Training Interventions with Parents of Children with Disabilities: A Description of Process, Content and Outcomes in Clincal Practice. *Child and Adolescent Mental Health*, 15, 171-175.

Appendix E: Intervention E - overview of the investigation and key findings

Specialist Health Visitor Sleep Support Programme *An individually delivered sleep support intervention for parents of disabled children.* *(Intervention details overleaf)*		
Mean costs of delivering the intervention	£290 (where 4-6 follow-up home visits) £165 (where 3-6 follow-up telephone calls)	
Research 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.	
Sample	HV= 6; TS=7. Retention rates: post-intervention=92%; 12 wk f/up=62%.	
EVIDENCE ON EFFECTIVENESS[11]		
	Post-intervention	**12 week follow-up**
PARENT-SET GOALS (% improved)		
Home visit support	60%	80%
Telephone support	100%	100%
	Effect size statistic[12]	
PARENTING SENSE OF COMPETENCE: Satisfaction subscale *(Satisfaction with the parenting role)*		
HV	0.26	0.56
TS	*-0.9*	*0.0*
PARENTING SENSE OF COMPETENCE: Efficacy subscale *(Feelings of efficacy as a parent)*		
HV	0.13	0.43
TS	*0.26*	*0.27*
CHILD SLEEP HABITS QUESTIONNAIRE		
Total Score		
HV	0.31	0.41
TS	0.14	0.50
Bedtime Resistance subscale		
HV	0.13	0.69
TS	*0.76*	*0.53*
Sleep Anxiety subscale		
HV	0.33	0.38
TS	*0.49*	*1.02*
Night Wakings subscale		
HV	*0.0*	*0.16*
TS	*0.07*	*0.81*

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[11] Intervention effectiveness was examined comparative statistical tests and tests of clinical significance (i.e. reliable change, effect size). Full reports of these analyses are presented in the project report. Here we present effect size data only.

[12] The effect size statistic quantifies the difference between scores taken at two time points. 0.2 is defined as a 'small' effect size, 0.5 as a medium effect size, and 0.8 as a 'large' effect size. Effect size is calculated by dividing the difference between the means by the pooled standard deviation.

Specialist Health Visitor (SHV) Sleep Support Programme
INTERVENTION OVERVIEW

Aims	To support parents to address their child's sleep problems.
Mode	Individually delivered intervention including a period of support to parents as they implement an individualised sleep strategy. This support delivered face-to-face and/or via the telephone
Target population	Parents of disabled 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.)
Age range	Children aged 0 – 5 years.
Structure & approach	Sleep problems actively enquired about during routine clinic appointments with community paediatricians. Detailed history used to ascertain if sleep problem is of a behavioural nature. If this is the case parent asked to complete a sleep diary for 2 weeks and family is referred to the Specialist Health Visitor Sleep Support Programme. A home assessment conducted by specialist health visitor, informed by a parent completed sleep diary, and leading to the production of an individualised sleep strategy. Parents supported in the implementation of that strategy by either home visits or telephone support. 6 weeks is the typical duration of strategy implementation.
Practitioners	Delivered by consultant paediatricians and specialist health visitors based in a Child Development Centre.
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.
Intervention authors	Intervention developed by Dr Megan Thomas, Marion Lingard and Margaret Carter; Blenheim House Child Development and Family Support Centre, Blackpool.
Contact for further information	Dr Megan Thomas, Consultant Community Paediatrician Blackpool, Fylde and Wyre Hospitals NHS Foundation Trust, Blenheim House Child Development and Family Support Centre 145-147 Newton Drive, Blackpool, Lancashire. FY3 8LZ Tel: 01253 651615 (reception)

Appendix F: Intervention F - overview of the investigation and key findings

Neighbourhood Early Years (NEYS) Sleep Service *An individually delivered sleep support intervention for parents of disabled children.* *(Intervention details overleaf)*		
Mean costs of delivering the intervention	£195	
Research design	Exploratory, before and after study. Outcomes measured pre- & post-intervention and 12 week follow-up.	
Sample	12 parents. Retention rates: post-intervention=50%; 12 wk f/up=42%.	
EVIDENCE ON EFFECTIVENESS[13]		
	Post-intervention	**12 week follow-up**
PARENT-SET GOALS (% improved)	75%	71%
Effect size statistic[14]		
PARENTING SENSE OF COMPETENCE: Satisfaction subscale *(Satisfaction with the parenting role)*		
	1.24	0.17
PARENTING SENSE OF COMPETENCE: Efficacy subscale *(Feelings of efficacy as a parent)*		
	0.71	0.0
CHILD SLEEP HABITS QUESTIONNAIRE		
Total Score	0.42	0.67
Bedtime Resistance subscale	0.25	0.29
Sleep Anxiety subscale	0.0	0.96
Night Wakings subscale	-0.08	0.21

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[13] Intervention effectiveness was examined using comparative statistical tests and tests of clinical significance (i.e. reliable change, effect size, movement around clinical cut-off points). Full reports of these analyses are presented in the project report. Here we present effect size data only.

[14] The effect size statistic quantifies the difference between scores taken at two time points. 0.2 is defined as a 'small' effect size, 0.5 as a medium effect size, and 0.8 as a 'large' effect size. Effect size is calculated by dividing the difference between the means by the pooled standard deviation. A negative effect size indicates deterioration.

Neighbourhood Early Years (NEYS) Sleep Service **INTERVENTION OVERVIEW**	
Aims	To support parents to address their child's sleep problems.
Mode	Individually delivered intervention including period of support to parents implement an individualised sleep strategy. This support is delivered either by home visits or Sleep Clinic appointments at a local Children's Centre.
Target population	Parents of disabled children with sleep problems.
Age range	Children aged 0 – 5 years.
Structure & approach	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. Delivered from Children's Centres. Referral to the service from paediatricians, other practitioners or self-referral. First appointment at Children's Centre comprises a detailed sleep assessment after which parent completes two week sleep diary. Second appointment is a home visit at the end of which a sleep strategy is devised. Subsequent, fortnightly, sessions (at home or Children's Centre) with practitioner support the family to implement a sleep strategy. Typical duration of intervention is 12-16 weeks.
Practitioners	Intervention delivered by SEN/Disability Link Workers trained and supervised by senior LD nurse and consultant clinical psychologist.
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.
Intervention authors	Intervention adapted from the '*Sleep Scotland*' approach (http://www.sleepscotland.org/). For copy of intervention manual and materials used by NEYS Sleep Service use contact details below.
Contact for further information	Karen Mpetha, Operational Manager/ Nurse Specialist (Learning Disability Team), Alder Hey Children's NHS foundation Trust, 1st Floor, Mulberry House, Liverpool, L12 2AP. Tel: 0151 2933568. Email: karen.mpetha@alderhey.nhs.uk
Associated publications	Brady, A., Mpetha, K., Humphreys, S. & Carney, A.-M. 2011. Developing a sleep service for children with learning disabilities or autistic spectrum disorders aged 0-5: Setting up the service and lessons from practice. *Clinical Psychology Forum*. Number 222, June 2011

Appendix G: Intervention G - overview of the investigation and key findings

Managing your Child's Behaviour to Promote Better Sleep

A group-delivered intervention for parents of children with ASC and/or learning and/or sensory disabilities. (Intervention details overleaf)

Mean costs of delivering the intervention	£1,700
Research design	Exploratory, before and after study. Outcomes measured pre- & post-intervention and 12 and 24 week follow-up. Sample for evaluation recruited from 4 deliveries of the intervention. Intervention integrity=100%
Sample	23 parents (representing 20 children). Retention rates: post-intervention=70%; 12 wk f/up=65%; 24 wk f/up=78%;

EVIDENCE ON EFFECTIVENESS[15]

	Post-intervention	**12 week follow-up**	**24 week follow-up**
PARENT-SET GOALS (% improved)	93%	87%	78%
	Effect size statistic[16]		
PARENTING SENSE OF COMPETENCE: Satisfaction subscale *(Satisfaction with the parenting role)*			
	0.38	0.13	0.40
PARENTING SENSE OF COMPETENCE: Efficacy subscale *(Feelings of efficacy as a parent)*			
	0.82	0.84	0.99
CHILD SLEEP HABITS QUESTIONNAIRE			
Total Score	0.20	0.44	0.34
Bedtime Resistance subscale	0.29	1.05	0.42
Sleep Anxiety subscale	0.04	0.30	0.32
Night Wakings subscale	-0.18	0.25	0.36

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[15] Intervention effectiveness was examined using tests to measure the statistical significance of changes in scores on outcome measures (repeated measures ANOVA), and tests of clinical significance (i.e. reliable change and effect size). Full reports of these analyses are presented in the project report. Here we present effect size data only.

[16] The effect size statistic quantifies the difference between scores taken at two time points. 0.2 is defined as a 'small' effect size, 0.5 as a medium effect size, and 0.8 as a 'large' effect size. Effect size is calculated by dividing the difference between the means by the pooled standard deviation. A negative effect size indicates deterioration.

Managing your Child's Behaviour to Promote Better Sleep
INTERVENTION OVERVIEW

Aims	To help parents manage their child's sleep difficulties.
Mode	Group. (Within this evaluation, maximum group size=8.)
Target population	Parents of children with ASC and/or learning and/or sensory disabilities. Both parents encouraged to attend.
Age range	Children aged 3 -18 years.
Structure & approach	Group delivered intervention comprising 4 sessions delivered over a five week period (2 week break between sessions 3 and 4). A 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.
Practitioners	The groups are facilitated by two practitioners trained in learning disability and behavioural approaches to behaviour management (e.g. LD nurses, clinical psychologists).
Follow-up	There are no follow up sessions. Attendance may, however, result in referral for individual support from CAMHS LD team.
Intervention authors	Julie Curtis and Patti Boon
Contact for further information	Julie Curtis, CALD Team Co-ordinator / Samantha Ives, Secretary to CALD Team, The Modular Building, Northgate Hospital, Morpeth, NE61 3BP. Tel: 01670 394032. Email: Samantha.Ives@nhs.net

Appendix H: Intervention H - overview of the investigation and key findings

Sleep Solutions 'Time2Sleep' Workshop *A day workshop for parents of disabled children seeking help with sleep problems.* *(Intervention details overleaf)*		
Mean costs of delivering the intervention	£612	
Research design	Exploratory, before and after study. Outcomes measured 12 and 24 weeks after attending a workshop. Intervention integrity=99%. Sample for evaluation recruited from 10 deliveries of the workshop.	
Sample	26 parents. Retention rates: 12 wk f/up=69%; 24 wk f/up=62%.	
EVIDENCE ON EFFECTIVENESS[17]		
	12 week follow-up	**24 week follow-up**
PARENT-SET GOALS (% improved)	65%	87%
	Effect size statistic[18]	
PARENTING SENSE OF COMPETENCE: Satisfaction subscale *(Satisfaction with the parenting role)*		
	0.11	0.01
PARENTING SENSE OF COMPETENCE: Efficacy subscale *(Feelings of efficacy as a parent)*		
	-0.15	-0.21
CHILD SLEEP HABITS QUESTIONNAIRE		
Total Score	0.02	0.27
Bedtime Resistance subscale	0.10	0.34
Sleep Anxiety subscale	0.11	0.33
Night Wakings subscale	-0.49	-0.27

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[17] Intervention effectiveness was examined using tests to measure the statistical significance of changes in scores on outcome measures (repeated measures ANOVA), and tests of clinical significance (i.e. reliable change and effect size). Full reports of these analyses are presented in the project report. Here we present effect size data only.

[18] The effect size statistic quantifies the difference between scores taken at two time points. 0.2 is defined as a 'small' effect size, 0.5 as a medium effect size, and 0.8 as a 'large' effect size. Effect size is calculated by dividing the difference between the means by the pooled standard deviation. A negative effect size indicates deterioration.

Sleep Solutions ‘Time2Sleep’ Workshop
INTERVENTION OVERVIEW

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	Single day workshop.
Target population	Parents of children with additional needs and practitioners. Where availability allows, parents may attend with their partner, another family member or carer.
Age range	Children aged 2 -19 years.
Structure & approach	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. The workshop aims to cover many common sleep issues that children may face, the impact of sleep problems on the family, and introduces simple cognitive behavioural therapy techniques and increase background understanding of sleep. Participants receive a ‘Delegate Resource Pack’ of useful materials to take away.
Practitioners	Facilitators have attended ‘Sleep Counsellor Training’ delivered by ‘Sleep Scotland’ (http://www.sleepscotland.org/sleeptraining.php) or the Children’s Sleep Service, Solent NHS Trust.
Follow-up	This is a one-off workshop with no follow-up.
Intervention authors	Vicki Dawon and Jackie Logue (SCOPE), (with Jane Ansell, *Sleep Scotland*)
Contact for further information	Karen Hunt, Sleep Solutions National Service Development Manager, Scope, Suite 18, The Rural Enterprise Centre, Vincent Carey Road, Rotherwas Industrial Estate, Hereford. HR2 6FE Tel: 01432 355308 www.sleepsolutions.org.uk, or www.scope.org.uk/sleep
Associated Publications	Department For Education (2010) *Information for Parents Booklet – Sleep.* Downloadable from: https://www.education.gov.uk/publications/standard/EarlySupport/Page1/ES82

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