
Managing Behaviour and Sleep Problems in Disabled Children: An Investigation into the Effectiveness and Costs of Parent-Training Interventions

Appendix A Rapid Reviews

Rapid Review 1

Rapid Review 1

Evidence on Effectiveness of Behavioural Interventions to Help Parents Manage Sleep Problems in Young Disabled Children: A Rapid Review

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Contents

	Page
List of Tables and Figures	i
Acknowledgements	iii
1. Introduction	1
2. Methods	3
2.1 Searches	3
2.2 Inclusion and exlusion criteria	4
2.3 Data extraction	4
3. Results	5
3.1 Study selection	5
3.2 Overview of included studies	5
3.3 Non-specific behavioural intervention	9
3.3.1 <i>General information sessions</i>	10
3.3.2 <i>Individual treatment plans</i>	12
3.4 Extinction	17
3.5 Sleep restriction	21
3.6 Faded bedtime with response cost	23
4. Discussion	25
4.1 Summary of the evidence	25
4.2 Gaps in the evidence	27
References	28
Appendices	
Appendix A: Search Strategy	31
Appendix B: Excluded Studies (from full paper screening)	39
Appendix C: Quality Assessment of RCTs	43
Appendix D: Data Extraction	45

List of Tables and Figures

		Page
Tables		i
Chapter 2		
Table 1	Databases searched for research evidence on behavioural interventions for sleep problems in disabled children	3
Table 2	Inclusion and exclusion criteria	4
Chapter 3		
Table 3	Overview of included studies	7
Table 4	Details of participants (non-specific behavioural interventions)	9
Table 5	Details of interventions (non-specific behavioural intervention studies)	16
Table 6	Details of participants (extinction studies)	18
Table 7	Details of intervention (extinction studies)	20
Table 8	Details of participants (sleep restriction studies)	21
Table 9	Details of intervention (sleep restriction studies)	22
Figures		
Chapter 3		
Figure 1	Study selection	5
Box 1	Information on behavioural techniques provided to parents in Montgomery <i>et al.</i> study	10
Box 2	Summary of a tailored behavioural intervention (Wiggs and Stores)	12
Box 3	Intervention used by before and after studies (Quine and Wade and Hewitt)	13
Box 4	Non-graduated extinction	17

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1. Introduction

Sleep problems are common among all children but they appear to be more common among disabled children. For example, Quine¹ found that settling problems were reported for 41 per cent of children aged 4-12 in special schools compared with 27 per cent of children in mainstream schools; figures for night waking were 45 per cent compared with 13 per cent. Figures for children with severe learning disability are particularly high: for example, Bartlett *et al.*² 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 Prior³ reported prevalence of 34-80 per cent in children with autism. Such problems appear to be very persistent. For instance, Wiggs and Stores⁴ showed average duration of current sleep problem was 7.13 years, and problems are not likely to disappear without intervention.⁵

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 impact on sleep¹. This can be particularly the case for technology dependent children. Recent research on the experiences of families of children dependent on medical technology shows that sleep disturbance for the child and parents is common due to the need to attend to technology, such as feeding pumps or dialysis machines, during the night, and to machine alarms going off frequently.⁶ Problems in cognition and learning can 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.⁷

Sleep problems have a number of implications for the child and family. For parents, they are associated with high levels of stress and irritability.⁸ For the children they are associated with poor concentration and daytime learning, and increased probability of daytime behaviour problems.⁵ These findings emphasise the need to take sleep problems seriously. However, only a minority of families who have a child with a severe sleep problem appear to receive any help.⁴

In considering whether intervention is needed, it is important to note that it is normal for young children to wake a number of times during the night.^{9,10} What distinguishes normal sleep from a sleep problem is what children do when they awaken. In normal sleep, children wake briefly and resume sleep themselves (self-settling). Children with sleep problems signal when they wake and elicit a response from parents, this can act as a reward and result in the child needing parental attention to resume sleep. As France *et al.*⁹ note 'intervention does not involve changing the child's sleep per se ... but involves teaching the child to replace the behaviour of signalling upon awakening with the behavioural quietude necessary for the resumption of sleep' (p.583). Young children also often spend some time settling themselves to sleep when put to bed. However this becomes a problem when a child makes repeated calls on parents after being put to bed. Again the aim of intervention is to teach the child to fall asleep alone.

Sleep problems encountered in studies of disabled children are broadly of two types: a) 'behavioural' problems relating to the initiation and maintenance of sleep, as described above, and linked to parental management; and b) 'physical' problems, such as upper airway obstruction and other physiological factors. However, these often co-exist, and it is important that a full assessment of the problems and their causes is carried out to inform the choice of intervention. Stores and Wiggs¹¹ suggest that questions regarding the child's sleep-wake patterns should be a routine part of any general assessment. They recommend the following screening questions:

1. Does the child have any difficulty getting to sleep or staying asleep?
2. Is the child excessively sleepy/over-active during the day?
3. Does the child have any disturbed episodes at night?

1. Introduction

Positive answers to these questions should lead to a detailed investigation, including sleep history and physical examination, and choice of interventions should be individually tailored to the child's problems.¹¹

This rapid review focuses on interventions for behavioural sleep problems in young disabled children (up to age eight years), specifically interventions that can be carried out by parents in the home.

2. Methods

A rapid review was undertaken on the effectiveness of behavioural interventions for sleep problems in disabled children.

2.1 Searches

The search was structured to combine the following concepts:

Sleep problems AND (children terms in close word proximity to disabled terms)
AND behavioural interventions

Case studies, letters, notes, comments and editorials were excluded from the searches. Searches were restricted to English language studies published since 1985. The full search strategies are reported in Appendix A.

A range of databases and websites were searched (see Table 1). Records were downloaded and added to Endnote bibliographic software. The records were deduplicated.

Table 1: Databases searched for research evidence on behavioural interventions for sleep problems in disabled children

Database	Interface	Date searched
Cochrane Database of Systematic Reviews (CDSR)	Cochrane Library 2008 Issue 3	22/8/2008
DARE	Cochrane Library 2008 Issue 3	22/8/2008
MEDLINE	Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1950 to Present>	22/8/2008 22/9/2008 (Revised search)
EMBASE	OvidSP, 1980 to 2008 Week 33	22/8/2008
PsycINFO	OvidSP, 1967 to July Week 5 2008	22/8/2008 22/9/2008 (Revised search)
CINAHL	OvidSP, 1982 to August Week 3 2008	22/8/2008
CENTRAL	Cochrane Library 2008 Issue 3	22/8/2008
SPECTR and C2-RIPE (Campbell Collaboration)	http://geb9101.gse.upenn.edu	22/8/2008
HMIC	Ovid to July 2008	22/8/2008
NRR archive	https://portal.nihr.ac.uk/Pages/NRRArchiveSearch.aspx	22/8/2008
CERUK	http://www.ceruk.ac.uk/	22/8/2008
ERIC	Dialog/Datastar	22/8/2008
Childdata	http://www.childdata.org.uk/library_search.asp	26/8/2008
Australian Education index (AUEI)	Dialog/Datastar	29/8/2008
British Education Index (BRIE)	Dialog/Datastar	29/8/2008

2. Methods

2.2 Inclusion and exclusion criteria

For the review of sleep interventions two researchers independently screened titles and abstracts. Full papers were ordered for any records identified by either researcher as potentially relevant. These were also screened by two researchers based on the criteria below (Table 2). Any disagreements were resolved by discussion and a consensus decision was made.

Table 2: Inclusion and exclusion criteria

Exclusion criteria
<ul style="list-style-type: none">• Not English language• Published before 1985• Research not concerned with intervention to manage/address/resolve a sleep problem• Pharmacological intervention only• Interventions other than those adopting a behavioural approach• Interventions which only and specifically address the following sleep problems:<ul style="list-style-type: none">◦ night terrors◦ sleep walking◦ sleep apnoea• Research does not include any evaluative element• Research where the sample includes disabled and non-disabled children, and no separate analysis• Case studies, letters, notes, editorials• No quantitative outcome measures used• Age of sample 9 years or older (inclusive)• Sample <u>only</u> includes children with the following as their 'primary need':<ul style="list-style-type: none">◦ attention deficit hyperactivity disorder (ADHD)◦ mental health problems◦ emotional/social/behavioural difficulties

Inclusion criteria
<ul style="list-style-type: none">• Intervention includes at least a behavioural intervention element to manage/address/resolve a sleep problem <i>and</i>• Intervention for disabled children aged 8yrs and under <i>and</i>• Evaluation of that intervention which includes, at least, a quantitative element

During screening, it became apparent that an age cut-off of eight years old was not commonly used by studies. We made the decision to included studies including children older than eight provided they included a substantial proportion of children who were our population of interest (i.e. young children under eight).

2.3 Data extraction

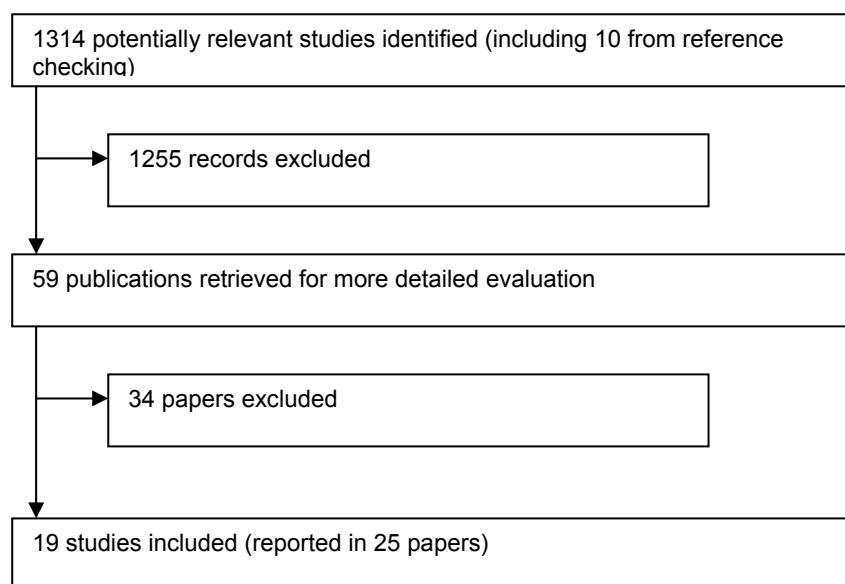
Data were extracted into a standardised form (see Appendix D) by one researcher. A sample of four sets of data extraction was checked by a second researcher. Study design was classified according to the Maryland Scale of Scientific Methods.¹² Studies with a control/or comparison group were also quality appraised using criteria from the Effective Public Health Practice Project Quality Assessment Tool for Quantitative Studies.¹³

3. Results

3.1 Study selection

1,314 records were screened for relevance, 1,304 from the electronic searches and 10 publications identified through reference checking and other sources (see Figure 1). 1,255 records were excluded and 59 publications were retrieved for more detailed evaluation. Twenty-five papers met the inclusion criteria for the review reporting on 19 individual studies. Thirty-four papers were excluded. See Appendix B for list and reasons for exclusion.

Figure 1: Study selection



3.2 Overview of included studies

The included studies have been grouped by type of intervention (Table 3). Six studies ($n=239$) evaluated a non-specific behavioural intervention i.e. they did not focus on a single behavioural technique;¹⁴⁻¹⁹ seven evaluated extinction or graduated extinction ($n=48$);²⁰⁻²⁶ two evaluated sleep restriction ($n=6$);^{27,28} and three evaluated faded bedtime with response cost ($n=21$).²⁹⁻³² Full details of one study ($n=5$) (available in an MSc thesis) had not arrived at the time of writing therefore this study is not discussed any further.³³

Based on the Maryland Scale of Scientific Methods, only study designs at Level 3 to 5, which encompass various study designs with a control or comparison group, are sufficient to inform whether an intervention works, does not work or is promising. Only four of the 19 studies met the criteria for Level 3 or above on the Maryland scale: three were of a non-specific behavioural intervention¹⁴⁻¹⁶ and one was of faded bedtime with response cost.²⁹ The remaining studies were all before and after design and did not have a control group. When evaluating whether or not an intervention works the absence of a control group is a key limitation as it is not possible to rule out with any certainty the possibility that factors other than the intervention may have led to change. However, in the absence of any better quality available evidence, details of these studies are provided below as they provide potentially useful information on acceptability of different interventions and the feasibility of using them with different groups of disabled children.

3. Results

Some caution also needs to be taken when considering how the findings of any of the studies included in this review might be generalised to other disabled children with sleep problems. A key question is whether the parents who participated in a particular study are representative of parents of disabled children with sleep problems. Such parents may differ in many ways. For example, there is the possibility that parents who participate in such studies are more highly motivated and/or feel more confident about dealing effectively with their child's sleep problems and/or are at a stage where they can feel they can take such an intervention on. In this instance it is possible that when delivering this intervention outside the context of a research study that the results may not be as good.

3. Results

Table 3: Overview of included studies

Author	Year	Study design Maryland Level	Number of participants	Intervention	Comparator	Country and setting
<i>Non-specific behavioural intervention</i>						
Montgomery ¹⁴	2004	RCT Level 5	N=66	(a) Behavioural intervention (BI) delivered to parents face-to-face (b) BI delivered through a booklet	Waiting-list control	UK Home
Stores ¹⁵	2004	RCT Level 4	N=46	Single session of instruction on behavioural techniques plus booklet	Waiting-list control	UK Home
Wiggs ¹⁶ Related publications Wiggs ³³ Wiggs ³⁴	1998	RCT Level 4	N=31	Tailored BI	Waiting-list control	UK Home
Bartlet ¹⁷	1998	BA Level 2	N=61	Tailored BI (mainly graded change)	No	UK Home
Hewitt ¹⁸	1985	BA Level 2	N=10	Tailored BI (positive bedtime routine and conditioning)	No	UK Home
Quine ¹⁹ Related publications Quine ³⁵ Quine ³⁶ Quine ³⁷	1991	BA Level 2	N=25	Tailored BI (positive bedtime routine and conditioning)	No	UK Home
<i>Extinction</i>						
Bramble ²⁰ Related publications Bramble ³⁸	1996	BA Level 2	N=15	Extinction	No	UK Home
Didden ²¹	2004	BA Level 2	N=3	Extinction (n=2); differential reinforcement of incompatible behaviours plus response cost (n=1)	No	Netherlands Home
Didden ²²	2002	BA Level 2	N=4	Extinction	No	Netherlands Home
Didden ²³	1998	BA Level 2	N=6	Extinction	No	Netherlands Home
Durand ²⁴	1996	BA Level 2	N=4	Graduated extinction	No	USA Home

3. Results

Thackery ²⁵	2002	BA Level 2	N=3	Extinction with positive bedtime routine	No	Australia Home
Weiskop ²⁶	2005	BA Level 2	N=13	Extinction with positive bedtime routine	No	Australia Home
<i>Sleep restriction</i>						
Christodulu ²⁷	2004	BA Level 2	N=4	Positive bedtime routine and sleep restriction	No	USA Home
Durand ²⁸	2004	BA Level 2	N=2	Positive bedtime routine and sleep restriction	No	USA Home
<i>Faded bedtime with response cost</i>						
Piazza ²⁹	1997	RCT Level 4	N=14	Faded bedtime with response cost	Bedtime scheduling	USA Inpatient
Piazza ³⁰	1991	BA Level 2	N=3	Faded bedtime with response cost	No	USA Inpatient
Piazza ³¹	1991	BA Level 2	N=4	Faded bedtime with response cost	No	USA Inpatient
<i>Unclear</i>						
Colville ³²	1996	BA Level 2	N=5	BI (details not provided)	No	UK Home

BI: behavioural intervention, BA: before and after study design, RCT: randomised controlled trial.

3.3 Non-specific behavioural intervention

All six studies of a non-specific behavioural intervention were conducted in the UK and the intervention was delivered by parents to their children in their own home. The age range of children varied between studies (Table 4). With the exception of one study that included children with a chronic illness,¹⁷ the majority of participants had learning disabilities which were mainly severe. One study, with the objective of assessing the effectiveness of a simple behavioural approach for prevention as well as minimisation of sleep problems, included children with and without sleep problems.¹⁵ The remaining five studies used different methods to assess the severity of the children's sleeping problems at baseline making it difficult to be certain about the similarity of the populations across the study. However, overall the children appear to have had severe sleep problems which were predominantly long-standing. The most commonly reported problems were difficulties in settling at bedtime and related disruptive behaviour, several episodes of night waking leading to disrupted sleep for parents and other members of the household and co-sleeping.

Table 4: Details of participants (non-specific behavioural interventions)

Study (N)	Disability	Age	Baseline severity of sleep problem
Randomised controlled trials			
Montgomery ¹⁴ Face-to-face n=20 Booklet n=22 Control n=24	Severe LD	Range 2-8 years	Severe sleep problem (CSDS score ≥ 4) was an entry requirement CSDS mean 6.55 (SD 1.31)
Before and after studies			
Bartlet ¹⁷ n=61	N=22 chronic illness; n=39 disability (most commonly severe LD)	Mean 4yr 11mth Range 11mth-17yr	SDI score mean 6.36
Hewitt ¹⁸ n=10	Severe LD	Mean 6yr 11mth Range 3yr 11mth-16yr 6mth	Average time to settle ranged from 34min to 2.5hr; 6 to 28 night waking episodes in one week
Quine ¹⁹ n=25	Severe LD	Range 1yr 9mth to 21 yrs	Mean time to settle 111 min (range 45-180); mean 3.1 times waking per night (range 2.2-4.0)

LD: learning disability, CSDS: Composite Sleep Disturbance Score (ranges from 0 to 8, higher score more severe problem), SDI: Sleep Disturbance Index (ranges from 0 to 8, higher score more severe problem), I: intervention group, C: control group, [†] There were n=16 allocated to the intervention but one dropped out before receiving the intervention.

Although all six studies were similar in that they provided parents with information on more than one behavioural technique, they did vary in how the intervention was implemented

3. Results

(Table 5). Two RCTs^{14,15} provided single general information sessions for parents on behavioural techniques and one RCT¹⁶ and the before and after studies¹⁷⁻¹⁹ provided individual treatment plans for each child based on a functional assessment.

3.3.1 General information sessions

Montgomery *et al.*¹⁴ evaluated the effectiveness of (i) a single information session on behavioural interventions delivered to parents face-to-face in their own home and (ii) information on behavioural interventions delivered through a booklet. There were 20 participants in the face-to-face group, 22 in the booklet group and 24 participants in a waiting list control group (Table 4). The aim was to train parents in both the face-to-face and booklet groups in the same behavioural techniques (see Box 1). At baseline participants in all the groups completed a sleep questionnaire and kept a sleep diary for two weeks. The intervention groups then received a 90 minute visit from a researcher to explain the behavioural techniques (face-to-face) or received a 14 page illustrated booklet providing the same information (Table 5). The intention was that parents would then implement the techniques with their children over a six week period.

Box 1: Information on behavioural techniques provided to parents in Montgomery *et al.* study¹⁴

- a) Explanation of the benefits of normal sleep
- b) Introduction to behavioural techniques in general (e.g. how behaviours can be triggered by preceding events, ignoring and consistency)
- c) Recording behaviour in a sleep diary to devise and monitor treatment plans
- d) Good sleep habits (e.g. clear routines, putting children to sleep while drowsy)
- e) Techniques for changing settling and waking problems (ignoring child, checking and briefly at increasingly longer intervals and with minimal contact)
- f) Removing child from parental bed using the settling techniques above
- g) Rewards for desirable behaviour

The primary outcome measure was the Composite Sleep Disturbance Score (CSDS) which scores duration and frequency of settling and waking problems based on sleep diaries completed by parents. The possible score range is from 0 to 8 with a higher score indicating greater sleep problems. At baseline the mean score was six or greater for both intervention groups and the control group (see Appendix D for full data).

There was a statistically significant improvement for both of the intervention groups compared to the control group at end of treatment. Post-treatment the mean CSDS was 2.4 (SD 1.93), 2.55 (SD 2.76) and 5.75 (SD 1.54) for the face-to-face, booklet and control group respectively. This improvement was maintained for the two intervention groups at six month follow-up.

Prior to the intervention, parents were asked what minimum improvement would make the intervention worthwhile: 83 per cent said that having the problem reduced by half would make it worthwhile. Based on this a positive treatment response (responder) was defined as a reduction of at least 50 per cent on the CSDS. Based on this classification there were 15 responders and five non-responders in the face-to-face group; 15 responders and seven non-responders in the booklet group; and all non-responders in the control group. Parents who had used the booklet were asked to rate its usefulness, ease of understanding and relevance. On a rating scale with a maximum score of 12 the mean score was 10.17 (SD 1.87).

This was a good quality RCT with a low risk of bias (see Appendix C for full quality assessment) therefore the findings are likely to be reliable. There are two key points that need to be kept in mind when interpreting the findings. Firstly, as emphasised by the authors

3. Results

the study was not designed to directly compare the effectiveness of delivery of information face-to-face with delivery face-to-face. It is not powered (i.e. does not have enough participants) to detect whether one mode of delivery is more effective than the other: it assesses whether each of the interventions is better than no intervention. Secondly, the booklet group also (in common with the face-to-face group) had a total 90 minutes one-to-one contact with the researchers throughout the duration of the study for the purpose of assessing progress. This contact may have had a supportive and motivational value for parents and it is possible that this contact may have contributed to the effectiveness of the booklet intervention. Further work is required to unravel the contribution of the booklet and the contact with researchers/clinicians. In terms of generalising the findings, it is possible that providing a booklet, outside the research context with no regular contact with the clinical team, may not be as effective as in this study.

Stores and Stores¹⁵ compared a single session of instruction on behavioural techniques plus provision of a booklet to a waiting list control group. Forty-six children were randomised to either the intervention group or control group. (The number of participants in each group was not explicitly stated.) The instruction session lasted approximately 90 minutes including 30 minutes for discussion and was delivered to small groups of about five mothers. There were separate sessions for mothers of very young children (six months to 2.5 years old) and young children (2.5 to five years old). The session included provision of information and advice about children's sleep and explanation of behavioural techniques for encouraging good sleep habits such as establishing a positive bedtime routine, rewarding good behaviour, ignoring unwanted behaviour and gradual change. Case studies were used to illustrate the techniques. The intention was that parents would then implement the techniques with their children over a four week period.

Sixty-five per cent of the children had at least one behavioural sleep problem and 35 per cent did not have any sleep problems. On the Composite Sleep Problem Score (CSPS) with a possible score range of 0 to 14 (a higher score indicated worse sleep problems) the mean baseline score for the intervention and control group was 3.83 (SD 3.41) and 3.38 (SD 3.58) respectively. Based on a three (baseline, one month and six month follow-up) by two (intervention and control group) analysis of variance there was no statistically significant effect for time or group or interaction between group and time. There was a statistically significant difference between the intervention and control group at six months based on a post-hoc test; however this should be treated with caution as, in the absence of any statistically significant differences based on the ANOVA, this may be a spurious finding.

The study also assessed the impact of the intervention on mothers' knowledge as assessed by two questionnaires. At one month follow-up, mothers in the intervention group scored more highly than the control group on the Knowledge of Behavioural Principles as Applied to Children Questionnaire and the Knowledge of the Sleep of Young Children Questionnaire and the differences were statistically significant (see Appendix D for complete data). Ninety-four per cent rated the information session and booklet as very easy to understand. Twenty-two per cent rated the presentation as 'very useful' and 61 per cent as 'quite useful'; 17 per cent rated the booklet as 'very useful' and 50 per cent as quite useful; the remaining participants gave a rating of 'not very useful'.

Although this study was an RCT, the use of a mixed group of children with and without sleeping problems limits how informative it is about the effectiveness of behavioural interventions for children with sleep problems. The aim of the study was to investigate the usefulness of the intervention for the prevention of sleep problems as well as treatment. Because the data from children with and without sleep problems was analysed as one group the mean severity of sleep problems at baseline was fairly low. As a result there was limited room for improvement on the scale that was used (i.e. a ceiling effect). It is therefore not

3. Results

surprising that there was not a statistically significant difference between the two groups in the main analysis.

The Maryland criteria require at least two Level 3 evaluations showing effectiveness to classify an intervention as effective and one Level 3 evaluation to classify an intervention as promising. Based on these criteria, the provision of information on behavioural techniques to parents in a single session (face-to-face) or through a booklet is a promising intervention for dealing with severe behavioural sleep problems in children with learning disabilities.

3.3.2 Individual treatment plans

One RCT¹⁶ and three before and after studies¹⁷⁻¹⁹ provided individual behavioural treatment plans for each child based on a functional assessment. Wiggs and Stores¹⁶ compared a tailored behavioural intervention received by 15 children (see Box 2) to a waiting list control group of 15 children. The children had severe learning disabilities and one or more daytime challenging behaviours (see Table 4 and 5). Only children with a severe sleep problem were included in the study.

Following an introductory visit to meet parents at home and explain baseline questionnaires there was a second visit to undertake a functional analysis of the sleep problem and to agree the behavioural programme. This visit lasted between 1.5 and 2.5 hours. The functional assessment was based on sleep diaries completed by parents and a semi-structured interview to take a detailed sleep history. During this visit there was also discussion of possible factors maintaining their child's sleep problem as well as discussion of the positive and negative aspects of different behavioural techniques that might be useful. The techniques discussed included extinction, graded extinction, stimulus control procedures and positive reinforcement. The aim was to enable parents to make an informed choice about whether they would be able to implement a particular technique with their child. A behavioural programme was agreed with parents and following the visit they were sent a written outline of the agreed programme. The intention was that parents would then implement the agreed programme with their children over a four week period. Progress was monitored by regular telephone calls. Both the intervention and control group received the preliminary visit and four visits to deliver and collect questionnaires.

Box 2: Summary of a tailored behavioural intervention (Wiggs and Stores)¹⁶

- a) Functional analysis of child's sleep problem
- b) Establish what the parents' aims of treatment were
- c) Discussion of factors and mechanisms that maintain the child's problems in settling and or night-waking
- d) Discussion of different behavioural techniques, their advantages and disadvantages and how they might be applied to the specific family situation
- e) Identification and anticipation of any problems that might arise with the intervention
- f) Identification of target/s for the first stage
- g) Written outline of the agreed behavioural programme sent to parents following the visit

Outcome was assessed at the end of the four week intervention (one month follow-up) and three months following the commencement of treatment (three month follow-up). Nine groups of child and parent-related outcomes were reported.

In terms of child sleep problems the intervention group showed a statistically significant improvement from baseline to one month follow-up and baseline to three month follow-up on the Composite Sleep Index (CSI), whereas there was no change in the control group (see Appendix D for details of analysis). The CSI had a possible range of 0 to 12 with a higher score indicating greater severity. The mean score reduced from 6.73 (SD 2.31) at baseline

3. Results

to 3.79 (SD 1.89) and 2.96 (SD 2.24) at one and three month follow-up respectively. The mean CSI score for the control group for the same time periods was 7.23 (SD 2.26), 6.62 (SD 1.89) and 6.29 (SD 2.60). There were no between group differences in change in child sleep over time as measured by a wristwatch activity monitor. Also there was no change in daytime behaviour measured by the Aberrant Behaviour Checklist completed by mothers and teachers or in the severity and frequency of target challenging behaviours again assessed by mothers and teachers.

Several parental outcomes were assessed. There was a statistically significant increased sleep period (as measured by a wristwatch activity monitor) for mothers in the intervention group, from baseline to one month follow-up, compared to control (see Appendix D). Mother and father satisfaction with their own sleep and their child's sleep also improved from baseline to one month and three month follow-up for the intervention group compared to control. There was also increased satisfaction amongst intervention mothers in how they coped with their child's sleep pattern, though no difference in how they rated their ability to control their child's sleep-related problems. Mothers in the treatment group reported reduced stress (The Malaise Inventory) from baseline to three month follow-up compared to control. There were no between group differences for fathers' stress. Based on the Internal/External Locus of Control Scale there was an increase in treatment group fathers' externality and a reduction for the control group. There was no statistically significant between group differences for mothers.

Although this study was an RCT it does have some limitations which may introduce the risk of over-estimating the effectiveness of the intervention (see Appendix C for full quality assessment). Randomisation was by school rather than individual child to avoid contamination. While this can be an appropriate way to avoid contamination, details of the methods were not reported, for example the number of schools randomised was not reported therefore it is unclear how many clusters there were. Additionally, the method of statistical analysis does not seem to have taken into account the clustering effect within schools in terms of characteristics such as type of disability, severity of disability or social background.

The three before and after studies used a similar tailored intervention to that of Wiggs and Stores¹⁶ above (see Table 6) with 10,¹⁸ 25,¹⁹ and 61¹⁷ participants. In particular, the treatment approaches described by Quine and Wade and Hewitt were very similar (see Box 3). Bartlet and Beaumont do not provide a detailed report of their intervention, from the information provided they appear to have taken a similar approach.¹³ They report that the most commonly used strategies by parents were cueing, graded change, extinction and positive reinforcement.

Box 3: Intervention used by before and after studies (Quine and Wade¹⁹ and Hewitt¹⁸)

- a) Positive bedtime routine including set bedtime and avoidance of overstimulation in the hour before bed; a regular routine providing clear stimuli for the child that bedtime is approaching
- b) Teaching a relaxation response after getting into bed through use of a bedtime story or soft music
- c) Gradual distancing of parent from bedroom once relaxation response was established
- d) Identification of factors that were maintaining disruptive behaviours and advice for more constructive parental responses
- e) During wakeful episodes the stimulus being used to condition the child to fall asleep was repeated. Parents were advised to interact with the child as little as possible and avoid prolonged routines and overstimulation during waking episodes
- f) Parents were made aware of the importance of consistency and the possibility that progress may be slow

3. Results

There were one-to-one meetings with parents at home or in a clinic to introduce the study and to develop an individual treatment plan for each child. Although a range of behavioural techniques was used, positive bedtime routine with graded change was predominant.

Support for parents was fairly intensive. There were weekly visits from a nurse or health-visitor initially in two studies (Table 5).^{18,19} In the third study contact with parents was usually by telephone: on average five phone calls per family ranging in duration from five to 60 minutes.¹⁷

A key difference between the before and after studies and the RCT on individual behavioural treatment plans was that three before and after studies did not have a pre-specified duration of implementation. The intervention was implemented until parents were satisfied with the progress made (Table 5) and then the outcomes of interest were assessed. While this makes clinical sense, in terms of evaluating the effectiveness of an intervention it does make it more likely that a positive impact of an intervention will be found, particularly in the context of a before and after study. The study by Quine and Wade compared their cohort of participants to an age-matched random sample of children with sleep problems from another health district who had not sought or been offered treatment. However, the outcomes of the two groups were not directly compared: before and after comparisons were made within each group, not between groups. This study was therefore classified as a before and after study though a summary of the outcomes for the control group was extracted (see Appendix D).

All three studies showed improvement on child sleep outcomes and the two studies assessing parental outcomes also showed positive changes post-intervention (see Appendix D for full details).¹⁷⁻¹⁹

The authors of the studies make a number of points of interest in relation to implementing behavioural sleep interventions in families with a young disabled child. Hewitt¹⁸ highlights that many programme modifications were necessary to ensure that the individual interventions suited individual parenting styles and family resources.

Bartlet and Beaumont¹⁷ described their experience during a one year project based at Southampton General hospital staffed by a part-time experienced health visitor and a child psychiatrist four hours per week. The authors comment that treatment was often found by the parents as being more onerous than the literature had previously suggested. Forty-five children improved following the intervention and seven parents found the programme difficult to manage or ineffective.

A preliminary intervention was required for approximately one third of parents prior to being trained in the behavioural techniques to be used with their child.¹³ Particular issues for parents included physical exhaustion, disagreement between partners about the way forward, low self-esteem, and a concern that the child would suffer as a result of the intervention. Tearfulness and feelings of hopelessness were common and three mothers were identified as clinically depressed and were referred to their GP for help. The aim of the preliminary intervention with parents was to allow time to develop trusting relationships with the project workers and to give them time to think and contemplate changing their routines. Specific details of the preliminary intervention were not provided other than that a holistic, dynamic approach was used with strategies such as understanding, support, empowerment and opportunities to talk through past traumatic experiences.

This experience is of particular interest from this study as it is based on one year's experience at a clinic therefore the participants may be more representative of parents of disabled children than parents recruited into a research project.

3. Results

Based on the Maryland Criteria, a behavioural intervention delivered through an individual treatment plan is a promising intervention for dealing with severe sleep problems in disabled children.

3. Results

Table 5: Details of interventions (non-specific behavioural intervention studies)

Study	Details of intervention	Duration of implementation	Support for parents
Randomised controlled trials			
Montgomery ¹⁴	(a) Face-to-face – 90 minutes single session to explain range of behavioural techniques (in individual homes) (b) Booklet – were provided with 14 page booklet explaining same behavioural techniques Range of behavioural techniques.	Six weeks	No support specified beyond the initial session to (a) explain the technique or (b) give booklet.
Stores ¹⁵	Small group 90 minute single session to explain range of behavioural techniques. Separate sessions for mothers of under 2.5 year olds and 2.5 to 5yr olds. Also provided with booklet. Range of behavioural techniques.	One month	No support beyond single session.
Wiggs ¹⁶	One-to-one meeting with parents at home (1.5 to 2.5hr duration) to undertake functional analysis and agree detailed behavioural programme. Written details of agreed programme sent to parents. Range of behavioural techniques.	One month	Progress was monitored by regular telephone calls.
Before and after studies			
Bartlet ¹⁷	One-to-one meeting with parents at home or clinic (one or two appointments depending on needs). About one third of parents received a preliminary intervention prior to this before they were ready to become involved in the programme. Range of behavioural techniques. Graded change was used in a high proportion of cases.	Until parents were satisfied with the progress made. Generally three months.	Contact usually by telephone. Mean number of calls 4.95; duration ranged from 5 to 60min.
Hewitt ¹⁸	One-to-one meeting with parents at home to agree behavioural programme (two appointments). Details written up for parents. Mainly positive bedtime routine and graded change. Tailored to individual needs.	Until parents were satisfied with the progress made. Mean 6.7 weeks; range 2-15.	Weekly visits from nurse and visits from psychologist at three week intervals. Visits gradually withdrawn as progress occurred. Joint visits for complex cases.
Quine ¹⁹	One-to-one meeting with parents at home to agree behavioural programme (two appointments). Details written up for parents. (Based on Hewitt ¹⁴) Mainly positive bedtime routine and graded change. Tailored to individual needs.	Until parents were satisfied with the progress made. Range 5-30 weeks.	Weekly visits from health-visitor initially and then frequency agreed with parents. There was a follow-up appointment after three months.

3.4 Extinction

There were no studies of extinction found that were Level 3 or above on the Maryland Scale (Table 3) therefore the effect of extinction on the sleep problems of disabled children is classified as unknown. There were seven very small before and after studies; the number of participants ranged from three to 15. Most of the participants had learning disabilities. One used graduated extinction²⁴ and six used non-graduated extinction.^{20,23,25-26} Generally, extinction was described as being used in conjunction with a positive bedtime routine. The studies of non-graduated extinction all used a similar approach (see Box 4).

Box 4: Non-graduated extinction

- a) Establish a positive and regular bedtime routine
- b) Settle child into bed
- c) Say goodnight and leave the bedroom
- d) Ignore child's protestations and do not re-enter the room (except in case of illness)
- e) If the child comes out of their room, take the child immediately back to be with minimum interaction
- f) When child sleeps through the night give them positive attention in the morning and explain why

The study of graduated extinction used different schedules for each of the families.²⁴ Parents started with waiting three and five minutes before entering their child's bedroom and responding to their crying or protests. The length of time gradually increased each night.

Most of the studies reported that the intervention was explained to parents in a single one-to-one session, though this was not always fully reported. This session was accompanied by daily telephone contact with parents at least on the days following initial implementation of extinction (Table 7). In one study parents received three training sessions²⁶ and in one they received two two-hour sessions²⁵ (see Appendix D for full details). Two studies explicitly focused on partner support strategies as part of the intervention given to parents.²⁵⁻²⁶ The aim was to facilitate consistent parenting and to teach communication and problem-solving skills that help partners assist and encourage each other in their parenting tasks. Three studies had a set duration of implementation: two²⁰ and seven weeks.²⁵⁻²⁶ The remaining studies used a variable duration (see Table 8).

All of the studies reported improvement in children's sleep problems following the intervention though because of the study design it is unclear whether improvement can be directly attributed to the intervention. Three of the studies reported an extinction burst in some children (i.e. a temporary increase in severity of the target behaviour following the first days of implementation of the intervention); this occurred in seven out of 13 children,²⁶ two out of three;²⁵ and one out of four.²² (See Appendix D for full details of the individual study results.)

3. Results

Table 6: Details of participants (extinction studies)

Study	Disability	Age	Baseline severity of sleep problem
Bramble ²⁰ n=15	Severe LD	Mean 7.2yr Range 3.5-12yr	Severe sleep problem was an entry requirement. Mean severity 8 (SD 1.34) on 10-point VAS
Didden ²¹ n=3	Moderate LD; seizure disorder; mild LD with ADHD	Range 9.2-12.4yrs	Mean duration of night-time disruption ranged from 44min to 131min
Didden ²² n=4	Severe LD; moderate LD; mild LD	Range 1yr 11mth-25yr	Mean duration of night-time disruption ranged from 27min (SD 20.9) to 45min (SD 29.2)
Didden ²³ n=6	Spinal muscle atrophy, ADHD, Prader-Willi syndrome [†]	Range 2-4yrs	Mean duration of night-time disruption ranged from 21 to 131min
Durand ²⁴	Mild to moderate LD, pervasive developmental delay, autism	Range 2 -12yr	% of nights with bedtime disturbance range from 65% to 100% and night waking from 36% to 94% of nights
Thackery ²⁵ n=3	Severe LD; moderate LD; mild LD	Range 5-10yrs	Based on BEDS questionnaire had clinically significant sleep problems
Weiskop ²⁶ n=13	Autism; Asperger syndrome; fragile x syndrome	Mean 5yrs Range 1yr 1mth-9yr 1mth	Unclear; Problems reported were bedtime disturbances, sleeping in parental bed, night waking and disruptive behaviour

VAS: visual analogue scale, BEDS: Behavioural Evaluation of Disorders of Sleep questionnaire, [†]The study included six children but one had sleep terrors and one had sleep problems related to epilepsy which were not relevant to the review. Before and after data were available for three of the remaining four children and data were extracted for these three only.

One of the benefits put forward for use of extinction is that improved behaviour can occur over a shorter period of time than a graduated behavioural approach. From the information available in these studies there appears to be considerable variability in how rapid the response is. Only one study explicitly measured time to response. Bramble asked parents how long it took for their child to positively respond to the extinction technique. The mean time within which change was observed by parents was 3.6 nights (SD 1.9, range 1 to 7).²⁰ However, in the studies using a variable duration of intervention depending on response to treatment, the length of time is considerably longer (Table 8). This may be due to differences between the studies in factors such as the severity of the participants' sleep, the motivation of parents, how they were selected for the study, how rigorously parents implemented the intervention and/or the quality of the training they received.

Weiskop *et al.*²⁶ who conducted one of the two larger studies of extinction (13 participants), observed that extinction did not seem appropriate for early morning waking or night rocking possibly because they were not positively reinforced by parental responses. Two children who were withdrawn from their study were older and more non-compliant than those who remained: the authors suggest that extinction may be too difficult or stressful to implement with extremely non-compliant or older children.

Three studies formally elicited parents' views on extinction. One study, using the Program Evaluation Questionnaire (PEQ), reported that the best aspects of the programme were the good outcome, the support provided and the training, record-keeping was the aspect they liked least. Two parents reported that it was difficult to stick to a bedtime routine, one found

3. Results

the training sessions too long and three thought the programme was too time-consuming.²⁶ Another study using the PEQ reported that the three parents were very satisfied with the outcomes of the intervention and the techniques used. They thought the programme was very appropriate for their child and would strongly recommend it to a friend. They particularly like the support they received but did not like ignoring their child when they called.²⁵ The third study, which was conducted in the UK, reported that in terms of the acceptability of the approach 12 parents thought the treatment approach was 'just right' for their child and three thought it was 'rather tough'. There was high overall satisfaction with the treatment amongst parents.²⁰ The authors of two studies commented that parents found the intervention difficult to implement, though were satisfied with the results.²¹ In the study of graduated extinction the authors stated that parents were at first hesitant to delay attending to their children but found the short delay easy to tolerate.²⁴

3. Results

Table 7: Details of intervention (extinction studies)

Study	Details of intervention	Duration of implementation	Support for parents
Bramble ²⁰	Regular and positive bedtime routine. For extinction parents were instructed to rapidly settle child, leave bedroom, ignore child protestations unless in case of illness, if child leaves room after settling time firmly tell child to return to bed and, if necessary physically carry back to bed with minimal affective contact. Treatment was explained in single on-to-one session at home or clinic.	Two weeks	Telephone contact on the three days following the first session to offer encouragement and deal with problems. Additional telephone contact as needed. Only a minority required more than four calls.
Didden ²¹	Extinction (similar to above) [†] There was at least one meeting with parents at home to conduct a functional assessment and provide information on the technique.	40 and 80 nights (approx six and 11 weeks)	Daily telephone contact. The authors state that this was an important part of the intervention especially during initial treatment.
Didden ²²	Extinction (similar to above) There was at least one meeting with parents at home to conduct a functional assessment and provide information on the technique.	10 to 120 nights	Not explicitly stated though the authors advise daily contact between parents and therapist especially in the first week of treatment.
Didden ²³	Extinction (similar to above).	29 to 54 nights	Not explicitly stated.
Durand ²⁴	Graduated extinction and consistent bedtime routine. The extinction schedule varied between children. In response to night waking or disruptive behaviour neutral and minimal reassurance was provided at gradually increasing intervals e.g. one parent started by waiting three minutes before entering the room and the delay was increased by two minutes each night. Two one-to-one meetings with parents.	8 to 16 weeks	Regular telephone contact during baseline and treatment sessions.
Thackeray ²⁵	Extinction with regular and positive bedtime routine, reinforcement, effective instructions and partner support. Two week training programme delivered individually to parents at clinic (based on McDonald & Patzold five Step Sleep Programme).	Seven weeks	Telephone contact on at least three of the mornings after extinction implemented and weekly during the rest of the programme. There was 6 hours face-to-face contact in total.
Weiskop ²⁶	Extinction with regular and positive bedtime routine, reinforcement, effective instructions and partner support. Initial interview and functional assessment followed by three, weekly training sessions delivered individually to parents (at home and clinic). The different types of extinction were explained. All parents chose standard extinction which was also the therapist's preference.	Seven weeks	Daily telephone contact in the days following implementation of extinction and weekly during the rest of the programme. There was also a review session after training ended.

[†] A single child received differential reinforcement of incompatible behaviours Details not reported as only single case)

3. Results

3.5 Sleep restriction

There were no studies of sleep restriction found that were Level 3 or above on the Maryland Scale (Table 3) therefore the effect of sleep restriction on the sleep problems of disabled children is classified as unknown. There were two small studies of two²⁸ and four²⁷ participants where sleep restriction was used in conjunction with a positive bedtime routine. This intervention involved restricting the amount of time the child slept in bed to 90 per cent of the total time that the child normally slept at baseline. The child's bedtime and/or wake-time were adjusted for the new schedule. The intention is that this can be faded back to an age appropriate length of sleep time at the end of the intervention. Parents were also instructed to establish consistent bedtime routines (See Appendix D for full details). The extent of support received by parents in the two studies was unclear. Both studies reported improvements in child sleep problems (see Appendix D for full details of results) though because of the study design it is unclear whether improvement can be directly attributed to the intervention. One child experienced an increase in sleep-walking by the third week of the intervention (mean 2.3 episodes per week). This child also experienced two episodes of sleep terrors during the intervention.²⁸ The views of parents were not formally elicited. The authors of both studies stated that the parents found the intervention easy to implement on a regular basis. They suggest that the intervention is suitable for parents who are uncomfortable about using extinction or graduated extinction.

Table 8: Details of participants (sleep restriction studies)

Study	Disability	Age	Baseline severity of sleep problem
Christodulu ²⁷ n=4	Developmental disabilities	Range 2yr 9mth to 5yr 11mth	Mean duration of bedtime disturbances ranged from 88 to 849 mins/week and duration of night waking from 92 to 682mins.
Durand ²⁸ n=2	Autism; developmental delay	Both 4yr	Duration of bedtime disturbances 1.27hrs/week and 1.38 hrs/week.

3. Results

Table 9: Details of intervention (sleep restriction studies)

Study	Details of intervention	Duration of implementation	Support for parents
Christodulu ²⁷	Sleep restriction and consistent bedtime routine. Positive bedtime routine was introduced first. Parents were also instructed to return children to their own bed if they got out of bed or got into parental bed. Sleep restriction involved restricting the amount of time the child was in bed to 90% of the time the child normally slept (based on parent sleep diaries). Bedtime and/or sleep time was adjusted for the new schedule.	Positive bedtime routine lasted from a few days to approximately six wks; sleep restriction plus bedtime routine lasted approximately 14 to 18wks	Details not provided.
Durand ²⁸	Sleep restriction and consistent bedtime routine. Consistent bedtime routines were established and parents were instructed to return children to their own bed if they got out of bed or got into parental bed. Sleep restriction involved restricting the amount of time the child was in bed to 90% of the time the child normally slept (based on parent sleep diaries). Bedtime and/or sleep time was adjusted for the new schedule.	Approximately 15 and 25 weeks	Details not provided.

3. Results

3.6 Faded bedtime with response cost

There was one study of faded bedtime with response cost classified as above Level 3 on the Maryland Scale (Table 3). This was an RCT of 14 participants, using bedtime scheduling as a comparator, which had some methodological limitations (Appendix C).²⁹ There were also two before and after studies with three and four participants.³⁰⁻³¹ All of these studies were conducted in hospital settings in the US and it is unclear how easily such an intervention could be applied in the home setting. Full details of each of these studies are reported in Appendix D, though the intervention is not discussed in any detail here due to the lack of information on its use in a home-setting.

The intervention involved setting a bedtime at which sleep onset was highly likely within 15 minutes of being put to bed (this was half an hour later than the average time of sleep onset at baseline). A consistent bedtime routine was also established. The child was not permitted to go to sleep before the new bedtime and was woken at a set time each morning. The response cost occurred if the child did not fall asleep within 15 minutes: they were removed from bed and kept awake for one hour (played with toys, watched TV, etc.). They were then returned to bed and this was repeated until the child was put to bed and fell asleep within 15 minutes. If the child fell asleep within 15 minutes of bedtime, bedtime was made half an hour earlier the next night. If they did not fall asleep it was made half an hour later.

4. Discussion

4.1 Summary of the evidence

We conducted a rapid evidence review focusing on interventions for behavioural sleep problems in young disabled children (up to age eight years), specifically interventions that can be carried out by parents in the home. Of the 19 studies identified, four were RCTs and 15 were before and after studies, most of which had less than 10 participants. Three of the four RCTs had been conducted in a UK setting. The majority of participants had learning disabilities ranging from mild to severe and had serious sleep problems of long-standing duration.

Evidence was identified on three different behavioural approaches conducted in the home setting: interventions using multiple behavioural techniques (non-specific behavioural interventions); extinction (graduated and non-graduated); and sleep restriction. Evidence was also identified on faded bedtime with response cost; however this was implemented in an in-patient setting for most of the participants and it is unclear from the evidence available how easily this method would transfer to a home setting.

There were two types of non-specific behavioural interventions evaluated: general information giving and a more individually tailored intervention combining information giving to parents with an individual treatment plan for each child based on an assessment of the sleep problem. The main characteristic that these two groups of studies had in common was that they did not evaluate a single behavioural technique, but provided parents with information on a range of approaches. Two studies evaluated the provision of general information on behavioural techniques to parents, with the intention that parents would then implement the techniques with their children. There was evidence from a single RCT that a 90 minute session explaining behavioural approaches to child sleep problems, delivered to parents in their own home, was more effective than no intervention in reducing sleep disturbance post-treatment and six months later.¹⁴ There was evidence from the same study that provision of the same information through a booklet only was also more effective than no intervention in reducing sleep disturbance over the same time period. The second study (based on the main statistical analysis) did not find any benefit with a 90 minute instruction and discussion session with small groups of mothers.¹⁵ Interpretation of this study is complicated by the inclusion of children with and without sleep problems.

Unfortunately there is not a large enough body of appropriate evidence to conclude that such an intervention works. Overall, there is sufficient evidence to conclude that the provision of information to parents of children with a severe learning disability and a severe behavioural sleep problem, either in a single face-to-face session or through a booklet, is a promising approach. Further research across a range of children with different disabilities is required. It would seem reasonable to conclude that such techniques would be transferable to other disabled groups. However, a key question is whether the parents who participated in the study are more highly motivated and/or feel more confident and are at a stage of readiness to deliver such an intervention with their children compared to a general population.

There were four studies that evaluated provision of information in conjunction with individual treatment plans. The interventions in these studies were more intensive than the two described above. In addition to the individual treatment plans parents were also provided with ongoing information and support (by telephone or face-to-face) while they implemented the techniques with their children. There was evidence from a single RCT of children with a severe learning disability and one or more daytime challenging behaviours.¹⁶ A functional analysis of the individual children's sleep problem in combination with an agreed written

4. Discussion

behavioural programme delivered by parents and provision of information on behavioural techniques was more effective than no intervention in reducing sleep problems but not daytime challenging behaviour. There were also some benefits for parental outcomes in this study. The remaining three studies did not have a control group, though their findings supported the results from this RCT. Overall, there is evidence that the intervention in this RCT is a promising one for children with severe learning disabilities. One of the before and after studies also used a similar intervention in children with a range of chronic illnesses, as well as in children with learning disabilities.¹⁷ Unfortunately outcome data were not reported for the two groups.

It is interesting that two interventions that vary intensity are both promising interventions.^{14,16} Arguably in the study of the lower intensity interventions which focused on provision of information (either face-to-face or through a booklet) participants will probably have received support indirectly as researchers spent a total of 90 minutes with all participants gathering outcome data. Data was gathered from the control group in a similar way but it is possible that the contact in the two intervention groups encouraged parents to implement the intervention. But even if this was the case, the intervention was still less intensive in that there was not a functional assessment or a written action plan for each child.

It is unlikely that the lower intensity intervention is an appropriate approach for all families and some may prefer to have a tailored intervention to implement rather than trying to apply general information to their own specific situation. Equally some parents may prefer to avoid the time commitment of a more intensive intervention. There would be benefit in evaluating the relative cost-effectiveness of the two approaches as well as parental preferences. In the absence of such information it may be beneficial, where practical, to make available the less intensive approach to all families in the first instance and to provide the more intensive approach to families who feel that they need the extra support or for whom the less intensive approach is not effective.

Although there were several studies evaluating extinction (mainly non-graduated extinction), no controlled studies were identified. In the absence of a control or comparison group there is uncertainty as to whether the improvement evident in the studies was a direct result of the intervention. However, given that sleeping problems in children with learning disabilities can be long-standing and unlikely to spontaneously improve (it was stated in several studies that parents had already tried other approaches that had failed) these studies indicate that extinction may be a feasible approach to use. An argument for the use of extinction is that improvement may be quicker than with other graduated methods. Based on the group of included studies there was considerable variability across and within studies in the length of time for benefit to occur. One of the disadvantages of extinction is that parents need to leave the child to cry if they do so after they are put to bed. This may be difficult for some parents to tolerate. Overall the parents in these small studies were positive about the approach, though some expressed that they disliked ignoring their child. Parents may have been selected or selected themselves into these studies on the basis of their finding extinction acceptable therefore it is unclear how acceptable the technique would be to parents of disabled children general.

As with extinction, only before and after studies were available on sleep restriction. Both studies showed improvement in sleep outcomes but because of the study design it is unclear whether the improvement can be directly attributed to the intervention. The authors suggest that sleep restriction may be particularly suitable for parents who are uncomfortable about using extinction or graduated extinction.

4.2 Gaps in the evidence

Previous reviews in this field in 1999⁵ and 2000³⁹ highlighted the need for further and better research. Some valuable work has been done since then, in particular in the UK; however, the evidence base remains limited. Further research is required on behavioural interventions for behavioural sleep problems in young children with disabilities; in particular there is a lack of studies with a control or comparison group. Ideally future studies would compare different types of interventions, though, as highlighted by Montgomery this may not be practical due to the large number of participants required. Further research on the longer-term outcomes following a behavioural intervention is also required. Do any short-term benefits continue into the long-term or do parents need refresher courses and/or longer term follow-up?

The interventions in the included studies are effectively complex multi-component interventions and it is unclear from the studies what aspects of the interventions are essential for a beneficial effect. For example, as pointed out by Hewitt,¹⁸ in addition to the specific behavioural technique, factors such as directly involving parents, a written treatment programme, daily feedback for parents from diaries and weekly support visits may have been important.

The components that are important for an effective intervention may also vary depending on the particular needs of parents it is being delivered to. While there was evidence that a booklet alone was effective in one study, in another study one third of parents needed a preliminary intervention before they were ready to cope with the main intervention. This emphasises the importance of being aware of the needs of parents as well as focusing on the behavioural sleep problems of the child. Most of the included studies did not formally elicit the views of parents therefore it is unclear what parents' views were about some of the approaches and what aspects of the interventions they found most helpful. Further research on this would be helpful in developing future services. In particular, a clearer perspective on parents' views, and on the views of professionals who provide interventions, is required in relation to 'real-life' services and interventions, as opposed to specifically within the context of a research study evaluating effectiveness. As Robinson and Richdale,⁴⁰ little is known about interventions offered to families in 'real-life' settings.

The participants in the studies did not cover the whole spectrum of children's disabilities. Most of the participants in the included studies had a range of learning disabilities from mild to severe. Further evidence is required on the issues around delivering such interventions to children with other disabilities and children with complex health needs, for example, children with physical conditions which require night-time assistance and medication in addition to a behavioural sleep problem.

Sleep problems may be both behavioural and physical and this points to the need for careful evaluation of disabled children's sleep problems before planning an intervention. Stores and Wiggs⁴¹ suggest that a three tier service is needed:

- *Primary care*, for relatively straightforward sleep problems, for example settling or night waking problems, which can be treated by health visitors or GPs;
- *Community or hospital paediatric services* for more difficult diagnostic or treatment problems; and
- *Specialised sleep disorder services*, at a regional level, for the most complex problems.

For this system to be effective, all personnel involved need to have basic training in identifying and managing sleep disorders.

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Appendix A: Search Strategy

The search strategies used to search the databases are described in detail below.

Cochrane Database of Systematic Reviews (CDSR), DARE and CENTRAL

```

#1 MeSH descriptor Sleep Disorders explode all trees
#2 (sleep* or night* or nocturnal):ti,ab,kw
#3 (bedtime or "bed time" or settl* or waking or wake*):ti,ab,kw
#4 (#1 OR #2 OR #3)
#5 (infant* or baby or babies or toddler* or child* or preschool*):ti,ab,kw
#6 MeSH descriptor Disabled Persons explode all trees
#7 MeSH descriptor Mental Disorders explode all trees
#8 (disabled or disability or disabilities or handicap* or retard* or autist* or asperger* or
blind or blindness or deaf or deafness or or (attention near/2 deficit) or adhd):ti,ab,kw
#9 (intellectual* impair*):ti,ab,kw
#10 ("complex needs" or "special needs"):ti,ab,kw
#11 ((life near limit*) or (life near threaten*)):ti,ab,kw
#12 (learning near (disorder* or disab*)):ti,ab,kw
#13 (technolog* near depend*):ti,ab,kw
#14 ((cerebral palsy) or ("down* NEAR/2 syndrome")):ti,ab,kw
#15 (#6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14)
#16 MeSH descriptor Psychotherapy explode all trees
#17 (behav* near (intervention* or therap* or treatment* or program* or approach* or
techniqu* or strateg*)):ti,ab,kw
#18 (avers* near/2 therap*):ti,ab,kw
#19 (biofeedback or chronotherap* or (contingency next manage*) or extinction or
(negative next consequence*) or schedul*):ti,ab,kw
#20 (reinforc* or routine* or (response next cost*) or separation or desensit* or (omission
next train*) or faded or fading):ti,ab,kw
#21 (cbt or (cognitive near/3 therap*)):ti,ab,kw
#22 (#16 OR #17 OR #18 OR #19 OR #20 OR #21)
#23 (#4 AND #5 AND #15 AND #22)

```

MEDLINE, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1950 to Present>

```

1 exp sleep disorders/ (41103)
2 ((sleep$ or night$ or nocturnal) adj3 (disturb$ or problem$ or behav$ or disorder$ or
disrupt$ or difficult$ or regulat$ or habit$ or questionnaire$)).ti,ab. (23448)
3 (bedtime or bed time or settl$4 or sleepless$ or waking or wake$1 or wakeful$).ti,ab.
(29939)
4 or/1-3 (75199)
5 exp child/ or exp infant/ (1684476)
6 exp child behavior/ or exp infant behavior/ (10514)
7 (infant$ or baby or babies or toddler$ or child or children or preschool$).ti,ab. (861375)
8 or/5-7 (1858948)
9 exp disabled persons/ (35898)
10 exp mental disorders diagnosed in childhood/ (112868)
11 (disabled or disability or disabilities or handicap$ or retard$).ti,ab. (168251)
12 intellectual$ impair$.ti,ab. (919)
13 ((complex or special) adj3 needs).ti,ab. (4372)
14 (life adj (limit$ or threaten$)).ti,ab. (35724)
15 learning disorder$.ti,ab. (676)
16 technolog$ depend$.ti,ab. (208)

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17 (cerebral palsy or down\$2 syndrome).ti,ab. (24456)
18 (autist\$ or asperger\$ or blind or blindness or deaf or deafness or adhd or attention deficit).ti,ab. (162781)
19 or/9-18 (464869)
20 exp psychotherapy/ (120601)
21 (behav\$ adj3 (intervention\$ or therap\$ or treatment\$ or program\$ or approach\$ or techniqu\$ or strateg\$)).ti,ab. (28975)
22 avers\$ therap\$.ti,ab. (202)
23 (biofeedback or chronotherapy\$ or contingency manage\$ or extinction or negative consequence\$ or schedul\$).ti,ab. (93784)
24 (reinforc\$ or routine\$ or response cost\$ or separation or desensit\$ or omission train\$ or faded or fading).ti,ab. (352585)
25 (cbt or (cognitive adj3 therap\$)).ti,ab. (6930)
26 or/20-25 (566280)
27 4 and 8 and 19 and 26 (335)
28 limit 27 to (english language and yr="1985 - 2008") (260)
29 limit 28 to (case reports or comment or editorial or letter) (39)
30 28 not 29 (221)

The search was amended on 23/9/8 to search for 'delayed development' by adding in an additional search line as follows to disability concept:

(develop\$ adj3 delay\$).ti,ab.

Three new records were identified from MEDLINE, but all had already been found from other searches.

EMBASE, OvidSP, <980 to 2008 Week 33>

1 exp sleep disorders/ (70163)
2 ((sleep\$ or night\$ or nocturnal) adj3 (disturb\$ or problem\$ or behav\$ or disorder\$ or disrupt\$ or difficult\$ or regulat\$ or habit\$ or questionnaire\$)).ti,ab. (19942)
3 (bedtime or bed time or settl\$4 or sleepless\$ or waking or wake\$1 or wakeful\$).ti,ab. (24838)
4 or/1-3 (95487)
5 exp child behavior/ or exp infant behavior/ (12472)
6 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$).ti,ab. (545840)
7 limit 4 to (infant <to one year> or child <unspecified age> or preschool child <1 to 6 years> or school child <7 to 12 years>) (8686)
8 (4 and (5 or 6)) or 7 (11644)
9 exp Disabled Person/ (2582)
10 exp Mental Disease/ (684814)
11 exp Disability/ (40748)
12 exp Handicapped Child/ (2719)
13 (disabled or disability or disabilities or handicap\$ or retard\$).ti,ab. (124793)
14 intellectual\$ impair\$.ti,ab. (776)
15 ((complex or special) adj3 needs).ti,ab. (2691)
16 (life adj (limit\$ or threaten\$)).ti,ab. (30533)
17 learning disorder\$.ti,ab. (500)
18 technolog\$ depend\$.ti,ab. (126)
19 (cerebral palsy or down\$2 syndrome).ti,ab. (18087)
20 (autist\$ or asperger\$ or blind or blindness or deaf or deafness or adhd or attention deficit).ti,ab. (133842)
21 or/9-20 (917539)
22 exp psychotherapy/ (75871)

- 23 (behav\$ adj3 (intervention\$ or therap\$ or treatment\$ or program\$ or approach\$ or techniqu\$ or strateg\$)).ti,ab. (25578)
- 24 avers\$ therap\$.ti,ab. (112)
- 25 (biofeedback or chronotherap\$ or contingency manage\$ or extinction or negative consequence\$ or schedul\$).ti,ab. (73647)
- 26 (reinforc\$ or routine\$ or response cost\$ or separation or desensit\$ or omission train\$ or faded or fading).ti,ab. (281295)
- 27 (cbt or (cognitive adj3 therap\$)).ti,ab. (7750)
- 28 or/22-27 (431281)
- 29 8 and 28 and 21 (915)
- 30 limit 29 to (english language and yr="1985 - 2008") (814)
- 31 limit 30 to (editorial or letter or note) (21)
- 32 30 not 31 (793)

PsycINFO, OvidSP, <1967 to July Week 5 2008>

- 1 exp sleep apnea/ or exp sleep deprivation/ or exp sleep disorders/ or exp sleep onset/ or exp sleep talking/ or exp sleep treatment/ or exp sleep wake cycle/ or exp sleepiness/ or exp sleepwalking/ (11597)
- 2 ((sleep\$ or night\$ or nocturnal) adj3 (disturb\$ or problem\$ or behav\$ or disorder\$ or disrupt\$ or difficult\$ or regulat\$ or habit\$ or questionnaire\$)).ti,ab. (10750)
- 3 (bedtime or bed time or settl\$4 or sleepless\$ or waking or wake\$1 or wakeful\$).ti,ab. (12812)
- 4 or/1-3 (26111)
- 5 limit 4 to 100 childhood <birth to age 12 yrs> (3038)
- 6 exp childhood development/ (44795)
- 7 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$).ti,ab. (355589)
- 8 (4 and (6 or 7)) or 5 (4024)
- 9 exp disabilities/ (38564)
- 10 exp mental disorders/ (315804)
- 11 exp mental retardation/ (34781)
- 12 exp learning disorders/ (25979)
- 13 exp attention deficit disorder/ (12050)
- 14 (disabled or disability or disabilities or handicap\$ or retard\$).ti,ab. (103746)
- 15 intellectual\$ impair\$.ti,ab. (790)
- 16 ((complex or special) adj3 needs).ti,ab. (5099)
- 17 (life adj (limit\$ or threaten\$)).ti,ab. (2695)
- 18 learning disorder\$.ti,ab. (971)
- 19 technolog\$ depend\$.ti,ab. (61)
- 20 (cerebral palsy or down\$2 syndrome).ti,ab. (7027)
- 21 (autist\$ or asperger\$ or blind or blindness or deaf or deafness or adhd or attention deficit).ti,ab. (52668)
- 22 or/9-21 (456767)
- 23 exp behavior modification/ (34956)
- 24 exp psychotherapy/ (142119)
- 25 (behav\$ adj3 (intervention\$ or therap\$ or treatment\$ or program\$ or approach\$ or techniqu\$ or strateg\$)).ti,ab. (50670)
- 26 avers\$ therap\$.ti,ab. (357)
- 27 (biofeedback or chronotherap\$ or contingency manage\$ or extinction or negative consequence\$ or schedul\$).ti,ab. (46417)
- 28 (reinforc\$ or routine\$ or response cost\$ or separation or desensit\$ or omission train\$ or faded or fading).ti,ab. (85220)
- 29 (cbt or (cognitive adj3 therap\$)).ti,ab. (13138)
- 30 or/23-29 (291706)
- 31 8 and 22 and 30 (274)
- 32 limit 31 to (english language and yr="1985 - 2008") (226)

- 33 limit 32 to ("comment/reply" or editorial or letter) (4)
- 34 32 not 33 (222)
- 35 from 34 keep 1-222 (222)

The search was amended on 23/9/8 to search for 'delayed development' by adding in an additional search line, as follows, to disability concept:

(develop\$ adj3 delay\$).ti,ab.

Five new records were identified from PsyCINFO. Three of these had already been found from other searches.

CINAHL, OvidSP, <1982 to August Week 3 2008>

- 1 exp sleep disorders/ (7241)
- 2 ((sleep\$ or night\$ or nocturnal) adj3 (disturb\$ or problem\$ or behav\$ or disorder\$ or disrupt\$ or difficult\$ or regulat\$ or habit\$ or questionnaire\$)).ti,ab. (3325)
- 3 (bedtime or bed time or settl\$4 or sleepless\$ or waking or wake\$1 or wakeful\$).ti,ab. (2889)
- 4 or/1-3 (10802)
- 5 exp child/ or exp infant/ (170003)
- 6 exp child behavior/ or exp infant behavior/ (3656)
- 7 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$).ti,ab. (105377)
- 8 or/5-7 (192886)
- 9 exp disabled/ (16225)
- 10 exp mental disorders/ (124183)
- 11 exp developmental disabilities/ (2156)
- 12 (disabled or disability or disabilities or handicap\$ or retard\$).ti,ab. (30208)
- 13 intellectual\$ impair\$.ti,ab. (99)
- 14 ((complex or special) adj3 needs).ti,ab. (2765)
- 15 (life adj (limit\$ or threaten\$)).ti,ab. (4246)
- 16 learning disorder\$.ti,ab. (82)
- 17 technolog\$ depend\$.ti,ab. (134)
- 18 (cerebral palsy or down\$2 syndrome).ti,ab. (3693)
- 19 (autist\$ or asperger\$ or blind or blindness or deaf or deafness or adhd or attention deficit).ti,ab. (15261)
- 20 or/9-19 (170487)
- 21 exp psychotherapy/ (47175)
- 22 (behav\$ adj3 (intervention\$ or therap\$ or treatment\$ or program\$ or approach\$ or techniqu\$ or strateg\$)).ti,ab. (6229)
- 23 avers\$ therap\$.ti,ab. (7)
- 24 (biofeedback or chronotherap\$ or contingency manage\$ or extinction or negative consequence\$ or schedul\$).ti,ab. (8557)
- 25 (reinforc\$ or routine\$ or response cost\$ or separation or desensit\$ or omission train\$ or faded or fading).ti,ab. (20842)
- 26 (cbt or (cognitive adj3 therap\$)).ti,ab. (1825)
- 27 or/21-26 (77320)
- 28 4 and 8 and 20 and 27 (72)
- 29 limit 28 to (english language and yr="1985 - 2008") (69)

SPECTR and C2-RIPE (Campbell Collaboration), <http://geb9101.gse.upenn.edu>
(sleep) or (wake) or (waking) or (night) or (bedtime) or ("bed time") (in either "indexed" or "non-indexed" fields)

AND

(infant) or (baby) or (babies) or (toddler) or (child) or (preschool) (in either "indexed" or "non-indexed" fields)

HMIC, OvidSP, < July 2008 >

- 1 sleep\$.mp. (526)
- 2 ((sleep\$ or night\$ or nocturnal) adj3 (disturb\$ or problem\$ or behav\$ or disorder\$ or disrupt\$ or difficult\$ or regulat\$ or habit\$ or questionnaire\$)).mp. (221)
- 3 (bedtime or bed time or settl\$4 or sleepless\$ or waking or wake\$1 or wakeful\$).mp. (481)
- 4 exp sleep/ or exp sleep disorders/ (130)
- 5 or/1-4 (1024)
- 6 child\$.mp. or exp children/ (24726)
- 7 (infant\$ or baby or babies or toddler\$ or preschool).mp. (3616)
- 8 or/6-7 (26362)
- 9 exp disabilities/ (27219)
- 10 (disabled or disabilit\$ or handicap\$ or retard\$).mp. (14077)
- 11 (intellect\$ adj2 impair\$).mp. (23)
- 12 ((complex or special) adj3 needs).mp. (1013)
- 13 (life adj (limit\$ or threaten\$)).mp. (299)
- 14 technolog\$ depend\$.mp. (14)
- 15 (cerebral palsy or down\$2 syndrome).mp. (314)
- 16 (autist\$ or asperger\$ or blind or blindness or deaf or deafness or adhd or attention deficit).mp. (1393)
- 17 (learning adj3 (disab\$ or disorder\$)).mp. (5570)
- 18 or/9-17 (31892)
- 19 exp psychotherapy/ (1946)
- 20 (behav\$ adj3 (intervention\$ or therap\$ or treatment\$ or program\$ or approach\$ or techniqu\$ or strateg\$)).mp. (1083)
- 21 avers\$ therap\$.mp. (3)
- 22 (biofeedback or chronotherap\$ or contingency manage\$ or extinction or negative consequence\$ or schedul\$).mp. (1419)
- 23 (reinforc\$ or routine\$ or response cost\$ or separation or desensit\$ or omission train\$ or faded or fading).mp. (4832)
- 24 (cbt or (cognitive adj3 therap\$)).mp. (229)
- 25 or/19-24 (8890)
- 26 25 and 8 and 18 and 5 (12)
- 27 limit 26 to yr="1985 - 2010" (11)

NNR archive, <https://portal.nihr.ac.uk/Pages/NRRArchiveSearch.aspx>.

This is a difficult interface to search. Searches have to be constructed with the most general concept first and then more specific concepts used to narrow down the retrieved set. There is no facility to record the search history or to export the results.

"sleep*" or "wake*" or waking or bedtime or "settl*" or "night*"
AND
"infan*" or baby or babies or "toddler*" or "child*" or "preschool*"
AND
"disab*" or "disorder*" or "handicap*" or "retard*" or "impair*" or special or palsy or syndrome or "autis*" or "asperger*" or "blind*" or "deaf*" or adhd

sleep*
AND
child OR infant
AND
psychotherapy OR behavior-therapy OR "cognitive*" OR biofeedback

CERUK, <http://www.ceruk.ac.uk/>

Search terms were entered one by one.

Sleep*
Waking
Wake*
bedtime
“bed time”
Night*
settl*

ERIC, Dialog/Datastar

sleep OR bedtime OR bed ADJ time OR settl\$4 OR sleepless\$ OR waking OR wake\$1 OR
wakeful\$ OR ((sleep\$ OR night\$ OR nocturnal) NEAR (disturb\$ OR problem\$ OR behav\$
OR disorder\$ OR disrupt\$ OR difficult\$ OR regulat\$ OR habit\$ OR questionnaire\$))
AND

(Children#.W..DE.) OR (Child-Behavior#.W..DE.) OR (infant\$ OR baby OR babies OR toddler\$ OR child OR children OR preschool\$)

AND

(Disabilities#.W..DE.) OR (disabled OR disability OR disabilities OR handicap\$ OR retard\$) OR (intellectual\$ NEAR impair\$) OR ((complex OR special) NEAR needs) OR (life ADJ (limit\$ OR threaten\$)) OR (learning ADJ (disorder\$ OR disab\$)) OR (technolog\$ ADJ depend\$) OR (cerebral ADJ palsy OR down\$2 ADJ syndrome OR autist\$ OR asperger\$ OR blind OR blindness OR deaf OR deafness OR adhd OR attention ADJ deficit))

AND

(Conditioning#..W..DE.) OR (Psychotherapy#..W..DE.) OR (behav\$ NEAR (intervention\$ OR therap\$ OR treatment\$ OR program\$ OR approach\$ OR techniqu\$ OR strateg\$)) OR (avers\$ ADJ therap\$) OR biofeedback OR chronotherap\$ OR contingency ADJ manage\$ OR extinction OR negative ADJ consequence\$ OR schedul\$ OR reinforc\$ OR routine\$ OR response ADJ cost\$ OR separation OR desensit\$ OR omission ADJ train\$ OR faded OR fading OR (cbt OR cognitive NEAR therap\$)

limited to English language and publication date 1985 or later

Childdata

The search interface does not allow complex searches so a series of searches was undertaken:

sleep OR bedtime OR bed OR settling OR sleepless OR sleeplessness OR waking OR wakeful

sleep/title and disability/keyword
Sleep/abstract and disability/keyword
bed/title and disability/keyword
bed/abstract and disability/keyword
settling/title and disability/keyword
settling/abstract and disability/keyword
sleepless/title and disability/keyword
sleepless/abstract and disability/keyword
sleeplessness/title and disability/keyword
sleeplessness/abstract and disability/keyword
wakeful/title and disability/keyword
wakeful/abstract and disability/keyword

British Education Index, Dialog/Datastar, 1975 to date (BREI) and Australian Education Index

These databases were searched together and the results downloaded together

1	sleep.DE.	24
2	sleep.TI,AB.	26
3	(bed ADJ time).TI,AB.	0
4	bedtime.TI,AB.	2
5	settl\$.TI,AB.	52
6	(sleepless\$ OR waking OR wake\$1 OR wakeful\$).TI,AB.	26
7	sleeplessness	2
8	waking	4
9	(disturb\$ OR problem\$ OR behav\$ OR disorder\$ OR disrupt\$ OR difficult\$ OR regulat\$ OR habit\$ OR questionnaire\$).TI,AB.	9034
10	(1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8) AND 9	15
11	children	20041
12	PRIMARY-SCHOOL-STUDENTS.DE. OR CHILDREN#.W..DE.	8124
13	CHILD-BEHAVIOUR#.DE.	0
14	(infant\$ OR baby OR babies OR toddler\$ OR child OR children OR preschool\$).TI,AB.	
	12989	
15	students	20276
16	students	20276
17	ages	2117
18	11 OR 12 OR 13 OR 14	20412
19	10 AND 18	10
20	DISABILITIES#.W..DE. OR SPECIAL-NEEDS-STUDENTS.DE. OR MENTAL-RETARDATION.DE. OR READING-DIFFICULTIES.DE. OR AUTISM.W..DE.	8076
21	disabled OR disability OR disabilities OR handicap\$ OR retard\$ OR intellectual\$ NEAR impair\$ OR (complex OR special) NEAR needs OR life ADJ (limit\$ OR threaten\$) OR learning ADJ (disorder\$ OR disab\$) OR technolog\$ ADJ depend\$ OR (cerebral ADJ palsy OR down\$2 ADJ syndrome OR autist\$ OR asperger\$ OR blind OR blindness OR deaf OR deafness OR adhd OR attention ADJ deficit).TI,AB.	9333
22	19 AND (20 OR 21)	7

Appendix B: Excluded Studies (from full paper screening)

Adlington, K., A. J. Liu, and R. Nanan. 2006. "Sleep disturbances in the disabled child--a case report and literature review." <i>Australian Family Physician</i> 35:711-715.	Not a primary study (review/discussion paper)
Bartlet, L. B. 2006. "Treating the sleep disorders of childhood: Current practice in the United Kingdom." <i>Journal of Indian Association for Child and Adolescent Mental Health</i> 2:89-95.	Not a primary study (review/discussion paper)
Didden, R., P.C. Duker, and H. Korzilius. 1997. "Meta-analytic study on treatment effectiveness for problem behaviours with individuals who have mental retardation." <i>American Journal on Mental Retardation</i> 101:387-399.	Not a primary study
Buschbacher, Pamelazita, Lise Fox, and Shelley Clarke. 2004. "Recapturing Desired Family Routines: A Parent-Professional Behavioral Collaboration." Pp. 15-39, <i>Research and Practice for Persons with Severe Disabilities RPSD</i> .	Case study; no sleep problem
Dorris, Liam, Nicola Scott, Sameer Zuberi, Neil Gibson, and Colin Espie. 2008. "Sleep problems in children with neurological disorders." <i>Developmental neurorehabilitation</i> 11:95-114.	Not a primary study (review/discussion paper)
Espie, C. A., and A. Wilson. 1993. "Improving sleep-wake schedules amongst people with mental handicaps: Some preliminary case material." <i>Behavioural Psychotherapy</i> 21:51-55.	None of the participants were under 8 years old
France, K. G., J. M. T. Henderson, and S. M. Hudson. 1996. "Fact, act, and tact: A three-stage approach to treating the sleep problems of infants and young children." <i>Child and Adolescent Psychiatric Clinics of North America</i> 5:581-599.	Not a primary study (review/discussion paper)
Glaze, D. G., C. L. Rosen, and J. A. Owens. 2002. "Toward a practical definition of pediatric insomnia." <i>Current Therapeutic Research - Clinical and Experimental</i> 63:B4-B17.	Not a primary study (review/discussion paper)
Hoban, T. F. 2000. "Sleeplessness in children with neurodevelopmental disorders: Epidemiology and management." <i>CNS Drugs</i> 14:11-22.	Not a primary study (review/discussion paper)
Johnson, K. P., and B. A. Malow. 2008. "Sleep in children with autism spectrum disorders." <i>Current Neurology and Neuroscience Reports</i> 8:155-161.	Not a primary study (review/discussion paper)
Johnson, Cynthia R. 1996. "Sleep Problems in Children with Mental Retardation and Autism." <i>Child and Adolescent Psychiatric Clinics of North America</i> 5:673-683.	Not a primary study (review/discussion paper)

Appendix B Excluded Studies

Keenan, Ruth A., Matt R. Wild, Irene McArthur, and Colin A. Espie. 2007. "Children with developmental disabilities and sleep problems: Parental beliefs and treatment acceptability." <i>Journal of Applied Research in Intellectual Disabilities</i> 20:455-465.	Does not evaluate an intervention (survey of parents)
Krakowiak, Paula, Beth Goodlin-Jones, Irla Hertz-Pannier, Lisa A. Croen, and Robin L. Hansen. 2008. "Sleep problems in children with autism spectrum disorders, developmental delays, and typical development: a population-based study." <i>Journal of Sleep Research</i> 17:197-206.	No intervention (prevalence study)
Lancioni, Giulio E., Reilly Mark F. O, and Gabriella Basili. 1999. "Review of Strategies for Treating Sleep Problems in Persons with Severe or Profound Mental Retardation or Multiple Handicaps." <i>American Journal on Mental Retardation</i> 104:170-186.	Not a primary study (review/discussion paper)
Lucas, P., K. Liabo, and H. Roberts. 2002. "Do behavioural treatments for sleep disorders in children with Down's syndrome work?" <i>Archives of Disease in Childhood</i> 87:413-414.	Review of reviews
Meltzer, Lisa J., and Jodi A. Mindell. 2004. "Nonpharmacologic treatments for pediatric sleeplessness." <i>Pediatric Clinics of North America</i> 51:135-151.	Not a primary study (review/discussion paper)
Morgenthaler, T. I., et al. 2006. "Practice parameters for behavioral treatment of bedtime problems and night wakings in infants and young children." <i>Sleep</i> 29:1277-1281.	Not a primary study (Report of American Academy of Sleep Medicine)
Morris, S., I. S. James-Roberts, J. Sleep, and P. Gillham. 2001. "Economic evaluation of strategies for managing crying and sleeping problems." <i>Archives of Disease in Childhood</i> 84:15-19.	Not disabled children
O'Callaghan, F. J., A. A. Clarke, E. Hancock, A. Hunt, and J. P. Osborne. 1999. "Use of melatonin to treat sleep disorders in tuberous sclerosis." <i>Developmental Medicine and Child Neurology</i> 41:123-126.	Not a behavioural intervention
Okawa, M., T. Nanami, S. Wada, T. Shimizu, and et al. 1987. "Four congenitally blind children with circadian sleep-wake rhythm disorder." <i>Sleep: Journal of Sleep Research & Sleep Medicine</i> 10:101-110.	Not a behavioural intervention
Paavonen, E., Taina Nieminen-von Wendt, Raija Vanhala, Eeva T. Aronen, and Lennart von Wendt. 2003. "Effectiveness of melatonin in the treatment of sleep disturbances in children with Asperger disorder." <i>Journal of Child and Adolescent Psychopharmacology</i> 13:83-95.	Not a behavioural intervention
Piazza, Cathleen C., and Wayne W. Fisher. 1991. "Bedtime fading in the treatment of pediatric insomnia." <i>Journal of Behavior Therapy and Experimental Psychiatry</i> 22:53-56.	Single case with disability as defined for purposes of the project
Quine, L. 1991. "Sleep problems in children with mental handicap." <i>Journal of Mental Deficiency Research</i> 35:269-290.	No intervention (prevalence study)

Appendix B Excluded Studies

Richdale, Amanda L. 1999. "Sleep problems in autism: Prevalence, cause and intervention." <i>Developmental Medicine and Child Neurology</i> 41:60-66.	Not a primary study (review/discussion paper)
Roane, Henry S., Cathleen C. Piazza, Laura E. Bodnar, and Kerri L. Zimmerman. 2000. "Sleep Difficulties in Children with Developmental Disabilities." <i>Infants and Young Children</i> 13:1-8.	Not a primary study (review/discussion paper)
Robinson, A., and A. Richdale. 2004. "Sleep problems in children with an intellectual disability: Parental perceptions of sleep problems, and views of treatment effectiveness." <i>Child: Care, Health and Development</i> 30:139-150.	No intervention (survey)
Schreck, K. A. 2001. "Behavioral treatments for sleep problems in autism: Empirically supported or just universally accepted?" <i>Behavioral Interventions</i> 16:265-278.	Not a primary study (review/discussion paper)
Stores, Gregory. 1992. "Sleep studies in children with a mental handicap." <i>Journal of Child Psychology and Psychiatry</i> 33:1303-1317.	Not a primary study (review/discussion paper)
Stores, G., and L. Wiggs. 2001. <i>Sleep disturbance in children and adolescents with disorders of development: its significance and management</i> . London: Mac Keith Press.	No primary studies not already identified
Stores, G. 2001. <i>A clinical guide to sleep disorders in children and adolescents</i> . Cambridge: Cambridge University Press.	No primary studies not already identified
Turk, J. 2003. "Melatonin supplementation for severe and intractable sleep disturbance in young people with genetically determined developmental disabilities: short review and commentary." <i>Journal of Medical Genetics</i> 40:793-796.	Not a primary study (review/discussion paper)
Wiggs, L., G. Stores. 2006. "A randomised controlled trial of behavioural intervention for sleeplessness in children with autism spectrum disorders." <i>Journal of Sleep Research</i> 15 (Suppl 1): S83	Only available as an abstract
Wiggs, L., and K. France. 2000. "Behavioural treatments for sleep problems in children and adolescents with physical illness, psychological problems or intellectual disabilities." <i>Sleep Medicine Reviews</i> 4:299-314.	Not a primary study (review/discussion paper)
Wiggs, L., and G. Stores. 1996. "Sleep problems in children with severe intellectual disabilities: What help is being provided?" <i>Journal of Applied Research in Intellectual Disabilities</i> 9:160-165.	No intervention (survey of parents)

Appendix C: Quality Assessment of RCTs

	Montgomery ¹⁴	Piazza ²⁹	Stores ¹⁵	Wiggs ¹⁶
A) SELECTION BIAS				
Are the individuals selected to participate likely to be representative of the target population?	Somewhat likely	Not likely	Somewhat likely	Not likely
What percentage of selected individuals agreed to participate?	75%	Unclear	60%	61%
Rate this section	Moderate	Weak	Moderate	Weak
B) STUDY DESIGN				
Was the study described as randomised?	Yes	Yes	Yes	Yes
If Yes, was the method described?	Yes	No	Yes	No
If Yes, was the method appropriate?	Yes	-	No	-
Rate this section	Strong	Weak	Moderate	Weak
C) CONFOUNDERS				
Were there important differences between groups prior to the intervention?	No	No ²	No	No
If yes, indicate the percentage of relevant confounders that were controlled in the design or analysis?	N/A	N/A	N/A	N/A
Rate this section	Strong	Strong	Strong	Strong
E) DATA COLLECTION METHODS				
Were data collection tools shown to be valid?	Yes ¹	No	No	Yes
Were data collection tools shown to be reliable?	Yes ¹	Partial ³	No	Yes
Rate this section	Strong	Moderate	Weak	Strong
F) WITHDRAWALS AND DROPOUTS				
Were withdrawals and dropouts reported in terms of numbers and/or reasons per group?	Yes	Yes	No	Yes
Indicate the percentage of participants completing the study	97%	100%	Unclear	97%
Rate this section	Strong	Strong	Unclear	Strong
H) ANALYSES				
Are the statistical methods appropriate for the study design?	Yes	Unclear ⁴	Partial	Unclear
Is the analysis on an intention to treat basis?	Yes (at post-treatment)	Yes	Unclear	Unclear

¹ Based on statement by authors; ² Hours of disturbed sleep at baseline seemed similar for both groups. Baseline disturbed sleep was used as a covariate in the analysis and this was statistically significant; ³ interobserver reliability; ⁴ unclear whether use of parametric appropriate.

Appendix D: Data Extraction

Publication details		
Author: Bartlet ¹⁷	Year: 1998	Related publications:
Stated aim: To gain experience in treating the sleep disorders of children with disabilities and illness and to support their families.		
Study design: Before and after		
The participants		
Number: N=61	Age: Mean 4yrs, 11mths (range 11mths to 17yrs)	Sex: 40 male, 21 female
Type of disability: 22 with chronic illness (most commonly asthma and upper respiratory tract infections and ear problems); 39 with a disability (most commonly non-specific severe learning disability, severe learning disability and a co-morbid condition and autism).		
Sleep problem: 80% (n=49) with settling problems; 97% (n=59) with night-waking problems. 38% (n=23) had parasomnias. In 42% of families (n=26) parents stayed in the child's bed and in 74% of families the child stayed in the parents' bed occasionally or regularly.		
How the sleeping problem was assessed: The Southampton Sleep Management Schedule was used. Conducted by a psychiatrist and/or health visitor and took 1.5-2hrs.		
Other information: 67 children were referred to the project over one year, 61 took up assessment and 57 received treatment (4 moved away after initial contact).		
The intervention		
Setting: Home-based. This was a one year project located at Southampton General Hospital. It was staffed by a part-time experienced health visitor, a child psychiatrist 4hrs per week.		
Type of behavioural intervention: Cueing, graded change, extinction and positive reinforcement depending on the sleep problem and parental preferences. In a 'high proportion' of cases the intervention was based on graded change.		
Description of intervention: Details were not provided of the specific behavioural methods. Eight children were prescribed hypnotics for 2-3 weeks where there was frequent night-time wakening in the presence of parental fatigue.		
Duration: Treatment was discontinued when parents were satisfied with the progress made.		
If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face-to-face, telephone, booklet): Following assessment families had one or two appointments with the project workers at home or at the hospital. Following this contact was usually by telephone. The mean number of calls was 4.95 and duration ranged from 5 to 60 minutes. Sleep diaries were used to plan and monitor progress. A <i>preliminary intervention</i> was required for many parents prior to being trained in the behavioural intervention. It was established early in the project that about one-third of parents of parents were not ready to become involved in a behavioural programme. Particular issues included physical exhaustion, disagreement between partners about the way forward, low self esteem, and a concern that the child would suffer as a result of the intervention. Tearfulness and feelings of hopelessness were common and three mothers were identified as clinically depressed and were referred to their GP for help. The aim of the preliminary intervention was to allow parents time to develop trusting relationships with the project workers and to give them time to contemplate changing their routines. Specific details were not provided other than that a holistic, dynamic approach was used with strategies such as understanding, support, empowerment and opportunities to talk through past traumatic experiences.		
Description of comparator: No comparator		
The outcomes measures		
Outcome 1: Sleep Disturbance Index (SDI)		
Details of measurement: Eight-point scale developed by Quine (1991). Four factors (settling, night waking, parents up at night, child in parental bed) are each rated as being a problem less than twice per week (0), a problem 2-4 times per week (1) or more than 4 times per week (2). The minimum score is 0 and the maximum 8. Internal reliability is high (Cronbach's alpha = 0.78).		
Outcome 2: Parent view of impact of intervention on sleep problem		
Details of measurement: Parents were asked if the sleep disturbance was 'better', 'same' or 'worse' following the intervention.		
Outcome 3: General Health Questionnaire (GHQ)-30		
Details of measurement: Administered to mothers at assessment and follow-up by postal		

<p>questionnaire. Scores above 4/5 defined as 'high' and associated in many cases with psychological distress. Sensitivity 74%, Specificity 82%.</p> <p>Length of follow-up: 3 to 6 months after end of treatment</p>
Summary of the results:
<ul style="list-style-type: none"> SDI (n=57) – The mean score reduced from 6.36 at baseline to 2.81 at follow-up and this was statistically significant based on a one sample t-test (mean difference 3.544 (SD 3.57), p=0.0000) Parent view – 45 families said the sleep disturbance was 'better'; 10 said it was the 'same'; 2 said it was 'worse'. GHQ-30 (n=52) – Mean score at baseline was 10.90 (SD 3.93) and 61% (n=36) were in the 'high' category. There was a statistically significant improvement in the GHQ-30 score at follow-up (mean difference 4.308 (SD 5.31), p=0.00)
Any negative consequences: Two families thought the sleep problem was worse following the intervention.
Views of parents: The authors state that few parents opted for the extinction technique. Parents in seven families found the programmes difficult to manage or ineffective. The authors state that of the 27 parents who commented on the project, the tone of the remarks was that specialist help was useful and should be more readily available.
Authors' conclusion: Forty-five children improved as a result of the intervention but treatment was found to be more onerous than the literature suggests.

Publication details				
Author: Bramble ²⁰	Year: 1996	Related publications: Bramble ³⁸		
Stated aim: To investigate the acceptability and safety of a behavioural modification programme aimed at the rapid extinction of night settling and night waking problems in children.				
Study design: Before and after				
<i>The participants</i>				
Number: N=15	Age: Mean 7.2yrs (range 3.5 to 12)	Sex: 10 male, 5 female		
Type of disability: Severe learning disability (four children also had cerebral palsy and 3 had epilepsy)				
Sleep problem: Lifelong severe night settling and/or night waking				
How the sleeping problem was assessed: Severe problem was defined as the child taking at least an hour to settle at bedtime and waking up most nights and disturbing parents.				
Other information: The participants were taken from a continuous series of referrals to the clinic. The majority were referred by specialist community nurses, paediatricians or a child psychiatrist.				
<i>The intervention</i>				
Setting: Home-based				
Type of behavioural intervention: Extinction				
Description of intervention: Parents were given the following advice (based on Pearce 1991): 1) regular bedtime; 2) establish regular routine before bedtime and calm children down; 3) set mood for sleep rather than wakefulness and play before bedtime; 4) rapidly settle the child into bed; 5) leave the bedroom; 6) ignore child protestations unless in case of illness; 7) if child leaves bedroom after settling time they are firmly told to return and, if necessary, physically carried back with minimal affective contact.				
Duration: 2 weeks				
If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet): Single face-to-face session at the clinic or participant's home to explain the treatment. There was brief telephone contact on the following three days to offer encouragement and deal with any problems. There was additional telephone contact if necessary. Based on a review of case notes the author states that only a minority required more than 4 phone calls and in only one case was there more than 7.				
Description of comparator: No comparator				
<i>The outcomes measures</i>				
Outcome 1: Sleep problem severity				
Details of measurement: Parents rated their child's sleep severity on a visual analogue scale (VAS) ranging from zero (no problem) to 10 (severe problem). Measured at baseline, at the end of treatment and at follow-up.				
Outcome 2: Sleeping with parents				
Details of measurement: The number of children still sleeping with parents at follow-up				
Outcome 3: Frequency of night waking				
Details of measurement: Based on a nightly sleep diary completed by parents				
Outcome 4: Time to settle				
Details of measurement: Based on a nightly sleep diary completed by parent				
Outcome 5: Daytime behaviour problems				
Details of measurement: Children's daytime behaviour problems were assessed using the Behaviour Problem Index (Cunningham 1986) with a score range of 0 to 64.				
Outcome 6: Maternal Stress				
Details of measurement: Assessed using Rutter's Malaise Inventory (Rutter 1970) scoring from 0 (no problems) to 11.				
Outcome 7: Maternal Sleep Scale				
Details of measurement: Completed by mothers to rate their own sleep quality. Used an adapted version of Maternal Sleep Scale (De Diana 1976). Yes/No responses were required to 11 statements about sleep quality. Score range from 0 to 11 (better sleep quality).				
Outcome 8: Helpfulness of the approach				
Details of measurement: Parents rated the overall helpfulness of the treatment on a VAS ranging from zero (no help at all) to 10 (extremely helpful). Measured at end of treatment and at 4 month follow-up.				
Outcome 9: Acceptability of approach				

<p>Details of measurement: Parents were asked to circle the phrase which best represented their view of the style of the treatment: 'too tough'; 'rather tough'; 'just right'; 'rather soft'; 'too soft'. Measured at 4 month follow-up</p> <p>Length of follow-up: end of treatment; 4 months and 18 months after treatment</p> <p>Summary of the results:</p> <ul style="list-style-type: none"> • Sleep problem severity - The mean severity reduced from 8 (SD 1.34; range 6 to 10) at baseline to 2.3 (SD 1.9, range 0 to 5) at end of treatment, 2.2 (SD 1.9, range 0 to 6) at 4 month follow-up and 2.9 (SD 2.2, range 0 to 6) at 18 month follow-up. ($p < 0.0001$; Friedman statistic 28.2; df3) • Speed of change - Parents were asked how soon improvements in their child's sleep occurred. The mean number of nights within which change was observed was 3.6 (SD 1.9, range 1 to 7 nights) • Sleeping with parents – At 4mth follow-up 10 of the 11 children who were regularly sleeping with their parents at baseline were no longer doing so. • Frequency of night waking – Complete data not reported. There was a 59% reduction in the reported frequency of night waking in the cohort. • Time to settle (based on data from 8 children) – There was a reduction in the mean time taken to settle from 58.6mins (SD 24.6) at baseline to 15.8mins (SD 7.8) at end of treatment and 17.5mins (SD 10.4) at 4 month follow-up. • Daytime behaviour problems – There was a statistically significant improvement in daytime behaviour from baseline (mean 32.6, SE 3.5) to 4-month follow-up (mean 22.1 SE 3.2) ($p < 0.01$) • Maternal Stress (Malaise Inventory) – There was a statistically significant reduction in maternal stress over time: Baseline mean 8.7 (SE 1.1); end of treatment mean 4.7 (SE 1.0); 4-month follow-up mean 3.4 (SE 1.0) ($p < 0.001$) • Maternal Sleep Scale – maternal sleep quality improved over time: Baseline mean 4.1 (SE 0.6); end of treatment mean 7.1 (SE 0.6); 4-month follow-up mean 9.0 (SE 0.4) ($p < 0.001$) <p>Any negative consequences: There were no reports of adverse effects</p> <p>Views of parents:</p> <ul style="list-style-type: none"> • Acceptability of approach - 12 parents were of the view that the treatment approach was 'just right' for their children and 3 thought it was 'rather tough'. • Satisfaction with treatment - There was high overall satisfaction amongst parents with the treatment (at end of treatment the mean satisfaction score was 8.6 (SD 1.6)) and at 4 month follow-up it was 8.9 (SD1.9)) <p>Authors' conclusion: The treatment approach was rapidly successful, well tolerated and acceptable.</p>

Publication details		
Author: Colville ³²	Year: 1996	Related publications: Waiting on MSc thesis which contains full report
Stated aim: To establish whether standard behavioural techniques such as those commonly used with children under five years by psychologists and health visitors in primary health-care settings could help reduce the heavy burden on families.		
Study design: Before and after		
The participants		
Number: N=5	Age: 5yrs 1mth to 7yrs 8mths	Sex: 2 male, 3 female
Type of disability: Sanfilippo syndrome (4 sub-type A, 1 sub-type B)		
Sleep problem: Bedtime disturbance, night waking and disruption		
How the sleeping problem was assessed: Questionnaire based on Richman and Graham (1986)		
The intervention		
Setting: Home-based		
Type of behavioural intervention: Behavioural intervention		
Description of intervention:		
Duration: 6 weeks		
If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet): Home visit by clinical psychologist before and during the intervention period to negotiate the treatment plan. Weekly telephone contact throughout the treatment period.		
Description of comparator: No comparator		
The outcomes measures		
Outcome 1: Goal achievement		
Details of measurement: Whether or not the treatment goal had been achieved		
Length of follow-up: End of treatment and 4 months after intervention started		
Summary of the results: There were two treatment goals for four children and three for the fifth child. For three of the four both treatment goals were achieved at the end of treatment, for the fourth child neither were achieved and for the fifth child two of the three goals were achieved. Follow-up data were available for three children: for one child both goals were maintained, for one child neither was maintained and one was maintained for the final child.		
Any negative consequences:		
Views of parents:		
Authors' conclusion: The results of the interventions were encouraging.		
Comments Full data not reported in this paper. Waiting on full report.		

Publication details		
Author: Christodulu ²⁷	Year: 2004	Related publications:
Stated aim: To investigate the effectiveness of positive bedtime routines and sleep restriction in reducing bedtime disturbances and night awakenings in children with developmental disabilities		
Study design: Before and after		
The participants		
Number: N=4	Age: 2yrs 6mths; 2yrs 9mths; 3yrs 11mths; 5yrs 11mths	Sex: 2 male, 2 female
Type of disability: Developmental disabilities (CHARGE association; pervasive developmental disorder, sensory integration and hypotonia; immune deficiency; autism)		
Sleep problem: Bedtime disturbances and night wakening. All of the children had an irregular sleep schedule with variation from night to night in bedtime and wakening time.		
How the sleeping problem was assessed: The Albany Sleep Problems Questionnaire was used to assess type and severity of sleep disturbance; the Sleep Intervention Questionnaire (designed for the study) to assess the appropriateness of using sleep restriction; the Parental Sleep Satisfaction Questionnaire (PSSQ); and parents were also interviewed and completed daily sleep charts and bedtime behaviour logs.		
The intervention		
Setting: Home-based		
Type of behavioural intervention: Positive bedtime routine and sleep restriction (sleep restriction only for one child)		
Description of intervention: 1) <i>Positive bedtime routine</i> - this was introduced prior to the introduction of sleep restriction. Parents were asked to create a routine that they could follow based on the following guidelines: a) have a regular routine in the 30mins before bedtime; b) include activities such as washing, putting on sleepwear and reading; c) keep the order and timing of the activities about the same each evening; d) do not include activities that could cause conflict; e) avoid watching television; f) avoid extending the length of the routine.		
2) <i>Sleep restriction</i> – The amount of time the child was in bed was restricted to 90% of the total time that the child slept (based on parent sleep diaries). The child's bedtime and/or the time the child was woken were adjusted for the new schedule.		
Duration: 1) The positive bedtime routine phase lasted from a few days to approximately 6 weeks.		
2) The sleep restriction plus positive bedtime routine phase lasted approximately 14-18 weeks		
If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet):		
Details not provided		
Description of comparator: No comparator		
The outcomes measures		
Outcome 1: Total sleep time		
Details of measurement: Based on parental sleep diaries		
Outcome 2: Number and duration of bedtime disturbances		
Details of measurement: Based on parental sleep diaries		
Outcome 3: Night wakening		
Details of measurement: Based on parental sleep diaries		
Outcome 4: PSSQ		
Details of measurement: Created for the study to assess parental satisfaction with their child's current sleep pattern. Score ranges from 6 (less satisfaction) to 36.		
Length of follow-up: End of treatment and one month follow-up		
Summary of the results:		
<ul style="list-style-type: none"> • Total Sleep Time – This decreased for three of the 4 children by 30 to 90 minutes following the intervention. The sleep restriction phase was not implemented for one child due to illness and the total time sleeping did not change from baseline • Bedtime disturbances – There was a reduction in the frequency and duration of bedtime disturbances for all 4 children. <i>Child 1</i> – Decreased from a mean frequency at baseline of 4.22 disturbances (range 2 to 7) per week to 0.00 (range 0) at follow-up and a mean duration of disturbances of 245mins per week (range 75 to 420) to 0mins (range 0) <i>Child 2</i> - Decreased from a mean frequency at baseline of 6.62 disturbances (range 2 to 7) 		

<p>per week to 0.50 (range 0 to 1) at follow-up and a mean duration of disturbances of 849mins per week (range 435 to 1,525) to 30mins (range 0 to 60)</p> <p><i>Child 3</i> (bedtime routine only)- Decreased from a mean frequency at baseline of 6.5 disturbances (range 4 to 7) per week to 2.5 (range 2 to 3) at follow-up and a mean duration of disturbances of 232mins per week (range 85 to 295) to 75mins (range 75)</p> <p><i>Child 4</i> - Decreased from a mean frequency at baseline of 3.10 disturbances (range 1 to 6) per week to 0.50 (range 0 to 1) at follow-up and a mean duration of disturbances of 88mins per week (range 15 to 420) to 23mins (range 0 to 45)</p> <ul style="list-style-type: none"> • Night Wakening - There was a reduction in the frequency and duration of night wakening for all 4 children. <p><i>Child 1</i> – Decreased from a mean frequency at baseline of 3.44 awakenings per week (range 1 to 7) to 0.05 (range 0 to 1) at follow-up and a mean duration of awakenings of 291mins per week (range 50 to 545) to 10mins (range 0 to 20)</p> <p><i>Child 2</i> – Decreased from a mean frequency at baseline of 8.27 awakenings per week (range 4 to 12) to 4.00 (range 4) at follow-up and a mean duration of awakenings of 682mins per week (range 280 to 1,180) to 278mins (range 275 to 280)</p> <p><i>Child 3</i> (bedtime routine only) – Decreased from a mean frequency at baseline of 9.29 awakenings per week (range 8 to 12) to 1.50 (range 1-2) at follow-up and a mean duration of awakenings of 92mins per week (range 52 to 180) to 8mins (range 5 to 10)</p> <p><i>Child 4</i> – Decreased from a mean frequency at baseline of 1.70 awakenings per week (range 0 to 4) to 1.00 (range 0 to 2) at follow-up and a mean duration of awakenings of 258mins per week (range 0 to 562) to 120mins (range 0 to 240)</p> • PSSQ – Parental satisfaction with their child's sleep increased from baseline to follow-up <p><i>Child 1</i> – Mean score increased from 14.67 (range 11-19) at baseline to 21.50 (range 18-25) at follow-up</p> <p><i>Child 2</i> - Mean score increased from 6.67 (range 6-7) at baseline to 24.00 (range 24) at follow-up</p> <p><i>Child 3</i> - Mean score increased from 11.71 (range 10-15) at baseline to 24.00 (range 24) at follow-up</p> <p><i>Child 4</i> - Mean score increased from 14.00 (range 12-16) at baseline to 28.00 (range 28) at follow-up</p> <p>Any negative consequences: The authors state that the children did not experience any adverse consequences due to the decreased sleep time.</p> <p>Views of parents: The authors state that the parents found the intervention easy and practical to implement.</p> <p>Authors' conclusion: The results support the use of sleep restriction, in conjunction with positive bedtime routines, for the treatment of sleep problems in children with developmental disabilities.</p> <p>Comments: Although reduction, some children still had disturbance/wakening</p>

Publication details		
Author: Didden ²¹	Year: 2004	Related publications:
Stated aim: To assess the effectiveness of functional assessment and behavioural treatment of sleep problems in children with developmental disability.		
Study design: Before and after		
The participants		
Number: N=3	Age: 9.2, 10 and 12.4yrs	Sex: 3 males
Type of disability: Moderate developmental disability with Downs Syndrome; seizure disorder; mild developmental disability with ADHD (taking Ritalin)		
Sleep problem: One displayed disruptive behaviour at bedtime and would only sleep if one of his two carers lay in bed with him until morning; and two had night wakening		
How the sleeping problem was assessed: Functional assessment based on parental interview and nightly recordings made by parents over one week that recorded each night antecedent and consequent event and number of minutes of disruptive behaviours.		
The intervention		
Setting: Home-based		
Type of behavioural intervention: Extinction for two children; differential reinforcement of incompatible behaviours (DRI) using tokens plus response cost for one child		
Description of intervention: 1) <i>Extinction</i> - Parents were asked to follow a bedtime routine. Toys were removed from the bedroom to prevent play during the night. After putting child to bed and saying goodnight they had to leave the room and were instructed not to re-enter the room until morning. When illness was suspected they could re-enter but attention was kept to a minimum. When the child slept through the night they were told that because they had been quiet during the night they had earned extra positive attention in the morning.		
2) <i>DRI plus response cost</i> – The child was given 10 tokens at bedtime and one token was taken away each time he showed disruptive behaviours. Five tokens by morning earned a preferred activity (e.g. playing Gameboy). After three consecutive nights earning a preferred activity the number of tokens required was increased by one. Extinction was then added and tokens were removed without any comment. Because these procedures were not effective a punishment was added: if 5 tokens or more were lost his bedroom door was locked for the rest of the night.		
Duration: Approximately 40 nights and 80 nights for extinction and 80 nights for DRI		
If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet):		
There was daily phone contact with parents. The authors state that this was an important part of the treatment programme especially during initial treatment.		
Description of comparator: No comparator		
The outcomes measures		
Outcome 1: Number of minutes of night-time disruption		
Details of measurement: Defined as any disruption (e.g. out of bed, hitting, kicking objects) of at least one minute between sleep time and wake time. Recorded by parents on a standardised sheet nightly.		
Length of follow-up: End of treatment and 6mths after treatment		
Summary of the results:		
<ul style="list-style-type: none"> Night-time disruption – Decreased in all three children. <i>Child 1</i> – Decreased from mean 44.1mins (SD 12.9, range 24-65) at baseline, to 11.1 (SD 15.7, range 0-59) during treatment and 0.3 (SD 0.5, range 0-1) at follow-up <i>Child 2</i> - Decreased from mean 131.4mins (SD 139.2, range 0-405) at baseline to 62.9 (SD 60.5, range 0-319) during treatment and 0.12 (SD 9.2, range 0-20) at follow-up. <i>Child 3</i> - Decreased from a mean of 65.2mins (SD 59.8, range 0-165) at baseline, to 48.5 (SD 20.3, range 03-83) during response cost and DRI, 49.8 (SD 28.4, range 0-90) during response cost, DRI and extinction, 23.1 (SD 28.1, range 0-121) during response cost, DRI, extinction and punishment and 12.6 (SD 14.2, range 1-34) at follow-up. 		
Any negative consequences: None reported		
Views of parents: The authors state that the parents found it difficult to implement the intervention initially but continued on the program and were 'highly contented' with the results.		
Authors' conclusion: The results demonstrate the effectiveness of functional assessment and behavioural treatment of severe sleep problems in three children with developmental disability.		

Publication details		
Author: Didden ²²	Year: 2002	Related publications:
<p>Stated aim: To assess the effectiveness of extinction of parental attention (planned ignoring) on night-time disruptive behaviours.</p>		
<p>Study design: Before and after</p>		
The participants		
Number: N=4	Age: 1yr, 11mths; 7yrs, 3mths; 6yrs, 5mths; 25yrs;	Sex: 3 males, 1 female
<p>Type of disability: Two with severe learning disabilities, one moderate to severe learning disabilities and one with mild delays in several developmental areas.</p>		
<p>Sleep problem: One went to bed willingly but woke several times during the night and behaved disruptively by screaming and yelling; one had problems settling as well as disruptive behaviours during the night; one refused to go to bed most nights and slept in parents bed most nights; one had problems settling and frequently woke during the night and cried.</p>		
<p>How the sleeping problem was assessed: Functional assessment based on interview with parents and nightly completion by parents of a form recording antecedent and consequent events and number of minutes of night-time disruptive behaviours.</p>		
The intervention		
<p>Setting: Home-based</p> <p>Type of behavioural intervention: Extinction</p> <p>Description of intervention: Parents were instructed to discontinue their usual management techniques. They were asked to put the child to bed, say 'good-night' and after leaving the bedroom not to re-enter until morning. In the case of illness they could re-enter the room but were asked to keep interaction to a minimum. When the child slept throughout the night they explained to him/her that they had earned positive attention during the morning because they had been quiet during the night.</p>		
<p>Duration: Varied across participants – ranged from to extinction periods of 10 nights each to an extinction period of 120 nights (figures approximate from graph)</p>		
<p>If delivered by parents, give description of training and support received: Not explicitly stated, though the authors advise daily contact between the therapist and parents particularly during the first week of the intervention</p>		
<p>Description of comparator: No comparator</p>		
The outcome measures		
<p>Outcome: Night-time disruption (any disruption by the child for at least one minute - such as crying, screaming, getting out of bed – between time of settling to sleep and wake-up time)</p>		
<p>Details of measurement: Measured nightly by one parent using a standardised form. Measured at baseline, during treatment and follow-up.</p>		
<p>Length of follow-up: end of treatment and 6 months after treatment</p>		
Summary of the results:		
<ul style="list-style-type: none"> • 7yr, 3mth old with severe learning disabilities – The mean number of minutes of disruption reduced from 45.4mins (SD 29.2) at baseline to 15.9mins (SD 31.9) during treatment and 3.8mins (SD 7.5) at follow-up. • 6yr, 5mth old with moderate to severe learning disabilities – The mean number of minutes of disruption reduced from 26.8mins (SD 20.9) at baseline, 32.4mins (SD 28.2) during treatment to 1.1mins (SD 2.1) at follow-up. • 1yr, 11mth old with mild developmental delays – The mean number of minutes of disruption were 1min (baseline 1); 28.7mins (SD 32.7) (extinction 1); 1min (baseline 2); 1.5mins (SD 3.2) (extinction 2); 0.4mins (SD 1.1) (follow-up) (there may be an error in these data as the pattern is very different to the other two children) 		
<p>Any negative consequences: There was a temporary increase in night-time disruptive behaviour during initial treatment sessions in one child.</p>		
<p>Views of parents: The authors state that parents found it difficult to implement the intervention during the initial treatment sessions. The parents had concerns about causing psychological trauma to their child and that the child might experience feelings of rejection and fear.</p>		
<p>Authors' conclusion: Treatment resulted in a normalised sleep pattern in all cases and effects were maintained across time.</p>		

Publication details		
Author: Didden ²³	Year: 1998	Related publications:
Stated aim: To assess the effectiveness of several procedures on sleeping problems with six developmentally delayed disabled children at young age who live at home		
Study design: Before and after		
The participants		
Number: N=3 (The study included 6 children but 1 had night terrors and 1 had sleep problems related to seizures. Before and after data were available for 3 of the remaining 4)	Age: 2, 4 and 6 yrs	Sex: 3 male
Type of disability: Spinal muscle atrophy, ADHD (both near normal IQ), Prader-Willi syndrome		
Sleep problem: Problems settling, night waking and co-sleeping with parents		
How the sleeping problem was assessed: Functional assessment based on interview with parents and nightly completion (6 nights) of standardised sleep diary recording antecedent and consequent events and duration of night-time disruptive behaviours.		
The intervention		
Setting: Home-based		
Type of behavioural intervention: Extinction (non-graduated)		
Description of intervention: Parents were instructed to discontinue their usual management techniques. They were asked to put the child to bed, say 'good-night' and after leaving the bedroom not to re-enter until morning. In the case of illness they could re-enter the room but were asked to keep interaction to a minimum. When the child slept throughout the night they explained to him/her that they had earned positive attention during the morning because they had been quite during the night.		
Duration: Varied across participants – approximately 50 nights, 54 and 29 nights		
If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet):		
Not explicitly stated		
Description of comparator: No comparator		
The outcomes measures		
Outcome 1: Night-time disruption (any disruption by the child for at least one minute - such as crying, screaming, getting out of bed – between time of settling to sleep and wake-up time)		
Details of measurement: Measured nightly by one parent using a standardised form. Measured at baseline, during treatment and follow-up.		
Length of follow-up: End of treatment and 3 months after treatment for child 1 and 6 months after for child 2 and 3		
Summary of the results:		
<ul style="list-style-type: none"> 2 year old with spinal muscle atrophy - The mean number of minutes of disruption reduced from 131mins at baseline to 0mins by the sixth night of treatment 4 year old with Prader-Willi syndrome - The mean number of minutes of disruption reduced from 90mins (range 45 to 180) at baseline to 22mins (range 5 to 180) during treatment to 0mins at follow-up. 6 year old with ADHD - The mean number of minutes of disruption reduced from 21mins (range 9 to 27) at baseline to 9mins (range 0 to 26) during treatment and 1.7mins (range 0 to 4) at follow-up. 		
Any negative consequences: None reported		
Views of parents: None reported		
Authors' conclusion: Behavioural procedures may be effective in decreasing sleeping disorders with young developmentally disabled children		

Publication details		
Author: Durand ²⁸	Year: 2004	Related publications:
Stated aim: To investigate the effectiveness of sleep restriction in reducing bedtime disturbances and night wakening in two children with developmental disabilities		
Study design: Before and after		
The participants		
Number: N=2	Age: Both 4yrs	Sex: 2 females
Type of disability: One with autism and one with developmental delays		
Sleep problem: One child with night wakening and getting into bed with parents and frequent crying and not getting back to sleep. This child also had severe bedtime disturbances which, at baseline were controlled with melatonin. One child with severe bedtime disturbances and periodical night wakening.		
How the sleeping problem was assessed: The Albany Sleep Problems Questionnaire was used to assess type and severity of sleep disturbances and the Parental Sleep Satisfaction Questionnaire (PSSQ) (Christodulu, 2000) to assess parental satisfaction with the child's current sleep pattern. Parents were also interviewed and completed nightly sleep charts. Sleep restriction was used because extinction had previously been unsuccessful.		
The intervention		
Setting: Home-based		
Type of behavioural intervention: Sleep restriction and consistent bedtime routines and practices		
Description of intervention: 1) Sleep restriction – The amount of time the child was in bed was restricted to 90% of the total time that the child normally slept at baseline (based on parent sleep diaries). The child's bedtime and/or the time the child was woken were adjusted for the new schedule. 2) Parents were instructed to establish consistent bedtime routines and ways of responding to bedtime disturbances and wakening. These included not getting into bed with the child or allowing the child to get into the parental bed. If the child left their bed they had to return her to her own bed, tell her to go to sleep and leave the bedroom.		
Duration: Approximately 15 and 25 weeks		
If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet):		
Not reported		
Description of comparator: No comparator		
The outcomes measures		
Outcome 1: Total Sleep Time		
Details of measurement: Based on parental sleep diaries.		
Outcome 2: Number and duration of bedtime disturbances		
Details of measurement: Based on parental sleep diaries.		
Outcome 3: Number and duration of night wakening		
Details of measurement: Based on parental sleep diaries.		
Outcome 3: PSSQ		
Details of measurement: To assess parental satisfaction with their child's current sleep pattern. Score ranges from 6 (less satisfaction) to 36.		
Length of follow-up: End of treatment		
Summary of the results:		
<ul style="list-style-type: none"> • Total Sleep time – Decreased from 8.75hrs per night at baseline to 7hrs during the intervention for the first child and from 10.85hrs per night at baseline to 9.5 during the intervention for the second. The authors state that when the programme was successful the amount of sleep was faded back to an age appropriate level. 		
<ul style="list-style-type: none"> • Bedtime disturbances <i>Child 1</i> - The melatonin used at baseline was effective in controlling bedtime disturbances. When the sleep restriction was introduced the melatonin was withdrawn without any return to bedtime disturbances. <i>Child 2</i> - Decreased from a mean frequency of 7 disturbances (range 7) per week at baseline to 0.25 (range 0-1) following intervention. Mean duration decreased from 1.05hrs per week (range 0.79-1.35) at baseline to 0.01 hrs (range 0-0.04) following intervention. 		
<ul style="list-style-type: none"> • Night wakening – The frequency and duration reduced for both children <i>Child 1</i> – Decreased from a mean frequency of 7.17 wakings per week (range 5-9) at baseline to 1.43 (range 0-4) per week following intervention. Duration decreased from a mean of 1.27hrs per week (range 0.18-2.2) at baseline to 0.18hrs per week (range 0-1.11) 		

following intervention.

Child 2 - Decreased from a mean frequency of 2.55 wakings per week (range 0-6) at baseline to 1.38 (range 0-3) per week following intervention. Duration decreased from a mean of 0.14hrs per week (range 0-0.37) at baseline to 0.07hrs per week (range 0-0.15) following intervention.

- PSSQ – Parental satisfaction with their child's sleep increased from baseline to follow-up.
Child 1 – Mean score increased from 6 at baseline to 23 following treatment
Child 2 – Increased from 8 at baseline to 30 following treatment

Any negative consequences: Child 1 experienced an increase in sleep walking by the third week of the intervention (mean 2.3 episodes per week). These decreased as the sleep time was extended. This child also experienced two episodes of sleep terrors during the intervention.

Views of parents: The authors state that the parents thought it was easy to implement sleep restriction on a regular basis.

Authors' conclusion: The results support the use of sleep restriction for the treatment of sleep disturbances in children with developmental disabilities.

Publication details		
Author: Durand ²⁴	Year: 1996	Related publications:
<p>Stated aim: To evaluate the effectiveness of behavioural interventions, including graduated extinction in reducing night wakening and bedtime disturbance in children with autism and other developmental disabilities</p>		
<p>Study design: Before and after</p>		
The participants		
Number: N=4	Age: 2, 7, 11 and 12 years old	Sex: 2 male, 2 female
<p>Type of disability: Two with mild to moderate learning disabilities, one with pervasive developmental delays and one with autism and challenging behaviours.</p>		
<p>Sleep problem: Two had frequent night-time wakening and two had disruptive behaviour at bedtime</p>		
<p>How the sleeping problem was assessed: The Albany Sleep Problems Questionnaire was used to assess type and severity of sleep disturbance. Parents were also interviewed and completed nightly sleep charts by parents.</p>		
The intervention		
<p>Setting: Home-based</p> <p>Type of behavioural intervention: Graduated extinction (and establishment of consistent bedtime routine)</p> <p>Description of intervention: A consistent bedtime routine was established for each child; the timing and nature of the routine varied between children depending on their needs. When children were disruptive during the night only neutral reassurance ('It is still time to sleep, go back to sleep') was given and physical contact kept to a minimum. Parents were instructed not to get into their child's bed during the night or to allow the child into their bed. The graduated extinction schedule in response to night wakening or disruptive behaviour varied between children: 1) parent started with waiting 3 minutes before entering bedroom and this increased by 2 minutes each night to a maximum of 10 minutes; 2) parent started with a 5 minute delay which increased by 5 minutes each night; 3) parent started with 3 minute delay increasing by 2 minutes each night; 4) no incremental delay</p>		
<p>Duration: 8 to 16 weeks (for one child formal assessment was 2 weeks as she developed an illness)</p>		
<p>If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet): The authors state that there was regular telephone contact with parents during the baseline and treatment sessions.</p>		
<p>Description of comparator: No comparator</p>		
The outcomes measures		
<p>Outcome 1: Night wakening</p> <p>Details of measurement: Based on daily sleep charts completed by parents. Reported as the percentage of nights per week with waking or disturbance.</p>		
<p>Outcome 2: Bedtime disturbances</p> <p>Details of measurement: Based on behaviour logs completed daily by parents. Reported as the percentage of nights per week with bedtime disturbances.</p>		
<p>Length of follow-up: end of treatment and for one participant there was follow-up at 2 and 6 months and for one at 1 and 2 months post-treatment.</p>		
<p>Summary of the results:</p> <ul style="list-style-type: none"> Night wakening – there was a reduction in the % of nights with night wakening per week for the two children with this problem. In one child this decreased from a mean of 36.4% (range 14.3 to 57.1) at baseline to 11.4% (range 0 to 28.6) during treatment; in the second child the decrease was from a mean of 93.6% (range 71.4 to 100) at baseline to 64.3% (range 57.1 to 71.4) during treatment, 50% at 2 months follow-up and 26.8% (range 25 to 28.6) at 6 months follow-up. Other behaviours that were a target of the intervention also showed improvement: the first child had a more regular bedtime and the mother of the second child no longer stayed in bed with her following awakenings. Bedtime disturbances - there was a reduction in the % of nights with bedtime disturbance per week for the two children with this problem. In one child this reduced from a mean of 100% at baseline to 22.3% (range 0 to 66%) during treatment; in the second child the 		

decrease was from a mean of 65.1% (range 14 to 100) at baseline to 22.3% (range 0 to 100) during treatment, 14% at 1 month and 0% at 2 months follow-up. The mean length of time to fall asleep for this child reduced from 133.3 minutes (range 50.7 to 233.6) to 44.4 minutes (range 0 to 162.9).

Any negative consequences: None reported

Views of parents: The authors state that parents were at first hesitant to delay attending to their children but found the short delay easy to tolerate.

Authors' conclusion: The results of the study support the use of behavioural interventions for night wakening and disruptive bedtime behaviour in children with developmental disabilities.

Publication details		
Author: Hewitt ¹⁸	Year: 1985	Related publications:
<p>Stated aim: To describe the application and effectiveness of behavioural treatment of sleeplessness in a sample of 10 children with severe learning difficulties</p>		
<p>Study design: Before and after</p>		
The participants		
Number: N=10	Age: Mean 6yrs 11mths (range 3yrs 2mths to 16yrs 6mths)	Sex: 8 male, 2 female
<p>Type of disability: Severe learning difficulties (7 Downs Syndrome, 1 Cornelia de Lange syndrome, 1 tuberous sclerosis and one of non-specific origin)</p>		
<p>Sleep problem: 4 night-time wakening, 1 bedtime disturbances, 3 with both, 1 with repeated waking plus head-banging while awake and asleep and 1 child that had occasional episodes of staying awake all night.</p>		
<p>How the sleeping problem was assessed: There was a joint initial interview between families and a clinical psychologist and community nurse in the family home. Sleep patterns were recorded by parents for a one week baseline period using a 24-hour chart.</p>		
<p>Other information: The children were identified from 29 referred to a clinical psychology department for behavioural problems, whose parents thought sleeping problems was the main difficulty.</p>		
The intervention		
<p>Setting: Home-based</p>		
<p>Type of behavioural intervention: Positive bedtime routine and conditioning; the precise intervention was tailored to the individual needs and resources of each family</p>		
<p>Description of intervention: A tailored behavioural treatment programme was developed and negotiated with each family which was written up on the weekly chart. The following general framework was used: 1) positive bedtime routine that included set bedtime, introduction of a regular routine before bedtime that provided clear stimuli for the child that bedtime was approaching, avoidance of overstimulation in the hour before bed; 2) teaching a relaxation response after getting into bed through use of a bedtime story or soft music; 3) gradual distancing of parent from bedroom once relaxation response was established; 4) identification of factors that were maintaining disruptive behaviours and advice for more constructive parent responses. During wakeful episodes the stimulus to which the child had become conditioned to fall asleep was repeated. Parents were advised to interact with the child as little as possible and avoid prolonged routines and overstimulation during waking episodes. Parents were made aware of the importance of consistency and the possibility that progress may be slow.</p>		
<p>Duration: Mean 6.7 weeks (range 2-15 weeks). Parents were asked to stop recording sleep behaviour when the child settled easily at night and/or no longer woke at night or the parent's sleep was less disrupted. Recording could also stop if difficulties were only occasional and this was considered a satisfactory outcome.</p>		
<p>If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet):</p>		
<p>Following the assessment period which consisted of two visits to the family home by a clinical psychologist and community nurse, the nurse monitored the child's progress on a regular (usually weekly) basis. The psychologist also visited at three-weekly intervals and gradually withdrew visits as progress occurred. More complex cases received joint visits. There were monthly case review meetings.</p>		
<p>Description of comparator: No comparator</p>		
The outcomes measures		
<p>Outcome 1: Brief summary of whether improvement occurred based on time to settle and frequency of night waking.</p>		
<p>Details of measurement: Based on parental sleep recordings</p>		
<p>Length of follow-up: End of treatment and approximately one year later</p>		
<p>Summary of the results:</p>		
<p>At baseline the average time taken to settle to sleep ranged from 34 minutes to 2.5hrs and the frequency of night waking from 6 to 18 episodes during the week. Following treatment eight of the 10 children showed a positive outcome: parents reported the children settling easily and/or no or only occasional night-time wakening. The mean length of time to a positive outcome was 6.7 weeks (range 2-15 weeks). One child did not receive behavioural treatment as it was established from the charts that there was a possible link with epilepsy. The child with repeated waking plus head-</p>		

<p>banging episodes did not improve. At one year follow-up 6 of the 8 maintained the improvement. Three had a slight relapse following a period of illness or disruption to the family routine. A regular sleeping pattern was re-established by parents with a minimum of professional involvement.</p> <p>Any negative consequences: None reported</p> <p>Views of parents: The authors state that some parents viewed sleeplessness as being directly attributable to their child's disability. It was important to 'sell' a behavioural approach prior to the intervention to these parents.</p>
<p>Authors' conclusion: The authors make a number of observations: they highlight that many programme modifications were necessary to ensure the individual interventions suited individual parenting styles and family resources; they state that it was not possible to identify the elements of the intervention that were most important and that in addition to the specific techniques factors such as directly involving parents, a written treatment programme, daily feedback for parents from recordings and weekly support visits may have been important.</p>

Publication details				
Author: Montgomery ¹⁴	Year: 2004	Related publications:		
<p>Stated aim: To investigate the efficacy of a media-based brief behavioural treatment of sleep problems in learning disabled children by comparing treatment delivered face-to-face to control and treatment delivered by booklet to control</p> <p>Study design: Randomised controlled trial</p>				
The participants				
Number: N=66	Age: 2 to 8 years	Sex: 42 male, 24 female		
<p>Type of disability: Severe learning disability (32% autism, 12% Down's Syndrome, 8% global developmental delay, 6% epilepsy, 21% other, 27% no diagnosis)</p> <p>Sleep problem: Night waking and/or settling problems. For entry into the trial children had to have severe sleep disturbance of at least 3 months duration unrelated to a physical problem. Severe problem was defined as night waking 3 or more times per week for more than a few minutes and disturbing parents or going into their room and/or problems settling 3 or more times per week where the child takes more than an hour to settle and causes disturbance during this time.</p> <p>How the sleeping problem was assessed: A brief screening questionnaire was used (Two papers are referenced regarding reliability and validity): Composite Sleep Disturbance Score was calculated based on a parent completed sleep diary over a 2 week period. Each group received a 90 minute assessment visit when a sleep history was taken during a semi-structured interview.</p> <p>Other information: The parents of all 268 children attending a special school or receiving pre-school teacher counsellor services in Oxford, Berkshire and Buckinghamshire were contacted to participate in the trial. 184 responded of whom 102 met the entry criteria. 76 consented to participate of whom 10 then dropped out</p>				
The intervention				
Setting: Home-based				
Type of behavioural intervention: 1) Behavioural intervention presented to parents face-to-face or 2) through a booklet.				
Description of intervention: 1) Face to face group – a single researcher spent approximately 90 minutes with parents in their own home explaining the techniques detailed below (a to g); 2) Booklet group - the second group were given a booklet detailing the same information. It was 14 pages long and also included cartoons and specifically addressed the needs of learning disabled children. Based on the Flesch Readability Test it was readable by someone educated up to 13 years old. Apart from the 90 minute assessment visit there was no contact with this group.				
<p>The aim was to train parents in both groups in the same behavioural techniques. (Consistency was checked by comparing a selection of taped face-to-face sessions against the content of the booklet.) The topics covered were a) normal sleep: setting realistic expectations and explanation of the benefits of normal sleep, b) introduction to behavioural techniques in general (e.g. ignoring, consistency and reward systems), c) monitoring behaviour to devise the intervention, d) good sleep habits (e.g. clear routines, putting children to sleep while awake but drowsy), e) techniques for changing settling and waking problems (ignoring the child, checking briefly at increasingly longer intervals and with minimal contact, gradually decreasing physical contact) f) removing child from parents bed using settling techniques above, g) rewards for desirable behaviour.</p> <p>Duration: 6 weeks</p>				
<p>If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet): Not explicitly stated but there does not appear to have been any contact beyond that described above.</p> <p>Description of comparator: Waiting list control group.</p>				
The outcomes measures				
<p>Outcome 1: Composite Sleep Disturbance Score (CSDS)</p> <p>Details of measurement: Derived from sleep diaries completed by parents over a 2 week period. Duration and frequency of settling and night waking problems were each scored from 0 to 2. This scale ranges from a minimum possible score of 0 (no sleep problems) to 8. In this study the minimum possible score for entry to the trial was 4. A random selection of CSDS were randomly cross-checked for consistency of scoring and agreement levels were greater than 95%</p> <p>Outcome 2: Reduction in CSDS of at least 50% (responders)</p> <p>Details of measurement: The cut-off was based on asking parents what was the minimum</p>				

<p>improvement that would make the intervention worthwhile: 83% said if the problem was reduced by half.</p> <p>Outcome 3: Parental views about the booklet</p> <p>Details of measurement: Rated from 0 to 4 on relevance, ease of understanding and usefulness. The minimum possible score was 0 (worst) and maximum 12 (best).</p> <p>Length of follow-up: End of intervention and 6 month follow-up</p>
<p>Summary of the results:</p> <ul style="list-style-type: none"> • CSDS – there was a statistically significant difference in the main comparison across the three groups (face-to-face, booklet and control) post-treatment ($H=34.174$, $df=2$, $p<0.001$). Post-hoc comparisons indicated that each of the intervention groups showed a greater improvement on the CSDS compared to the control group. This improvement was maintained at 6 months follow-up. <i>Baseline</i> – face-to-face (n=20) mean 6.55 (SD 1.31); booklet (n=22) mean 6.18 (SD 1.46); control (n=24) mean 6.0 (SD 2.35) <i>Post-treatment</i> - face-to-face mean 2.4 (SD 1.93); booklet mean 2.55 (SD 2.76); control mean 5.75 (SD 1.54) <i>6 month follow-up</i> - face-to-face mean 1.89 (SD 2.02); booklet mean 2.08 (SD 2.89) • 50% symptom reduction on CSDS – there were 15 'responders' versus 5 'non-responders' in the face to face group; 15 versus 7 in the booklet group and no responders for the control group. The waiting-list control group were randomised to treatment following the trial: there were 9 'responders' versus 3 'non-responders' in the face-to-face group and 8 versus 4 in the booklet group. • Parental views on the booklet – 23 participants rated the booklet (this included the group in the main trial and those in the waiting list group that later received the booklet intervention). Parents found the booklet helpful and appropriate (mean score 10.17 (SD 1.87).
<p>Any negative consequences: None reported</p>
<p>Views of parents: Not reported apart from views on the booklet</p>
<p>Other results: Sub-group analyses were conducted to investigate any variation in CSDS by sociodemographic characteristics (number of parents, number of siblings, social class). None were statistically significant.</p>
<p>Authors' conclusion: The study confirms the effectiveness of conventional behavioural treatment for sleep problems in children with learning disabilities and shows that brief delivery of this treatment using a booklet did not reduce its effect.</p>
<p>Comments: When applying the findings to outside the research setting need to bear in mind that the group given the booklet also spent 90 minutes visit with a member of the research team. Although this was for assessment purposes it may also have had a therapeutic effect. There is the possibility that using a booklet with no professional contact may not be as effective. The authors note that although there was no statistically significant difference between groups at baseline the face-to-face group had slightly worse sleep problems which may have been clinically important.</p>

Publication details		
Author: Piazza ²⁹	Year: 1997	Related publications:
Stated aim: To compare the efficacy of a faded bedtime with response cost treatment to bedtime scheduling in treating multiple sleep problems in learning disabled children		
Study design: RCT		
The participants		
Number: N=14	Age: Mean 7.8yrs (range 4 to 14)	Sex: Not stated
Type of disability: 6 had profound developmental disabilities, 4 severe, 1 moderate to severe, 2 moderate and 1 undetermined		
Sleep problem: Children were included in the study if they slept 90% or less of what would be expected for their age. The participants displayed a range of problems related to settling at bedtime and/or night-time waking.		
How the sleeping problem was assessed: Half-hourly observations over 24 hours		
Other information: The children had been admitted to the unit for displaying severe behaviour problems that posed a danger to self or others.		
The intervention		
Setting: In-patient unit specialising in the assessment and treatment of destructive behaviour problems.		
Type of behavioural intervention: Children were randomly assigned to one of two types of intervention (7 in each group): 1) Faded bedtime with response cost (FBRC); 2) Bedtime scheduling		
Description of intervention: 1) <i>Faded bedtime with response cost (FBRC)</i> – a bedtime at which sleep onset was highly likely with 15 minutes was set (half an hour later than the average time of sleep onset at baseline). A consistent bedtime routine was established. The child was not permitted to go to sleep before this time and was woken at a set time each morning. The response cost occurred if the child did not fall asleep within 15 minutes: they were removed from bed and kept awake for one hour (played with toys, watched TV etc). They were then returned to bed and this was repeated until the child was put to bed and fell asleep within 15 minutes. If the child fell asleep within 15 minutes of bedtime, bedtime was made half an hour earlier the next night. If they did not fall asleep it was made half an hour later. 2) <i>Bedtime scheduling</i> – the child was put to bed following a consistent bedtime routine, woken at the same time each morning and not allowed to sleep at other times unless a nap was age appropriate. If so there was a set nap time.		
Duration: Until the child was discharged from hospital which was on average 8 weeks.		
If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet): Not delivered by parents		
Description of comparator: See above		
The outcomes measures		
Outcome 1: Hours of disturbed sleep		
Details of measurement: Duration of inappropriate sleep (sleep outside appropriate sleep hours) plus the duration of time the child was awake when they should be asleep. The reliability of the observations was assessed by having two observers on 86% of the days. Inter-observer agreement was 98.2%.		
Length of follow-up: Varied depending on child's length of stay. The last 10 days of treatment were used.		
Summary of the results: There was a greater reduction in hours of disturbed sleep with FBRC than bedtime scheduling ($F 6.66, df=1, p<0.026$). At baseline the mean hours of disturbed sleep were 1.44hrs in the FBRC group and 1.37 in the bedtime scheduling group. Post-treatment they were 0.53hrs with FBRC and 1.10hrs with bedtime scheduling.		
Any negative consequences: None reported		
Views of parents: None reported		
Authors' conclusion: Faded bedtime with response cost was superior to the bedtime scheduling procedure in reducing the number of hours of disturbed sleep.		
Comments : In-patient setting – may not be generalisable to the home-setting		

Publication details		
Author: Piazza ³⁰	Year: 1991	Related publications:
Stated aim: To determine whether the sleep problems of girls with Rett syndrome was amenable to a faded bedtime procedure		
Study design: Before and after		
The participants		
Number: N=3	Age: Two aged 8rs and one of 4yrs	Sex: 3 female
Type of disability: Rett syndrome		
Sleep problem: One with delayed sleep onset with disruptive behaviour and excessive daytime sleep; one with night waking and self-injurious behaviour; and one with night waking, crying and screaming and getting into parental bed.		
How the sleeping problem was assessed: Half-hour observations over 24hr period		
The intervention		
Setting: In-patient for 2 and home setting for one child (Child 3)		
Type of behavioural intervention: Faded bedtime with response cost		
Description of intervention: A bedtime was set at which sleep onset was highly likely within 15 minutes (half an hour later than the average time of sleep onset at baseline). A consistent bedtime routine was established. The child was not permitted to go to sleep before this time and was woken at a set time each morning. The response cost occurred if the child did not fall asleep within 15 minutes: they were removed from bed and kept awake for one hour (played with toys, watched TV etc). They were then returned to bed and this was repeated until the child was put to bed and fell asleep within 15 minutes. If the child fell asleep within 15 minutes of bedtime, bedtime was made half an hour earlier the next night. If they did not fall asleep it was made half an hour later.		
Duration: Not stated, presumably until discharge		
If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet): With the exception of one child, the intervention was not delivered by parents. The training and support received by the parents of this child was unclear.		
Description of comparator: No comparator		
The outcomes measures		
Outcome 1: % of appropriate sleep		
Details of measurement: Number of hours of sleep during the defined sleep period divided by total number of hours in the defined sleep period. Based on half hourly observations over 24hrs.		
Outcome 2: % inappropriate sleep		
Details of measurement: Number of hours sleep during the defined wake time divided by the total number of hours in the defined wake time. Based on half hourly observations over 24hrs.		
Outcome 3: Frequency and duration of night waking		
Details of measurement: Night waking defined as wake periods during sleep time preceded and followed by at least a 15 minute sleep episode. Based on half hourly observations over 24hrs.		
Outcome 4: Delay to sleep onset		
Details of measurement: The number of hours beyond the scheduled sleep time in which sleep occurred. Based on half hourly observations over 24hrs.		
The reliability of the observations was assessed for one child. Overall agreement was high.		
Length of follow-up: Not stated, until discharge		
Summary of the results:		
<ul style="list-style-type: none"> • % appropriate sleep – Child 1 showed a marginal increase from an average of 87% at baseline to 90% following treatment; Child 2 increased from 69% at baseline to 75% following treatment; Child 3 increased from 81% at baseline to 92% following treatment. • % inappropriate sleep – Child 1 decrease from 12% to 2%; Child 2 this was not a problem at baseline; Child 3 reduced from 15% to 7.2%. • Frequency and duration of night waking – Child 1 not a problem at baseline; Child 2 frequency decreased from 1hr at baseline to 0.6hrs following treatment; Child 3 frequency decreased from 0.9 per night at baseline to 0.6 and duration from average of 1.8hrs per night at baseline to 0.5hrs. • Delay to sleep onset – For child 1 who had this problem this decreased from 1.25 hrs at baseline to 0.5hrs post treatment. 		
Any negative consequences: None stated		
Views of parents: Not reported		

Authors' conclusion: The treatment used in the current investigation appeared to affect the various sleep related difficulties experienced by girls with Rett Syndrome. However, the small sample size and the variability in improvement across the children limit the generalisability of the findings.

Comments: In-patient setting for two children – may not be generalisable to the home setting. Some of the improvements may not be clinically meaningful.

Publication details		
Author: Piazza ³¹	Year: 1991	Related publications:
Stated aim: To investigate the efficacy of a faded bedtime procedure for the treatment of paediatric insomnia		
Study design: Before and after		
The participants		
Number: N=4	Age: 3, 4, 13 and 19yrs	Sex: 2 male, 2 female
Type of disability: Profound learning disability		
Sleep problem: Met DSM III-R criteria for insomnia. Displayed a range of problems including problems settling, night waking, early waking and disruptive behaviours		
How the sleeping problem was assessed: Half hour observations over 24hr period.		
Other information: the children had been referred for the assessment and treatment of self-injury		
The intervention		
Setting: In-patient unit specialising in the assessment and treatment of severe behaviour disorders. One child was treated as an out-patient.		
Type of behavioural intervention: Faded bedtime with response cost (FBRC)		
Description of intervention: A bedtime was set at which sleep onset was highly likely within 15 minutes (half an hour later than the average time of sleep onset at baseline). A consistent bedtime routine was established. The child was not permitted to go to sleep before this time and was woken at a set time each morning. The response cost occurred if the child did not fall asleep within 15 minutes: they were removed from bed and kept awake for one hour (played with toys, watched TV etc). They were then returned to bed and this was repeated until the child was put to bed and fell asleep within 15 minutes. If the child fell asleep within 15 minutes of bedtime, bedtime was made half an hour earlier the next night. If they did not fall asleep it was made half an hour later.		
Duration: Not stated, presumably until discharge		
If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet): With the exception of one child, the intervention was not delivered by parents. The training and support received by the parents of this child was unclear.		
Description of comparator: No comparator		
The outcomes measures		
Outcome 1: % of intervals appropriate sleep		
Details of measurement: Number of sleep intervals occurring during the defined sleep period divided by the number of intervals of the defined sleep period. Based on half-hourly observations over 24 hours.		
Outcome 2: % of intervals of inappropriate sleep		
Details of measurement: Number of sleep intervals during the defined wake time divided by the total number of intervals of defined wake time. Based on half-hourly observations over 24 hours.		
Outcome 3: Frequency of night waking		
Details of measurement: Number of awake periods during defined sleep times that were preceded and followed by a sleep episode of at least 15 minutes. Based on half-hourly observations over 24 hours.		
The reliability of the observations was assessed by assessing the agreement between two observers for a proportion of the observations. Overall, agreement was high.		
Length of follow-up: End of treatment, for one child there was a 1 month follow-up post-discharge, for one child a one year follow-up and for 2 children no follow-up.		
Summary of the results:		
<ul style="list-style-type: none"> • Intervals of appropriate sleep – There were improvements for all participants, though in some instances these were very small: Child 1 increased from an average of 78% at baseline to 87% following treatment; Child 2 increased from 75.8% at baseline to 89.2% following treatment and 90% at one year (for this child the baseline and post-treatment assessment were conducted at home and the one year follow-up as an in-patient); Child 3 increased from 57% to 72%; Child 4 increased from 74% to 77% and 86% at one month follow-up. • Intervals of inappropriate sleep – Child 1 these were zero at baseline and following treatment; Child 2 decreased from an average of 11.3% at baseline to 2.1% post-treatment and 0.36% at one year; Child 3 decreased from 9% to 0%; Child 4 decreased from 0.9% to 0%. 		

- Frequency of night wakening – 3 children showed decreased night wakening though some changes may not have been clinically significant. Child 1 decreased from an average of 0.3 wakings per night at baseline to 0 post-treatment; Child 2 decreased from 1.09 to 0.64 and 0.09 at one year; Child 3 from 0.3 to 0.2; Child 4 data not given.
- The frequency of climbing in and out of bed decreased for the child with this problem from a 100% of nights at baseline to 16% of nights at follow-up (mean 30, range 15 to 51 at baseline to mean 1.1, range 0 to 20). The frequency of being brought into parents bed decreased for the child with this problem (mean 84.3 to 45.4). At one year the frequency was less than once every 2 months.

Any negative consequences: None reported

Views of parents: The authors state that anecdotally, the parents reported a high degree of satisfaction with the outcome.

Authors' conclusion: Each patient benefited from the intervention

Comments: In-patient setting – may not be generalisable to the home setting. Some of the improvements may not be clinically meaningful

Publication details		
Author: Quine ¹⁹	Year: 1991	Related publications: Quine ³⁵ Quine ³⁶ Quine ³⁷
Stated aim: To conduct an intervention trial with 25 families to assess whether training health professionals to teach behavioural techniques to parents of children with learning disabilities is effective in reducing children's sleep disturbance		
Study design: Before and after (for some of the measures the results were compared to an age-matched random sample of children with sleep problems from another district who had not sought or been offered treatment)		
The participants		
Number: N=25	Age: 1yr and 9mths to 21 years old	Sex: 17 male, 8 female
Type of disability: global developmental delay, cerebral palsy, Down's Syndrome, Steinert's disease, moderate and severe learning difficulties, microcephaly and developmental delay, autism, congenital rubella syndrome, Cri du Chat syndrome, right hemiplegia		
Sleep problem: Children were eligible for the study if they had night settling problems or night waking or limited sleep 3 or more times per week.		
How the sleeping problem was assessed: Interview with parents and two week sleep diary completed by the parents.		
Other information: The parents of all children attending Medway schools, social education centres and child assessment and care centres that ran playgroups for children with learning difficulties were approached. 40 families expressed an initial interest and 25 completed the programme. 1 dropped out during the programme and 14 dropped out before the intervention began (reasons provided).		
The intervention		
Setting: Home-based		
Type of behavioural intervention: Positive bedtime routine and conditioning; the precise intervention was tailored to the individual needs and resources of each family (based on Hewitt (1985))		
Description of intervention: A tailored behavioural treatment programme was developed and negotiated with each family which was written up on the weekly chart. The following general framework was used: 1) positive bedtime routine that included set bedtime, introduction of a regular routine before bedtime that provided clear stimuli for the child that bedtime was approaching, avoidance of overstimulation in the hour before bed; 2) teaching a relaxation response after getting into bed through use of a bedtime story or soft music; 3) gradual distancing of parent from bedroom once relaxation response was established; 4) identification of factors that were maintaining disruptive behaviours and advice for more constructive parent responses. During wakeful episodes the stimulus to which the child had become conditioned to fall asleep was repeated. Parents were advised to interact with the child as little as possible and avoid prolonged routines and overstimulation during waking episodes. Parents were made aware of the importance of consistency and the possibility that progress may be slow.		
Duration: Range 5 to 30 weeks. Parents were asked to stop recording sleep behaviour when the child settled easily at night and/or no longer woke at night or the parent's sleep was less disrupted. Recording could also stop if difficulties were only occasional and this was considered a satisfactory outcome.		
If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet): Following the assessment period progress was monitored by the health-visitor on a weekly basis. Frequency of home visits was agreed between the health-visitor and parent. Advice on maintaining improvement was given when a satisfactory outcome was reached and there was a follow-up appointment after 3 months. The project was staffed by 12 health visitors who were each responsible for two families. All 12 attended a 3-day course on behavioural approaches to sleep disturbance delivered by an educational psychologist, a social psychologist, a clinical psychologist and a lecturer in social work experienced in role playing techniques.		
Description of comparator: No comparator for sleep measures.		
The outcomes measures		
Outcome 1: Settling problems		
Details of measurement: Number of minutes to settle. Based on sleep diary		
Outcome 2: Night waking		

<p>Details of measurement: Number of times child woke each night and the number of minutes the child was awake. Based on sleep diary.</p> <p>Outcome 3: Maternal satisfaction with settling and wake patterns</p> <p>Details of measurement: Rated satisfaction on a 7-point scale (1 'not satisfied' to 7 'satisfied')</p> <p>Outcome 4: Behaviour Problem Index</p> <p>Details of measurement: Twenty items related to behaviour are rated to 0 (no or trivial difficulties) to 2 (marked difficulties) by the interviewer based on descriptions of behaviour from parents. Only items related to daytime behaviour were used.</p> <p>Outcome 5: Maternal Responsiveness</p> <p>Details of measurement: Checklist of 10 items to examine parental responses to sleep problems. Each item rated from 0 (never) to 4 (always). Internal reliability reported as high.</p> <p>Outcome 6: Maternal Stress and Morale (Malaise Inventory)</p> <p>Details of measurement: 24 item binary choice questionnaire adapted from Cornell Medical Index (Rutter <i>et al.</i> 1970). Scores of 5 or 6 were considered outside the normal range and a score of 7 or more as critical. Information provided on test-retest reliability and internal reliability.</p> <p>Outcome 7: Irritability and smacking</p> <p>Details of measurement: Appears to be frequency but unclear whether per day or per week.</p> <p>Outcome 8: Judson Self-rating Scale</p> <p>Details of measurement: Measures acceptance and adjustment of mother to child Judson and Burden 1980). 22 items are rated using a 7-point scale. Information provided on internal reliability.</p> <p>Outcome 9: Problems Faced by Mothers of Children with Sleep Problems (Problem Inventory)</p> <p>Details of measurement: Ten items scored from 0 (never a problem) to 4 (always a problem)</p> <p>Outcome 10: Mother's Perceptions of Self, Child and Husband</p> <p>Details of measurement: 20, 14 and 16 items respectively rated on a 7-point scale</p> <p>Length of follow-up: End of treatment (range 5 to 30 weeks) and 3 months from completion of treatment</p>
<p>Summary of the results:</p> <ul style="list-style-type: none"> Settling problems (15 children) – the time taken to settle decreased from a mean of 111mins (range 45-180) at baseline to a mean of 20.4mins (range 5-60) after the intervention. Night waking (15 children) – The frequency of night waking decreased from a mean of 3.1 times per night (range 2.2-4) at baseline to a mean of 0.3 (range 0-1.3). The duration decreased from a mean of 70.2mins per night (range 30-120) to a mean of 3.2mins (range 0-15). Eight children did not sleep in their own bed between 4 and 7 times per week at baseline. Post-treatment this had stopped for seven children and occurred once a week for the eighth child. Maternal Satisfaction with Settling and Waking Problems – Satisfaction improved with settling from a mean of 2.2 (SD 1.7) at baseline to 6.3 (SD 1.1) after the intervention ($p<0.001$). Satisfaction improved with waking from a mean of 2.7 (SD 1.9) to 6.2 (SD 1.4) ($p<0.001$). There was no statistically significant change in the satisfaction of mothers in the comparison group over the same time period. Behaviour Problem Index – Daytime behaviour improved from baseline (mean 13, SD 4.6) to post-treatment (mean 9.7, SD 4.3) (authors state this is statistically significant). There was no statistically significant change in the comparison over the same time period. Maternal Responsiveness – There was a decrease in the maternal responsiveness score from baseline to end of treatment indicating that mothers were more able to ignore inappropriate behaviour and reinforce appropriate behaviours (mean 22.4, SD 6.3) at baseline; mean 18.6 (SD 5.2) at end of treatment, $p<0.001$). There was no statistically significant change in the comparison group over the same time period. Maternal stress and morale – stress improved from baseline (mean 6.4, SD 4.1) to post-intervention (mean 3.8, SD 2.8) ($p<0.001$) and morale increased (mean 6.7, SD 2.2 to mean 7.6, SD 1.3) ($p<0.01$). There was no statistically significant change in the comparison group over the same time period. Irritability and smacking – There was a statistically significant improvement from baseline to post-treatment in feelings of irritability towards their child, frequency of smacking and fear of losing control and punishing their child too severely. Judson Self-rating Scale – Maternal acceptance of and adjustment to their child improved from baseline (mean 104.3, SD 16.2) to post-intervention (mean 128.4, SD 14.4) ($p<0.001$). There was no statistically significant change in the comparison over the same time period, though the baseline scores of the comparison group showed a more positive

<p>attitude to begin with.</p> <ul style="list-style-type: none"> • Problem Inventory – There was an improvement in the extent of the problems experienced by families from baseline (mean 20.3, SD 7.2) to post-treatment (mean 14, SD 6.9) ($p<0.001$). There was no statistically significant change in the comparison group over the same time period. • Mothers Perceptions of Self, child and Husband – Positive feelings towards self, child and husband improved from baseline (mean 97.4, SD 14.2; mean 65.4, SD 8.8; mean 84.3, SD 10.2 respectively) to post treatment (mean 113.1, SD 16.7; mean 72.6, SD 9.9; mean 100.8, SD 14.7 respectively) ($p<0.001$) • 3 months follow-up (based on 20 families) – 11/12 children with settling problems maintained the progress made and some improved further; 10/12 maintained their progress with night waking. Overall 17/20 had maintained progress or improved <p>Any negative consequences: None reported</p> <p>Views of parents: Several parents provided positive comments on the intervention. Some mentioned that it was difficult to do at the beginning in terms of having to be consistent, believing that it could work or leaving their child to cry. Some commented on the usefulness of recording information in the sleep diaries and some commented on the importance of support from the health visitors.</p>
<p>Authors' conclusion: The study produced a remarkably clear cut set of results. The results showed that it is possible to radically improve children's sleep behaviour and that the improvements result in a number of positive changes in relationships within the family.</p> <p>Comments The authors highlight the risk of selection bias. They compared their cohort to an age-matched random sample of children with sleep problems in another health district, who had not been offered or sought treatment. The study cohort had a greater proportion of boys, were more likely to have had their problem since birth, were more difficult to manage and there was greater marital unhappiness and maternal irritability.</p> <p>Care needs to be taken interpreting the comparisons with the comparison group. The statistical tests looked at change within each group rather than between group comparisons.</p>

Publication details		
Author: Stores ¹⁵	Year: 2004	Related publications:
Stated aim: To assess the effectiveness of a simple behavioural approach, based on instruction delivered to groups of mothers of young children with Down's Syndrome, in preventing or minimising sleep problems.		
Study design: RCT		
The participants		
Number: N=46	Age: Mean 2yrs 8mths (range 7mths to 4yrs 9mths)	Sex: 22 Male, 24 female
Type of disability: All had Down's Syndrome (details of severity of learning disability not available)		
Sleep problem: 65% (n=30) had at least one behavioural sleep problem: 14 bedtime settling problems, 26 night waking, 14 early morning waking and 7 sleeping in parental bed. Six children also had a sleep related breathing problem. 35% (n=16) did not have a sleep problem.		
How the sleeping problem was assessed: The Composite Sleep Problems Score and the Sleep-Related Breathing Problem Score were completed.		
Other information: Families with children aged 6mths to 5yrs were recruited from Oxfordshire Down Syndrome Service, the Hampshire Branches of Down's Syndrome Association, Downs Heart Group, health visitors, community paediatricians and child development centres. 77 eligible children were identified of whom 46 agreed to participate.		
The intervention		
Setting: Home-based. Mothers received instruction at a group session at the Oxford Down's Syndrome Resource Centre or the Down's Syndrome Educational Trust in Portsmouth.		
Type of behavioural intervention: One session of instruction and provided with booklet		
Description of intervention: There were separate sessions for mothers of children under 2.5 years and for those 2.5 to 5 yrs old. Small groups of about 5 mothers were brought together for the single instruction session. This lasted about 90 minutes including a discussion period of 30 minutes. The session consisted of information and advice about children's sleep and explaining behavioural techniques for encouraging good sleep habits such as establishing a positive bedtime routine, rewarding good behaviour, ignoring unwanted behaviour, gradual change. Case studies were used to illustrate the techniques. An illustrated booklet was provided (Encouraging Good Sleep Habits in Young Children with Down Syndrome). Both the instruction session and booklet had been piloted.		
Duration: One month		
If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet): No additional support was provided beyond the instruction session and booklet.		
Description of comparator: Waiting list control		
The outcomes measures		
Outcome 1: Composite Sleep Problem Score		
Details of measurement: Measures the frequency and duration of settling problems, night waking, early waking and sleeping in parental bed. The possible score range is from 0 (no problems) to 14.		
Outcome 2: Sleep-Related Breathing Problem Score (SRBPS)		
Details of measurement: Measure frequency of symptoms associated with sleep-related breathing problems.		
Outcome 3: Actometry (This is not reported for the intervention versus comparison group)		
Details of measurement: Wrist-watch device that measures basic sleep-wake patterns.		
Outcome 4: Educational impact		
Details of measurement: Knowledge of the Sleep of Young Children Questionnaire and Knowledge of Behavioural Principles as Applied to Children Questionnaire.		
Outcome 5: Mother's evaluation on the instruction session and booklet		
Details of measurement: Constructed for study.		
Length of follow-up: One month and 6 months		
Summary of the results:		
<ul style="list-style-type: none"> • CSPS – Based on a 3x2 ANOVA there was no statistically significant main effect or interaction for time or group. Baseline: Intervention mean 2.83 (SD 3.41); Control 3.38 (SD 3.38). 1 month: Intervention 2.67 (SD 2.93); Control 3.5 (SD 4.02). 6 month: Intervention 2.08 (SD 2.35); Control: 4.38 (SD 3.86). There was a statistically significant difference between groups at 6mths based on a post-hoc test. • SRBPS - Based on a 3x2 ANOVA was no statistically significant main effect or interaction 		

<ul style="list-style-type: none"> for time or group (data provided in paper) Educational impact – At 1-month follow-up mothers in the intervention group scored significantly higher on both knowledge questionnaire that the control group. Mothers' evaluation of intervention (based on 18 responses) – The presentation was rated as very useful (16%), quite useful (61%) and not very useful (17%). The booklet was rated as very useful (17%), quite useful (50%) and not very useful (22%). All but 2 mothers who gave the lowest rating said it was because their child did not currently have a sleep problem; 2 had tried the advice without success. 94% said that the presentation and the booklet were easy to understand. <p>Any negative consequences: None reported</p> <p>Views of parents: See above</p>
<p>Authors' conclusion: Group instruction offers some benefit regarding behavioural sleep problems but not for sleep-related breathing problems to which more attention should be given in children with Down Syndrome.</p> <p>Comments: Participants with and without a problem were in one group for analysis – this reduces the likelihood of a reduction in sleep problems in the group as a whole post-intervention. The length of follow-up may have been insufficient to assess the effectiveness of the intervention as a prevention measure.</p>

Publication details		
Author: Thackeray ²⁵	Year: 2002	Related publications:
<p>Stated aim: To demonstrate the effectiveness of standard extinction for treating sleeping problems in children with an intellectual disability, to obtain data on the social validity of the intervention and to assess whether there are any benefits for daytime behaviour in the school setting.</p>		
<p>Study design: Before and after</p>		
<i>The participants</i>		
Number: N=3	Age: 5yrs, 5yrs 6mths and 10 yrs	Sex: 3 male
<p>Type of disability: one severe, one moderate and one mild intellectual disability</p>		
<p>Sleep problem: Child 1 would not fall asleep and had tantrums unless father present and if he woke during the night disturbed the household until his father helped him re-settle; Child 2 would not fall asleep unless mother present, woke three times per night and sometimes early morning waking; Child 3 needed his mother present to fall asleep and got into bed with parents or sister during the night.</p>		
<p>How the sleeping problem was assessed: Parents completed screening questionnaire and the Behavioural Evaluation of Disorders of Sleep (BEDS) questionnaire</p>		
<p>Other information: 156 families were invited to participate through recruitment at a Special Developmental School and a Special School in northern Melbourne, Australia. Children with an intellectual disability according to international criteria, difficulties in settling, night waking or co-sleeping, not on current sleep medication and no epilepsy were eligible. Four families expressed an interest and were invited to participate. One withdrew after the first intervention session as they were not ready to make changes to their child's sleeping arrangements</p>		
<i>The intervention</i>		
<p>Setting: Home-based Parent training took place at a university psychology clinic.</p>		
<p>Type of behavioural intervention: Standard extinction with positive bedtime routine, reinforcement, effective instructions and partner support.</p>		
<p>Description of intervention: Parents received an intensive two session training programme based on 5 Step Sleep Programme (McDonald and Patzold). The first two hour session covered behavioural reinforcers, instruction giving and bedtime routine. Parents planned an appropriate routine and treatment goals were established. Parents were asked to implement what they had learned following the session. Parent support strategies and standard extinction were introduced at the second session. Standard extinction involved explaining the rules to the child and after putting the child to bed leaving the room and ignoring all crying or calling out. If the child came out of their room the parents were instructed to take the child immediately back to bed with minimum contact with child. If the child complied the child received positive reinforcement in the morning. Parents were advised of the possibility of an extinction burst. Modelling and role-playing was used during the sessions and written information and parent checklists also provided.</p>		
<p>Duration: 7 weeks</p>		
<p>If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet): In addition to the two training sessions parents received support by telephone from the therapist on at least three mornings after extinction was implemented as well as weekly phone calls during the rest of the programme. Including the pre-treatment and review sessions the therapist had six hours face-to-face contact with each family at the clinic.</p>		
<p>Description of comparator: No comparator</p>		
<i>The outcomes measures</i>		
<p>Outcome 1: Goal Achievement Scale</p>		
<p>Details of measurement: At the beginning of the programme parents identified two to four goals they wished to achieve in relation to their child's sleeping problem. They identified what they would consider total (100%) success for each goal. The level of success was assessed based on parent completed sleep diaries.</p>		
<p>Outcome 2: Actigraph</p>		
<p>Details of measurement: An Activwatch was worn over five consecutive nights in each assessment period. One minute sample periods were used.</p>		
<p>Outcome 3: Programme Evaluation Questionnaire</p>		
<p>Details of measurement: Assessed parent satisfaction with outcomes, acceptability of the</p>		

methods used, ease of understanding, ease of implementing the behavioural strategies and satisfaction with the therapist. They were also asked what they like most and least about the programme and what they would change.

Outcome 4: BEDS

Details of measurement: Parent completed questionnaire with 5 subscales

Outcome 5: Daytime behaviour

Details of measurement: 1) An observational checklist completed by trained observers for on-task behaviour and activity type and frequency counts of 4 target problem behaviours identified for each child; 2) teachers completed Developmental Behaviour Checklist – Teacher version; 3) a teacher-completed diary of child behaviour at lunchtime and after school; 4) a parent-completed diary of child behaviour before and after school.

Length of follow-up: End of treatment and 3 month follow-up

Summary of the results:

- Goal Achievement Scale – For three children, the goal of falling asleep independently every night was met with 100% success post-intervention and at 3-month follow-up (from 0 nights at baseline to 7 nights); for two children a goal was to fall asleep in own bed every night and this was met with 100% success at post-intervention and follow-up (from 4.3 and 6.3 nights at baseline to 7); for two children a goal was no co-sleeping on any night during the week and this was met with 100% success (from 1.5 nights and 7 nights at baseline to 0). For one child night waking showed some improvement post-intervention and 100% success was achieved at follow-up (from 2.2 nights at baseline to 0 at follow-up) and for one child there was no improvement (3 nights at baseline, 2.9 post-intervention and 3.9 at follow-up). For the later child there was a suggestion of sleep apnoea.
- Actigraph – Two children refused to wear it at follow-up. At end of treatment the duration of nighttime sleep increased from baseline for the three children by 53, 60 and 77 minutes
- BEDS – at baseline the 3 children had clinical or above average sleep problems which improved to normal levels for two children by follow-up and for one child did not change.
- Daytime behaviour – Based on parent and teacher ratings there were some small positive changes in behaviours for two children and a slight deterioration for the third. Based on the observational data each child showed improvement on a single behaviour but no others. Based on the DBC-T all three children showed a reduction in the total score but this was described as a convincing reduction for one child only.

Any negative consequences: Two children experienced an extinction burst.

Views of parents: Program Evaluation Questionnaire – The three parents were very satisfied with the outcomes of the intervention and the techniques used, they thought the programme was very appropriate for their child and would strongly recommend it to a friend. They particularly liked the support received. Things they did not like were the Actiwatch and Ignoring their child when calling.

Authors' conclusion: The study demonstrated the effectiveness of standard extinction for treating settling, co-sleeping and night waking problems in children with intellectual disabilities and has high social validity. Support for behaviour change as a result of improved sleep was equivocal.

Publication details		
Author: Weiskop ²⁶	Year: 2005	Related publications:
Stated aim: To evaluate the effectiveness of extinction for treating parent-referred sleep onset and maintenance difficulties in young children with an autism spectrum disorder or fragile X syndrome.		
Study design: Before and after		
The participants		
Number: N=13	Age: Mean 5yrs 1mth (range 1yr 1mth to 9yrs 1mth)	Sex: 10 males, 3 females
Type of disability: 5 autism, 1 Asperger syndrome, 7 fragile X syndrome (FXS)		
Sleep problem: bedtime disturbances, sleeping in parental bed, night waking and disruptive behaviour		
How the sleeping problem was assessed: Interview with parents and functional assessment using parent completed sleep diary from at least a 2-week period.		
Other information: With the exception of one child all lived in two parent families and apart from four fathers all parents participated in the programme. Parents were recruited through an advertisement in a disability newsletter or by referral from their medical practitioner. Criteria for inclusion were that the parents perceived their child had a sleeping problem, the child was diagnosed with an autism spectrum disorder or FXS and did not have epilepsy. Children with autism had to be between 2yrs 6mths and 7yrs and not taking medication for sleep problems or daytime behaviours. The age and medication requirements were not applied to children with FXS due to difficulties in recruitment.		
The results are based on 10 children. One family withdrew due to child illness, one withdrew as the parent had family issues to attend to and one was not included because although he completed the intervention there were several interruptions to the intervention due to illness.		
The intervention		
Setting: Home-based. Conducted in metropolitan Melbourne, Australia		
Type of behavioural intervention: Positive bedtime routine, reinforcement, effective instructions, partner support and extinction		
Description of intervention: There were three weekly training sessions for parents. These covered the topics of goal setting (what they wanted to achieve with their own child), the basic principles of learning theory (the influence of antecedents and consequences on child behaviour), positive bedtime routine, giving effective instructions, partner support strategies and extinction techniques. Different types of extinction were explained to parents: standard extinction, gradual ignoring and ignoring with parental presence. They were given a choice of which to use: all chose standard extinction which was also the therapist's preference. Standard extinction involved explaining the rules to the child and after putting the child to be leaving the room and ignoring all crying or calling out. If the child came out of their room the parents were instructed to take the child immediately back to bed with minimum contact with child. If the child complied the child received positive reinforcement in the morning. Parents were advised of the possibility of an extinction burst. Modelling and role-playing was used during the sessions and written information and parent checklists also provided. Five weeks after the training ended there was a review session where goals were re-evaluated and there was training in phasing out of reinforcers.		
Duration: A minimum of 7 weeks		
If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet):		
In addition to the initial interview and functional assessment (conducted at the university psychology clinic) parents received three weekly training sessions and a review session (details above). The sessions on goal setting and extinction were conducted in each family home and the sessions on effective instructions and the review session were conducted at the clinic. The therapist made weekly telephone contact with parents throughout the intervention and there was daily telephone contact during the initial days of implementing extinction. Parents were encouraged to contact the therapist if they had any problems or questions. The purpose of the contact was to check progress, obtain data, answer questions, assist with problems, prompt appropriate behaviour and praise success. After the review session, contact was gradually reduced.		
Description of comparator: No comparator		

<i>The outcomes measures</i>
Outcome 1: Overall change in sleep behaviours
Details of measurement: Data for each child were displayed on graphs (based on data from sleep diaries) to allow comparison between baseline, end of treatment and 3 and 12 months follow-up. Two clinicians (one not involved with the intervention) independently visually analysed the graphs and assessed the extent of change for each child (substantial improvement, moderate improvement, no change, moderate deterioration, substantial deterioration). Definitions were provided for each of these descriptors and the raters were blinded to which sleep variable they were assessing. Where there was disagreement, raters discussed and reached consensus on a rating. For overall change in sleep behaviours the two raters agreed on 80% of the comparisons.
Outcome 2: Bedtime disturbances (per week)
Details of measurement: Defined as any disruption between being put to bed and sleep onset (e.g. calling out, leaving bedroom). Measured as above.
Outcome 3: Falling asleep in own bed
Details of measurement: Defined as number of nights per week falling asleep in own bed. Measured as above.
Outcome 4: Sleep latency
Details of measurement: The average time (minutes) between being put to bed and falling asleep. Measured as above.
Outcome 5: Night waking
Details of measurement: Number of night wakings per week that parents were aware of. Measured as above.
Outcome 6: Co-sleeping
Details of measurement: Number of nights per week child co-slept (excluding the period of falling asleep). Measured as above.
Outcome 7: Sleep duration
Details of measurement: Average duration (minutes) of sleep per week. Measured as above.
Outcome 8: Program Evaluation Questionnaire
Details of measurement: A modified version of Griffin and Hudson (1978) questionnaire. Consisted of three open-ended questions about what they liked best, least and what they would change. A fourth question asked if their child currently had a sleep problem and to rate the severity. Five items were rated on a 5-point Likert scale: parental stress levels, approval of techniques, improvement in child's sleep and behaviour, and how strongly they would recommend the programme to a friend. The final three were combined to give an overall measure of parental satisfaction (maximum score 15).
Outcome 9: Goal Achievement Scale
Details of measurement: At the beginning of the programme parents identified two to three goals they wished to achieve in relation to their child's sleeping problem. They identified what they would consider total (100%) success for each goal. The level of success was assessed based on the sleep diaries.
Length of follow-up: End of treatment (last 4 weeks of intervention), three months after the review session and at 12 months for the children with autism.
Summary of the results:
<ul style="list-style-type: none"> • Overall change in sleep behaviours – <i>Baseline v end of intervention</i> (64 comparisons): substantial deterioration 0%, moderate deterioration 4.5%, no change 25%, moderate improvement 29.7%, substantial improvement 40.6%. <i>Baseline v 3-month follow-up</i> (63 comparisons): substantial deterioration 1.6%, moderate deterioration 4.8%, no change 27%, moderate improvement 23.8%, substantial improvement 41.3%. <i>Baseline v 12-month follow-up</i> (26 comparisons): substantial deterioration 0%, moderate deterioration 7.7%, no change 19.2%, moderate improvement 26.9%, substantial improvement 46.2%. • Bedtime disturbances – For all cases the frequency of bedtime disturbances was rated as improved from baseline to end of treatment, 3 month and 12 month follow-up. • Falling asleep in own bed – Rated as improved for 8 children from baseline to end of treatment, though one child had shown a trend towards improvement during the baseline period. Seven maintained the improvement at both follow-ups. Improvement was not expected for two children as this was not a problem at baseline. • Sleep latency – Rated as improved for 6 children from baseline to end of treatment, though one child had shown a trend towards improvement during the baseline period. Two children were rated as deteriorated and 2 as unchanged. Five maintained the improvement at follow-up but one deteriorated.

<ul style="list-style-type: none"> • Night waking – Rated as improved for 7 children at the end of intervention and at follow-up, though one child had shown a trend towards improvement during the baseline period. Three children were rated as unchanged though change was not expected for 2 as this was not a problem at baseline. • Co-sleeping – Of the 6 children for whom this was a problem at baseline this was rated as improved at end of intervention, at 3 month follow-up and for 5 at 12 month follow-up. • Sleep duration – The authors state that there was little consistency among participants in the rate of change across time. • Parents views of sleep problem (from Program Evaluation Questionnaire) – Five of the ten mothers stated that their child still had a sleep problem after the intervention. In four of these cases the severity had decreased. • Goal Achievement Scale – At end of intervention 12 out of 25 goals were achieved with 100% success and the mean Goal Achievement Score was 76.3%. In the autism group there was further improvement at 3-month follow-up (mean GAS 80.8) and at 12 months (mean GAS 89%). For the FXS group at 3-months the level of achievement increased for 4 goals and decreased for 4. <p>Any negative consequences: Seven participants experienced an extinction burst in the week that extinction was implemented.</p> <p>Views of parents: Program Evaluation Questionnaire – parents said the best aspects of the program were the outcome, the support provided, and the method of training. Record keeping was the thing they liked least. Two found it difficult to stick to a bedtime routine, one found the training sessions too long, three thought the programme time consuming. The mean parental satisfaction score was 13.8 (range 11 to 15). All said they would recommend the programme to a friend.</p> <p>Authors' conclusion: The results support the hypothesis sleep problems of children with autism or FXS will reduce after behavioural intervention.</p> <p>Comments: The authors raise a number of points to consider when interpreting the findings. 1) Extinction did not seem appropriate for early morning waking or night rocking possibly because they were not positively reinforced by parental responses prior to treatment. 2) They observe that in most cases improvement did not occur until extinction was implemented. 3) The extent to which the findings can be applied to a wider population is limited as the intervention needs to be tested across a wider range of disabilities. 4) They point out that the two children that were withdrawn from the study were more non-compliant than those who remained and were also older. They suggest that extinction may be too difficult or stressful to implement with extremely non-compliant or older children.</p>
--

Publication details				
Author: Wiggs ¹⁶	Year: 1998	Related publications: Wiggs ³³ Wiggs ³⁴		
<p>Stated aim: To explore the efficacy and mechanisms of treatment in children with severe learning disabilities, severe sleep problems and severe daytime challenging behaviour</p>				
<p>Study design: RCT (schools rather than families were randomly allocated to intervention or control in order to avoid discussion of the intervention between parents in the two groups)</p>				
The participants				
Number: N=31	Age: Intervention (n=15) – mean 8.21yrs (SD 2.7); Control(n=15) – mean 10.77yrs (SD 3.81)	Sex: 18 males, 12 females		
<p>Type of disability: The children had severe learning disabilities (Down syndrome, meningitis, microcephaly, cerebral palsy, CHARGE association, agenesis of the corpus callosum, Sanfillipo syndrome, Ring 15 chromosome disorder and unknown with autism). Eleven children also had uncontrolled epilepsy.</p>				
<p>Sleep problem: 10 settling; 6 settling and night waking; 5 settling, night waking and sleeping in parental bed; 1 night waking, 2 settling and sleeping in parental bed; 2 night waking and early waking; 2 night waking and sleeping in parental bed; 1 settling, night waking and sleeping in parental bed. For entry into the study children had to have a severe sleep problem (based on specific criteria).</p>				
<p>How the sleeping problem was assessed: Based on a detailed sleep history using a semi-structured interview. A severe sleep problem was defined as settling problems of more than one hour duration 3 or more times per week or night waking 3 or more times per week where the child disturbed parents or went into parents room or early waking before 5am, 3 or more times per week.</p>				
<p>Other information: Children were eligible for the study if they had a severe sleep problem and one or more daytime challenging behaviours (any item assessing challenging behaviour on the Aberrant Behaviour Checklist classified as quite serious or severe). They were recruited from families who had responded to a survey of special schools. There were 486 children included in the survey of whom 209 families completed a questionnaire (43%). 51 children met the inclusion criteria for the sleep study of whom 31 agreed to participate. One dropped out from the intervention group before it commenced. Of the 20 who declined 10 were too busy, 7 said their child's sleep had improved and the reason was unknown for 3.</p>				
The intervention				
Setting: Home-based				
Type of behavioural intervention: A range of behavioural techniques depending on the problem and parent preferences				
Description of intervention: Following a preliminary introductory visit to explain baseline questionnaires and the activity monitor watch there was a 1.5 to 2.5 hour visit to undertake a functional analysis of the problem. For the intervention group, a detailed behavioural programme was agreed. There was discussion of possible mechanisms maintaining sleep problems and the advantages and disadvantages of different approaches such as extinction, graded extinction, stimulus control procedures and positive reinforcement. Parents' aims for treatment and target(s) for the first stage were identified. After this visit parents were sent a written outline of the agreed behavioural programme.				
Duration: One month				
<p>If delivered by parents, give description of training and support received (including methods of delivery of support to parents for the intervention (e.g. face to face, telephone, booklet): In addition to the visit where the intervention was delivered progress was monitored by regular telephone calls. Both the intervention and control group received the preliminary visit and four visits to deliver and collect questionnaires.</p>				
<p>Description of comparator: Waiting list control</p>				
The outcomes measures				
Outcome 1: Composite Sleep Index				
Details of measurement: Modification of the Simonds and Parraga Sleep Questionnaire (1982). Scores frequency and duration of settling and night waking problems and frequency of early waking and sleeping in parental bed. Possible score range from 0 (no problem) to 12.				
Outcome 2: Activity monitor (child and mother)				
Details of measurement: The wrist watches were worn for three nights at each assessment period by the child and mother. Movement was calculated for every 30seconds during the				

recording period. Sleep period (time from sleep onset to waking), activity score (mean value of movement during sleep), movement index (% of sleep period spent moving) and fragmentation index (% of immobile phases during sleep period which were 30 seconds duration or less) were measured.

Outcome 3: General daytime behaviour

Details of measurement: 18 items enquiring about challenging behaviour from the Aberrant Behaviour Checklist (ABC) (Aman & Singh 1986) which were rated by mothers and teachers (baseline and 3 month follow-up only). These were entered into a factor analysis and five distinct categories of behaviour identified: irritability, lethargy, stereotypies, hyperactivity and inappropriate speech.

Outcome 4: Severity of challenging behaviour

Details of measurement: Mean severity rating by mother and teachers of each of 5 challenging behaviours: aggression, non-compliance, self-injury, temper tantrums and screaming.

Outcome 5: Frequency of challenging behaviour

Details of measurement: Mean severity rating by mother and teachers of each of the 5 challenging behaviours.

Outcome 6: Parental satisfaction with sleep

Details of measurement: Rated satisfaction with their own sleep and satisfaction with their ability to cope with their child's sleep pattern and daytime behaviour on a 6-point Likert scale from 0 totally satisfied to 6 totally unsatisfied.

Outcome 7: The Malaise Inventory (Rutter, Tizard & Whitmore 1970)

Details of measurement: 24-item binary choice questionnaire to assess parental stress. Test-retest reliability reported to be high.

Outcome 8: Epworth Sleepiness Scale (Johns 1991)

Details of measurement: 8-item self-report scale assessing daytime sleepiness. The items assess likelihood of falling asleep in everyday situations. Possible score ranges from 0 to 24 (maximum sleepiness).

Outcome 9: Internal/External Locus of Control Scale (Rotter 1966)

Details of measurement: 29-item forced choice to measure orientation to internal or external control beliefs.

Outcome 10: Perceived control

Details of measurement: Parents rated their ability to control any sleep-related problems shown by their child on a 100mm visual analogue scale with higher score indicating greater perceived control.

Length of follow-up: One month and 3 months following commencement of treatment.

Summary of the results:

- Composite Sleep Index – Based on 2x3 ANOVA there was a statistically significant main effect for time ($p<0.001$), group ($p=0.001$) and a significant interaction between group and time ($p<0.011$). Based on post-hoc tests (Scheffe's test) there was a statistically significant improvement from baseline to one month and baseline to 3 month follow-up for the intervention group: mean 6.73 (SD 2.31); 3.79 (SD 1.89) and 2.96 (SD 2.24) respectively; but no change for the control group mean 7.23 (SD 2.26); 6.62 (SD 1.89) and 6.29 (SD 2.70) respectively.
- Activity monitor – *Children's movements*: There were no between group differences. There was a statistically significant main effect for time only on each of the sleep variables. Based on post-hoc tests there was an improvement for both groups from baseline to 1 and 3-month follow-up for sleep period, activity score and movement index and improvement from baseline to 1-month for the fragmentation index but deterioration between 1 and 3-month follow-up. *Mothers' movements* – There was a statistically significant interaction between group and time ($p=0.03$) for sleep period. Based on post-hoc tests mothers in the intervention group showed an increased sleep period between baseline and 1-month and 3 month follow-up. There was a statistically significant main effect for time for the movement index ($p=0.011$). Based on post-hoc tests the intervention and control group showed a significant improvement from baseline to 1-month follow-up.
- General daytime behaviour – There were no statistically significant differences between intervention and control in how they changed over time. There was a statistically significant decrease in both groups from baseline to 1 and 3 month follow-up in irritability, lethargy and hyperactivity based on mother's ratings and for irritability and hyperactivity from baseline to 3 months on teachers rating.
- Severity of challenging behaviour – There were no statistically significant differences

- Frequency of challenging behaviours – There were no statistically significant differences between intervention and control over time for mother and teacher ratings. Based on teacher ratings there was a significant decrease in frequency of challenging behaviours over time in both groups.
- Parental satisfaction with sleep – *Mothers* (n=15 for each group): there was a statistically significant group by time interaction for satisfaction with own sleep, satisfaction with child's sleep and satisfaction coping with child's sleep. There was improvement from baseline to 1-month and 3-month follow-up which was greater in the intervention group. *Fathers* (12 in treatment group and 13 in control group): there was a statistically significant group by time interaction for satisfaction with own sleep, satisfaction with child's sleep. There was improvement from baseline to 1-month and 3-month follow-up which was greater in the intervention group.
- The Malaise Inventory – *Mothers*: there was a statistically significant group by time interaction for stress (p=.053). Mothers in the intervention group reported reduced stress from baseline to 3-month follow-up. *Fathers*: there were no statistically significant between group differences over time.
- Internal/External locus of control – *Mothers*: there were no statistically significant between group differences over time. *Fathers*: there was a statistically significant group by time interaction for externality. There was an increase post-intervention for the intervention group and a reduction for the control group.
- Perceived control - There were no statistically significant differences between intervention and control over time amongst mothers or fathers.

Any negative consequences: None reported

Views of parents: None reported

Authors' conclusion: Sleep problems can be successfully treated in this group of children but the mechanisms of treatment may not be as direct as supposed. The intervention did not appear to be associated with any change in the children's daytime behaviour. Such interventions can have a significant positive impact upon mothers, and to a lesser degree, fathers. There was evidence of improvement over time in child and parent outcomes for both the intervention and control group suggesting nonspecific effects of participating in the study.

Rapid Review 2

THE UNIVERSITY *of York*



Rapid Review 2

**The Effectiveness of Behavioural Interventions Which
Involve Parents in the Management of Behaviour Problems
Among Disabled Children: A Rapid Review**

Bryony Beresford

February 2009

Contents

	Page
List of Tables and Figures	i
Acknowledgements	iii
Chapter 1	Introduction
1.1	The principles of behaviour modification
1.2	Behavioural approaches and interventions to deal with problem behaviour in children
1.3	'Parent-involved' behavioural interventions with disabled children
	1
	2
	2
Chapter 2	Methods
2.1	Searches
2.2	Inclusion and exclusion criteria
2.3	Data extraction
	3
	3
	4
	6
Chapter 3	Results
3.1	Study selection
3.2	Overview of selected studies: research design and quality of research
3.2.1	Studies excluded on grounds of research design
3.2.2	Research quality of included studies
3.2.3	Research quality implications
3.3	The interventions
3.3.1	The scope of the interventions
3.3.2	The delivery of the interventions
3.3.3	Overview of the nature of the interventions
3.4	Overview of the studies
3.4.1	Research design
3.4.2	Type of disability or impairment
3.4.3	Severity of the behaviour problem
3.4.4	Child's age
3.4.5	Country
3.4.6	Outcome measures used
	7
	7
	8
	11
	11
	12
	13
	13
	19
	19
	23
	23
	23
	23
	23
	23
	24
Chapter 4	Findings on Intervention Outcomes
4.1	Interventions on behaviour management skills only
4.1.1	Child behaviour outcomes
4.1.2	Parental stress and mental health
4.1.3	Knowledge and implementation of behaviour modification principles
4.1.4	Other outcome measures
4.2	Interventions on behaviour management skills and the parent-child relationship
4.2.1	Child behaviour outcomes
4.2.2	Parent-child interaction
4.2.3	Parental stress
4.2.4	Child's impact on family life
4.3	Interventions on behaviour management and teaching skills
4.3.1	Child behaviour
	27
	27
	28
	28
	28
	33
	33
	33
	33
	33
	36
	36

4.3.2	Parenting stress and mental health	37
4.3.3	Parental knowledge and implementation of behaviour modification principles	38
4.3.4	Parenting skills	38
4.3.5	Parental sense of competence	38
4.4	Interventions on behaviour management skills and understanding of the condition	44
4.4.1	Child behaviour outcomes	44
4.4.2	Parents' self-efficacy in managing Asperger's syndrome	44
Chapter 5	Discussion	47
5.1	The evidence on effectiveness	47
5.2	Gaps in the evidence and implications for future research	51
References		53
Appendix A	Search Strategy	59
Appendix B	Quality Assessments	79
Appendix C	Outcome Measures	87
Appendix D	Results of Studies	91

List of Tables and Figures

	Page
Tables	
Chapter 2	
2.1 Databases searched for research evidence on behavioural interventions for behavioural problems in disabled children	3
2.2 Numbers of records downloaded and remaining after deduplication per database. Evidence on behavioural interventions for behavioural problems in disabled children using both search approaches	4
2.3 Inclusion and exclusion criteria	5
2.4 Data extraction headings	6
Chapter 3	
3.1 Research design of selected studies	9
3.2 Research quality: summary	12
3.3 The interventions under investigation	15
3.4 Delivery of the intervention	20
3.5 Overview of the studies	25
Chapter 4	
4.1 Outcomes of interventions on behaviour management skills only	29
4.2 Outcomes of interventions on behaviour management skills and the parent-child relationship	34
4.3 Outcomes of interventions on behaviour management and teaching skills	39
4.4 Outcomes of interventions on behaviour management skills and understanding of the child's condition	45
Chapter 5	
5.1 Overview of significant effects for each intervention	48
Appendix B	
B.1 Quality of randomised controlled trials	80
B.2 Quality of non-randomised controlled trials	83
Appendix C	
C.1 Outcome measures used by included studies	88
Appendix D	
D.1 Results of studies	92
Figures	
Chapter 3	
3.1 Study selection	8

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Chapter 1 Introduction

The rates of behaviour problems among young disabled children, and especially children with learning difficulties¹ are three to four times higher than among non-disabled children (Baker *et al.*, 2002; Baker *et al.*, 2003; Volkmar and Dykens, 2002). These behaviour problems typically continue to persist into later childhood and adolescence (Emerson, 2003) and, as the child increases in size, strength and speed, become more severe. This puts the child at increased risk of harm and also means they become more and more difficult for parents and schools to manage. Challenging behaviour is the main reason why children are placed in 38 or 52 week placements in residential schools (Abbott *et al.*, 2000), and is also a key factor for families being unable to access short breaks (or respite care), and/or the child being unable to access educational, therapeutic and/or community or social activities (Kahng and DeLeon, 2008).

High levels of unmet need in skills to manage their child's behaviour are reported by parents, and severity of the child's behaviour problem has been found to be associated with levels of maternal stress (for example, Baker *et al.*, 2003; Quine and Pahl, 1989).

1.1 The principles of behaviour modification

Over many years, behavioural theory and behaviour modification principles have been used to inform and determine interventions to address problem behaviour.

In essence, behavioural theory argues that whether or not behaviours (desired or undesired) are maintained (or continue to be exhibited) is dependent on what happens (in terms of changes in the situation, demands on the individual, and/or other people's reactions) when that behaviour is displayed. These are known as '*reinforcers*'. Reinforcers are conceived as positive or negative. Positive reinforcement is the *presentation of something* to the individual following a behaviour which makes it more likely that the behaviour will happen again (for example, attention from an adult). Negative reinforcement is the *removal of something* in the individual's environment following a behaviour that results in strengthening that behaviour (for example, removing a plate of food once a spoonful of a disliked vegetable has been eaten).

Based on this principle, in order to change any behaviour or remove an undesired or problem behaviour, it is necessary to stop reinforcing it. This is known as extinction. So, returning to the example of positive reinforcement given above, extinction would involve removing adult attention following an undesired behaviour. In the example of negative reinforcement, removing a plate of food once a spoonful of vegetable has been eaten may result in extinguishing the target behaviour (of fussing over eating vegetables). 'Punishment' is a third way in which behaviour can be modified. A punishment is anything which decreases the probability of the undesired behaviour occurring again because the individual experiences it as an unpleasant event or stimulus. What constitutes a punishment will, to some extent, vary between individuals because of the individual differences which exist in what people find pleasurable or unpleasurable.

The overall approach of behavioural interventions for behaviour problems involves: identifying what provokes or causes the problem behaviour and what is reinforcing the

¹ A number of different phrases can be used to describe children with impaired cognitive and learning abilities. Different countries use different phrases and, across time, the terms used have changed. Learning difficulties is the term chosen for use in this report and is the same as '*developmental delay*', '*intellectual disabilities*', '*mental retardation*' and '*learning disabilities*'.

behaviour (called functional analysis), and using this information to develop a strategy by which the behaviour can be modified through changing reinforcers and, sometimes, punishment. (See Emerson, 2001; Kahng and DeLeon, 2008 for more detailed descriptions of behavioural principles applied to managing behaviour problems among disabled children.)

1.2 Behavioural approaches and interventions to deal with problem behaviour in children

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 1960's and early 1970's 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 of the intervention 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).

More recently, researchers have been concerned with identifying the relative contribution different components of an intervention contribute to its effectiveness (Kaminski *et al.*, 2008), and the relative effectiveness of different media to deliver parent training programmes (Montgomery *et al.*, 2008).

1.3 'Parent-involved' behavioural interventions with disabled children

Parent-training programmes and other 'parent-involved' behaviour interventions were initially developed for non-disabled children. Differences in cognitive ability, the co-occurrence of physical impairments or autistic spectrum disorder, and possibly, the increased severity of the behaviour problem and/or the older age of the child (many of the generic programmes are designed for pre-schoolers and young children), have implications for the appropriateness and applicability of these generic interventions. Recently some generic programmes have been modified or adapted for use with parents of disabled children. In addition, specific programmes or approaches for disabled children have been developed (typically at a local and/or regional level).

The purpose of this rapid review is to review the evidence of the effectiveness of 'parent-involved' behavioural interventions in managing problem behaviours among disabled children.

Chapter 2 Methods

2.1 Searches

Searches were undertaken for research studies on the effectiveness of behavioural interventions for disabled children with behavioural problems. This is a complex topic to capture in searches because of the number of disabilities that might be involved, the variation in descriptions of behavioural problems, and the range of behavioural therapies that might be used. Several approaches to capturing the concepts in the search question were explored in preliminary searches varying the search terms and the number of concepts. Two search approaches were used for the full searches combining the following concepts:

Behavioural problems AND Children AND Disability AND behavioural interventions

Disabled people AND behavioural problems AND behavioural interventions AND reviews

Case studies, letters, notes, comments and editorials were excluded from the searches. Searches were restricted to English language studies published since 1980.

A range of databases and websites were searched (see Table 2.1). Records were downloaded and added to Endnote bibliographic software. The records were deduplicated.

Table 2.1 Databases searched for research evidence on behavioural interventions for behavioural problems in disabled children

Database	Interface	Date searched
Cochrane Database of Systematic Reviews (CDSR)	Cochrane Library 2008 Issue 3	23/9/08
DARE	Cochrane Library 2008 Issue 3	23/9/08
MEDLINE	Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1950 to Present>	23/9/08
EMBASE	OvidSP, 1980 to 2008 Week 38	23/9/08
PsycINFO	OvidSP, 1806 to September Week 2 2008	16/9/08
CINAHL	OvidSP, 1982 to September Week 3 2008	23/9/08
CENTRAL	Cochrane Library 2008 Issue 3	23/9/08
Campbell Library	http://www.campbellcollaboration.org/campbell_library/index.php	3/10/08
SPECTR (Campbell Collaboration)	http://geb9101.gse.upenn.edu/RIS/RISWEB.ISA	3/10/08
HMIC	OvidSP, to September 2008	23/9/08
NRR archive	https://portal.nihr.ac.uk/Pages/NRRArchiveSearch.aspx	24/9/08
CERUK	http://www.ceruk.ac.uk/	24/9/08
ERIC	Dialog/Datastar	23/9/08
Childdata	http://www.childdata.org.uk/library_search.asp	24/9/08
Australian Education index (AUEI)	Dialog/Datastar	23/9/08
British Education Index (BRIE)	Dialog/Datastar	23/9/08

The searches identified 10,592 records. After deduplication 7,908 records remained to be assessed for relevance. The result breakdown is shown in Table 2.2.

Table 2.2 Numbers of records downloaded and remaining after deduplication per database. Evidence on behavioural interventions for behavioural problems in disabled children using both search approaches

<i>Database</i>	<i>Number of records retrieved</i>	<i>Number of records remaining after deduplication</i>
Cochrane Database of Systematic Reviews (CDSR)	12	12
DARE	17	11
MEDLINE	1590	1288
EMBASE	2743	2041
PsycINFO	2304	1754
CINAHL	761	468
CENTRAL	239	49
Campbell Library	7	7
SPECTR	18	9
HMIC	152	133
NRR archive	13	13
CERUK	15	15
ERIC	2192	1695
Childdata	190	172
Australian Education index (AUEI)	203	177
British Education Index (BRIE)	136	64
Totals	10592	7908

2.2 Inclusion and exclusion criteria

The titles and abstracts were screened and full papers ordered for any records identified as potentially relevant. These were then screened using the screening criteria shown in Table 2.3.

Table 2.3 Inclusion and exclusion criteria

Exclusion criteria
<ul style="list-style-type: none"> • Not English language • Published before 1980 • Conference proceeding • Single subject design • Research not concerned with intervention to manage/address/resolve a behaviour problem • Intervention includes pharmacological element • Intervention focussed on behavioural <i>symptom/indicator</i> of a condition • Social skills intervention without an explicit problem behaviour component • Intervention does not include parental involvement in the delivery of the intervention • Intervention delivered entirely in school or care setting • Interventions which only and specifically address the following behaviour problems: <ul style="list-style-type: none"> ◦ Bullying ◦ Inappropriate sexual behaviour ◦ Criminal activities ◦ Self-harm associated with mental health problems • Case studies, letters, notes, editorials • Research where the sample includes disabled and non-disabled children, and not analysed separately • No quantitative outcome measures used • Age of sample (or some of sample) 19 years of age or older (inclusive) • Sample <u>only</u> includes children with the following as their 'primary need': <ul style="list-style-type: none"> ◦ Attention deficit hyperactivity disorder (ADHD) ◦ Mental health problems ◦ Emotional/social/behavioural difficulties ◦ Specific learning difficulties (for example, dyslexia) • Children with a 'dual diagnosis' – i.e. disability <i>and</i> psychological/psychiatric problem (but not ASD).

Inclusion criteria
<ul style="list-style-type: none"> • Intervention includes at least a behavioural intervention element to manage/address/resolve a behaviour problem <i>and</i> • Intervention for disabled children aged 18 years of age and under <i>and</i> • Evaluation of that intervention which includes, at least, a quantitative element.

2.3 Data extraction

Data were extracted onto standard tables, the headings of which are displayed in Table 2.4.

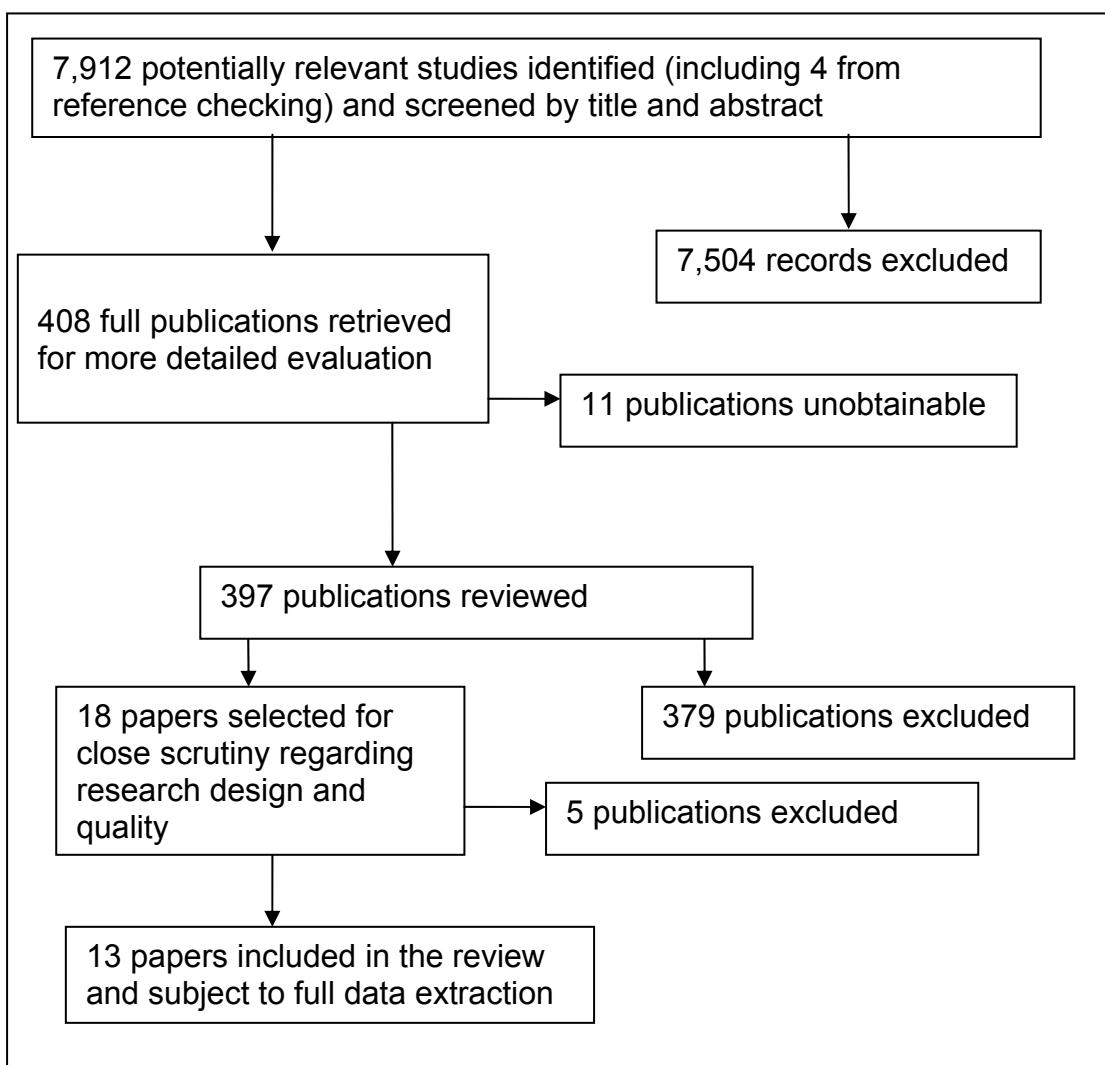
Table 2.4 Data extraction headings

- Author and year
- Focus of intervention (type of behaviour problem tackling)
- Disability-generic or disability-specific/Type of impairment
- How referring behaviour problem assessed
- Description of intervention (including behavioural principles)
- Duration of intervention
- Setting where intervention delivered
- Who delivers?
- Parent involvement in delivering intervention
- Service evaluation or research project?
- Research design
- Sampling
- Intervention and comparator samples
- Attrition/drop-out
- Outcome measures
- Outcome findings
- Country

Chapter 3 Results

3.1 Study selection

7,912 records were screened for relevance. 7,908 from the electronic searches and four publications identified through reference checking (see Figure 3.1). 7,504 were excluded and of the remaining 408 records, full copies of 397 publications were obtained for more detailed evaluation (11 were unobtainable). 379 publications were subsequently excluded. Amongst these, 65 publications provided useful background information or were literature reviews, and 31 were studies which were of relevance but used single subject research design. The remaining 18 papers, representing 18 studies, were submitted for close scrutiny in terms of research design and research quality. The outcome of this process is reported in the following section. The result of this process was that five studies were excluded leaving 13 studies included in the review.

Figure 3.1 Study selection

3.2 Overview of selected studies: research design and quality of research

Scrutiny of the 18 included studies with regard to research design and research quality formed a further stage in the study selection process. An overview of the research designs employed by these studies is provided in Table 3.1.

Table 3.1 Research design of selected studies

Author	Year of publication	Design (as described by author(s))	Maryland level	Number of participants	Follow-up?	Comparators	Country
Bagner and Eyberg	2007	Randomised controlled trial	Level 5	N=30	No	Intervention vs waiting list control	US
Brightman <i>et al.</i>	1982	Randomised controlled trial	Level 5	N=66	6 months	Group intervention vs individual intervention vs waiting list control	US
Buono and Citta	2007	Before and after	Level 2	N=40 ²	No	n/a	Italy
Butter	2007	Before and after	Level 2	N=17	No	n/a	US
Chadwick <i>et al.</i>	2001	Randomised controlled trial	Level 5	N=68	6 months	Group intervention vs individual intervention vs no intervention control	UK
Feldman and Werner	2000	Post intervention (variable time since intervention) assessment	Level 1	N=36	Variable	Waiting list	Canada
Gates <i>et al.</i>	2001	Controlled trial	Level 4	N=103	3, 6 and 12 months	Gentle teaching vs behaviour modification vs no intervention	UK
Hornby and Singh	1984	Controlled trial	Level 4	N=11	No	Treatment vs no treatment	New Zealand
Hudson <i>et al.</i>	2003	Controlled trial	Level 4	N=115	4-6 months	Group support vs telephone support vs self-directed vs no intervention	Australia
McIntyre	2008a	Randomised controlled trial	Level 5	N=44	No	Intervention vs usual care	US
Mullin <i>et al.</i>	1995	Before and after	Level 2	N=9	No	n/a	Ireland

² Mean age of sample given as 17 years. No further information on sample size given.

Chapter 3 Results

Author	Year of publication	Design (as described by author(s))	Maryland level	Number of participants	Follow-up?	Comparators	Country
Plant and Sanders	2007	Randomised controlled trial	Level 5	N=74	12 months	Standard intervention enhanced intervention vs waiting list control	Australia
Prieto-Bayard and Baker	1986	Randomised controlled trial	Level 5	N=20	6 months	Intervention vs waiting list control	US
Quinn <i>et al.</i>	2007	Controlled trial	Level 4	N=42	10 months	Intervention vs waiting list control	Ireland
Roberts <i>et al.</i>	2006	Randomised controlled trial	Level 5	N=44	6 months	Intervention vs waiting list control	Australia
Sofronoff and Farbotko	2002	Controlled trial	Level 4	N=89	3 months	Workshop intervention vs individual intervention vs waiting list control	Australia
Sofronoff <i>et al.</i>	2004	Randomised controlled trial	Level 5	N=51	3 months	Workshop intervention vs individual intervention vs waiting list control	Australia
Volenski	1995	Before and after	Level 2	N=47	No	n/a	US

Eight of the 18 studies were described by the authors as randomised controlled trials (Bagner and Eyberg, 2007; Brightman *et al.*, 1982; Chadwick *et al.*, 2001; McIntyre, 2008a; Plant and Sanders, 2007; Prieto-Bayard and Baker, 1986; Roberts *et al.*, 2006; Sofronoff *et al.*, 2004). A further five studies were of controlled trial design (Gates *et al.*, 2001; Hornby and Singh, 1984; Hudson *et al.*, 2003; Quinn *et al.*, 2007; Sofronoff and Farbotko, 2002). Four were before and after studies (Buono and Citta, 2007; Butter, 2007; Mullin *et al.*, 1995; Volenski, 1995), and the final study compared scores on a post-intervention sample (no standard time since intervention) with a waiting list sample (Feldman and Werner, 2000).

The Maryland Scale of Scientific Methods (Sherman *et al.*, 1988) was applied to these studies. This scale ranges from 1–5. Level 5 represents randomised controlled trials, Level 4 covers studies which use a control group, Level 3 is assigned to studies with another treatment comparator group, Level 2 are before and after studies (no comparator groups), and Level 1 applies to research where measures are only taken at one point in time.

It is widely accepted that only studies which score three or above on the Maryland scale are of robust enough design to potentially provide evidence with regard to whether or not an intervention works, does not work, or appears promising.

3.2.1 Studies excluded on grounds of research design

Five studies did not meet the Maryland criteria and were therefore excluded from the review at this stage. Three of these studies concerned structured, manual based, parent training interventions delivered to groups of parents (Buono and Citta, 2007; Butter, 2007; Feldman and Werner, 2002). These interventions were of a very similar nature to those evaluated by the trials included in this review.

The other two studies concerned non-manual based, therapeutic interventions delivered individually which included a functional assessment and development of a behaviour modification programme, followed by training and supporting parents in the delivery of that programme. This sort of intervention was not represented in the trials included in this review. One study (Buono and Citta, 2007) investigated the delivery of such an intervention via video-conferencing and email. The other (Feldman and Werner, 2002) followed up a sample of families discharged within the previous five years from a community behaviour management service and compared this sample to a sample of waiting list families. This latter study also represented the only service evaluation identified by the searches which fulfilled the inclusion criteria.

The absence in this review of investigations into the effectiveness of interventions being delivered by actual services represents a significant gap in the evidence. The innovative approach being taken by the intervention studied by Buono and Citta (2007), in which parents are trained and supported via video conferencing and email is an interesting use of e-health technology and hopefully one which, in the future, will be subject to rigorous evaluation.

3.2.2 Research quality of included studies

The quality assessment tool for quantitative studies developed by the Effective Public Health Practice Project (EPHPP) was used to assess the quality of the included studies. This tool assesses research quality and quality of reporting. Full results of the quality assessments can be found in Appendix B. Table 3.2, below, provides a summary.

Table 3.2 Research quality: summary

Randomised controlled trials								
	Bagner and Eyberg (2007)	Brightman <i>et al.</i> (1982)	Chadwick <i>et al.</i> (2001)	McIntyre (2008a)	Plant and Sanders (2007)	Preito-Bayard and Baker (1986)	Roberts <i>et al.</i> (2006)	Sofronoff <i>et al.</i> (2004)
Global rating³	Moderate	Moderate	Weak	Moderate	Moderate	Moderate	Moderate	Moderate
Controlled trials								
	Gates <i>et al.</i> (2001)	Hornby and Singh (1984)	Hudson <i>et al.</i> (2003)	Quinn <i>et al.</i> (2007)	Sofronoff <i>et al.</i> (2002)			
Global rating	Weak	Weak	Weak	Moderate	Moderate			

None of the studies achieved a 'strong' rating using the EPHPP assessment tool. In the randomised controlled trials RCTs key areas of poor quality concerned selection bias, withdrawal and/or dropout rates, and the outcome measures used. Seven of the eight RCTs used self-selecting samples, the remainder used referrals to the intervention programme from professionals or self-referrals (Bagner and Eyberg, 2007). In terms of withdrawal and/or dropout, only two RCTs performed strongly against this indicator, with five RCTs did not reporting reasons for withdrawal of dropouts and/or reported withdrawal and or dropout rates of greater than 20 per cent. Half of the RCTs used at least one measure where information about their reliability was either not was not reported or did not exist.

Amongst the controlled trials, selection bias was also a common difficulty, with three out of five studies using self-selected samples. Similarly, three out of the five controlled trials did not report nor had high dropout rates (greater than 40 per cent).

The EPHPP tool also assesses quality of the data analysis and intervention integrity. In terms of data analysis, the majority of studies used (at least in part) appropriate statistical methods (n=11/13), though only four reported analysing the data on an intention to treat basis.

Consistency of treatment delivery was a relevant quality dimension in 11 of the included studies as they concerned structured, manual based interventions. Seven of these studies reported how intervention integrity was monitored, with five studies reporting protocol adherence rates. In all cases these were very high.

3.2.3 Research quality implications

There are implications arising from the quality of the studies included in the review. A key issue is the fact that the majority of studies (10/13) used self-selecting samples. This means that the samples will not be representative of all families with a disabled child with behaviour problems. Families participating in such research projects may be different to the rest of the target population with respect to a number of important dimensions including readiness to

³ Rating based on ratings for: selection bias, study design, management of confounding variables, blinding, data collection methods/measures, withdrawal and dropout rates.

address their child's behaviour, motivation, having the capacity to take on implementing a behaviour management programme with the child, and the severity of their child's behaviour problem. More generally, it is known that level of education and socio-economic status affect participation in research which, again, affects representativeness. This limits the conclusions that can be drawn from individual study findings and syntheses of the evidence.

3.3 The interventions

The studies included in the review were all researching the effectiveness of parent training interventions, see Table 3.3 (pp 17-20).

The 13 included studies concerned 11 different parent training interventions. (There were two effectiveness studies each of two of the interventions.)

Six of the interventions were pre-existing with a manual or curriculum. Two (Steps to Independence, Baker *et al.*, 1976, 1977, 1978; Parents as Teachers, UCLA Project for Developmental Disabilities, 1980) had been developed for use with children with learning difficulties. The other pre-existing interventions had been developed (or previously used) with parents of children without learning difficulties. Two of these interventions were delivered without modification, namely:

- Parent Plus (Sharry and Fitzpatrick, 1998); (n=1 included study: Quinn *et al.*, 2007);
- Parent-Child Interaction Therapy (Eyberg *et al.*, 2008); (n=1 included study: Bagner and Eyberg, 2007).

The other two pre-existing intervention had been modified for use with parents of children with learning difficulties:

- Incredible Years Parenting Training (Webster-Stratton, 2001) (with minor modifications, McIntyre, 2008b); (n=1 included study: McIntyre, 2008a)
- Triple P – Positive Parenting Program (Sanders, 1999) (with minor modifications: Stepping Stones Triple – P (Sanders *et al.*, 2003); (n=2 included studies: Plant and Sanders, 2007; Roberts *et al.*, 2006).

The remaining five interventions had been developed by the author of the included studies and had not been used previously. One intervention was the subject of two separate studies. All are described by the authors as being manual-based, or having a fixed curriculum, sometimes with associated resources (for example, information booklets).

3.3.1 The scope of the interventions

Four studies concerned training on behaviour management skills (Chadwick, *et al.*, 2001; Gates *et al.*, 2001; Hornby and Singh, 1984; Quinn *et al.*, 2007). Two were concerned with training on behaviour management skills and nurturing the parent-child relationship (Bagner and Eyberg, 2007; McIntyre, 2008a). Five were studying interventions covering behaviour management skills and teaching skills (for example, teaching the child self-care and/or life skills) (Brightman *et al.*, 1982; Hudson *et al.*, 2003; Plant and Sanders, 2007; Prieto-Bayard and Baker, 1986; Roberts *et al.*, 2006). Finally, two studies investigated an intervention designed to improve parents' understanding of their child's condition as well as their behaviour management skills (Sofronoff and Farbotko, 2002; Sofronoff *et al.*, 2004).

The amount of information provided on the elements of the intervention varied considerably between papers. However, it would appear that all of the interventions sought to provide parents with a repertoire of behavioural behaviour management strategies as opposed to focusing on one or two behavioural strategies.

Most of the interventions included additional resources and/or activities for parents outside of intervention appointments or sessions. 'Homework' assignments (n=10), sometimes supported by a 'workbook' (n=3) were reported to form part of the intervention. In addition, reading material, in the form of manual/booklets or training presentation handouts, were a common feature of the interventions.

Table 3.3 The interventions under investigation

Author and year	Intervention	Description of behavioural approach
Intervention on parents' behaviour management skills only		
Chadwick <i>et al.</i> (2001)	<p>Training parents on the elements and techniques of behavioural analysis and behaviour management, and assisting parents in setting up focussed behaviour therapy programmes.</p> <p>Homework assignments used to reinforce learning and apply newly learnt skills.</p> <p>Parents given handouts of material covered in the training.</p>	<p>Sessions covered: behavioural analysis, principles of behaviour modification, setting-up focused behaviour therapy programmes and addressing obstacles to implementing the programme.</p>
Gates <i>et al.</i> (2001)	<p>The research compared training parents in behaviour modification with training parents in 'gentle teaching'.</p> <p>'The content of the behaviour modification workshops focussed on both the teaching and discussion of strategies to manage difficult behaviours that parents identify as problematic' (p.89).</p>	<p>'A package of interventions based on learning theory that emphasises contingent reinforcement' (p.88)</p>
Hornby and Singh (1984)	<p>Parent training in behavioural principles and application of principles to specific problems.</p> <p>Homework assignments used to reinforce learning and apply newly learnt skills.</p> <p>Parents given handouts of material covered in the training.</p>	<p>Lectures covered: contingent reinforcement of appropriate behaviour; decreasing inappropriate behaviours using extinction, time-out, punishment, over-correction, satiation and reinforcement of incompatible behaviour; increasing appropriate behaviour using: stimulus control, negative reinforcement, and contingency contracts; developing new skills: modelling, shaping and backward training.</p>
Quinn <i>et al.</i> (2007)	<p>The <i>Parent Plus</i> programme. A 'behavioural parent training programme' developed for use in an Irish context but modelled on US programmes (for example, Webster Stratton). Purpose is to 'help parents manage and solve discipline problems'.</p> <p>Parents given handouts of material covered in the training.</p>	<p>The programme uses a 'broadly cognitive behavioural model' but is also 'solution-focused, drawing on parents' strengths and expertise'.</p> <p>Topics covered include: 'parental attention to change behaviour, play and special time, encouragement and praise, using reward systems effectively, setting rules and helping children keep them, using active ignoring, using time-out and other sanctions and solution-building with children'. (p.346)</p>

Author and year	Intervention	Description of behavioural approach
Intervention on parents; behaviour management skills and parent-child relationship		
Bagner and Eyberg (2007)	<p><i>Parent-Child Interaction Therapy (PICT)</i>. A treatment manual provides session outlines.</p> <p>Two phases: Child-Directed Interaction Phase (enhancing the parent-child-relationship, increasing positive parenting and improving child social skills) and Parent Directed Interaction Phase (improving behaviour management skills). Coaching in interaction skills is maintained across the entire treatment period.</p> <p>Parents asked to practice newly learnt skills in 5–10 minute daily sessions.</p>	Sought to improve parents' ability to set limits and follow through consistently to reduce child non-compliance and disruptive behaviour.
McIntrye (2008a)	<p><i>The Incredible Years Parent Training (IYPT)</i> (Webster-Stratton ('with developmental disabilities adaptations')). The focus of the intervention is prevention or early intervention. Includes training parents in behaviour management and developing positive relationships with children, particularly through play and positive interactions.</p> <p>Homework assignments used to reinforce learning and apply newly learnt skills.</p>	Training in behaviour management included 'behaviour management, limit-setting, and reducing challenging behaviour' based on 'principles of operant theory and behaviour modification'.
Intervention on parents' behaviour management skills and teaching skills		
Brightman <i>et al.</i> (1982)	<p>The '<i>Steps to Independence</i>' programme. The programme consists of a fixed curriculum.</p> <p>Parents taught how to teach their child self-help-skills, toilet training, supporting speech and language development and how to manage behaviour problems.</p> <p>Homework assignments used to reinforce learning and apply newly learnt skills. Parents given a manual produced by the '<i>Steps to Independence</i>' programme.</p>	Parents trained in 'behavioural principles and behaviour modification'.
Hudson <i>et al.</i> (2003)	<p>Intervention used resources from the '<i>Signposts for Building Better Behaviour</i>' programme to train parents in teaching new skills their children and managing their child's behaviour problems.</p> <p>Parents given information booklets with videotape and workbook.</p>	Parents trained in managing behaviour using a functional assessment approach.

Author and year	Intervention	Description of behavioural approach
Plant and Sanders (2007)	<p><i>Stepping Stones Triple P (SSTP): adapted version of the Triple P-Positive Parenting Program (Sanders, 1999): delivered in its standard form (SSTP-S) (Sanders et al., 2003) and in its enhanced form (SSTP-E).</i></p> <p>A behavioural parent training programme which trains parents in skills to support their child's development, managing misbehaviour and generalising and maintaining those skills.</p> <p>The enhanced form included consists of six additional sessions which focused on assisting parents to cope with caring for a child with a developmental disability through improving coping skills and developing internal and external coping resources.</p> <p>Homework assignments used to reinforce learning and apply newly learnt skills. Parents given a workbook to enable parents to set and monitor goals for behaviour change.</p>	<p>Parents taught 11 strategies to manage misbehaviour (diversion, setting rules, directed discussion, planned ignoring, clear and direct instructions, communication, logical consequences, blocking, brief interruption, quiet time and time-out) and strategies to maintain and generalise parenting skills (plan ahead, set rules, select engaging activities, identify rewards and consequences, provide feedback to child).</p>
Prieto-Bayard and Baker (1986)	<p>Adapted version of 'Parents as Teachers': (UCLA Project for Developmental Disabilities, 1980). A group curriculum for parents of 'retarded children' which trains parents in teaching their children self-help skills and in behaviour problem management. Content adapted for Spanish speaking parents and those in low SES (for example, incentives for compliance with programme demands, video-modelling, direct supervision of teaching).</p> <p>Each week parents select one self-help skill and one behaviour problem to work on at home in between sessions. Parents given course reading materials.</p>	<p>Sessions cover 'behavioural techniques for assessment, self-help, play skill teaching and behaviour problem management'.</p>
Roberts et al. (2006)	<p><i>Stepping Stones Triple P programme.</i> This is a behavioural parent training programme which trains parents in skills to support their child's development, managing misbehaviour and generalising and maintaining those skills. Families with 'additional needs' took part in one or two <i>Enhanced Triple P modules</i>: Partner Support and Coping Skills which comprised four additional sessions.</p> <p>Homework assignments used to reinforce learning and apply newly learnt skills. A workbook was used to enable parents to set and monitor goals for behaviour change.</p>	<p>Parents taught 11 strategies to manage misbehaviour (diversion, setting rules, directed discussion, planned ignoring, clear and direct instructions, communication, logical consequences, blocking, brief interruption, quiet time and time-out) and strategies to maintain and generalise parenting skills (plan ahead, set rules, select engaging activities, identify rewards and consequences, provide feedback to child).</p>

Author and year	Intervention	Description of behavioural approach
Intervention on parents' behaviour management skills and understanding of their child's condition		
Sofronoff and Farbotko (2002)	<p>A manual-based intervention specifically designed for parents of children with Asperger Syndrome to 'increase parents' ability to manage and understand the child with Asperger Syndrome'. Intervention covered psycho-education; comic strip conversations; social stories; management of behaviour problems; management of rigid behaviours, routines and special interests; anxiety management.</p> <p>Parents given a manual for use during sessions and as a reference for home.</p>	<p>'Techniques were outlined for dealing with (problem behaviours) and then parents were asked to choose a particular problem behaviour and to outline a management strategy for that behaviour. The emphasis was on the parent's need to understand why the behaviour occurs'.</p>
Sofronoff <i>et al.</i> (2004)	<p>A manual-based intervention specifically designed for parents of children with Asperger Syndrome to 'increase parents' ability to manage and understand the child with Asperger Syndrome'. Intervention covered psycho-education; comic strip conversations; social stories; management of behaviour problems; management of rigid behaviours, routines and special interests; anxiety management.</p> <p>Parents given a manual for use during sessions and as a reference for home.</p>	<p>'Techniques were outlined for dealing with (problem behaviours) and then parents were asked to choose a particular problem behaviour and to outline a (behavioural) management strategy for that behaviour. The emphasis was on the parent's need to understand why the behaviour occurs'.</p>

3.3.2 The delivery of the interventions

Table 3.4 (pp 23-25) describes the interventions in terms of their mode of delivery, duration and setting. The delivery modes represented by the included studies were: individual work with parents, parent groups, one-off workshops and self-directed training.

Interventions on parents' behaviour management skills only

Two of the four interventions which focused only on parents' behaviour management skills were delivered through groups of parents (Hornby and Singh, 1984; Quinn *et al.*, 2007) with one also delivering the intervention individually (Chadwick *et al.*, 2001). All consisted of five to six weekly sessions (fortnightly if delivered individually). The fourth intervention (Gates *et al.*, 2001) consisted of a single, one day workshop. These interventions were delivered in a range of settings (community-based venues, clinics, home).

Interventions on parents' behaviour management skills and parent-child relationship

The two included studies which investigated the effectiveness of interventions on parents' behaviour management skills and parent-child relationship used different modes of delivery: individual and group. One of these interventions (McIntyre, 2008a) was a fixed duration (12 weekly sessions), the other (Bagner and Eyberg, 2007) continued until the desired outcomes had been achieved. It is not clear where these interventions were delivered.

Intervention on parents' behaviour management skills and teaching skills

There was also diversity in delivery of interventions which sought to improve parents' behaviour management skills and teaching skills. Two studies compared different delivery modes (group versus individual (Brightman *et al.*, 1982); group versus individual versus self-directed (Hudson *et al.*, 2003)). The other three were either delivered individually (n=2: Plant and Sanders, 2007; Roberts *et al.*, 2006) or to groups of parents (Prieto-Bayard and Baker, 1986). The duration of the interventions was between ten and 16 weeks. Three interventions were delivered weekly (Plant and Sanders, 2007; Prieto-Bayard and Baker, 1986; Roberts *et al.*, 2006), one was delivered fortnightly (Hudson *et al.*, 2003) and the other began with weekly sessions which then moved to fortnightly sessions towards the end of the treatment period (Brightman *et al.*, 1982). These interventions were also delivered in a range of settings (community-based venues, clinics, home).

Intervention on parents' behaviour management skills and understanding of child's condition

Finally, two studies studied the effectiveness of an intervention specifically developed for parents of children newly diagnosed with Asperger Syndrome (Sofronoff and Farbotko, 2002; Sofronoff *et al.*, 2004). This intervention sought to both improve parents' behaviour management skills and also their understanding of their child's condition. The intervention was delivered either as a single day workshop or in the form of six individual sessions over a period of six weeks. Both the workshop and individual sessions were delivered at a university clinic.

3.3.3 Overview of the nature of the interventions

There is quite a lot of variability between the interventions represented by the included studies in terms of mode and duration of delivery. This varies across the entire set of studies and within the different types of intervention (except for the two studies investigating an intervention which sought to improve parents' behaviour management skills and understanding of their child's condition, Sofronoff and Farbotko, 2002; Sofronoff *et al.*, 2004). This variability is a result of two key factors. First, where pre-existing manuals or curricula were being used the delivery mode would be pre-determined. The second factor (only operating where flexibility in delivery mode occurred) was the purpose of the research. Thus some studies were seeking to compare effectiveness across different delivery modes, others were not.

Table 3.4 Delivery of the intervention

Author and year	Intervention	Mode of delivery	How intervention delivered	Frequency	Duration	Period of intervention	Setting
Intervention on parents' behaviour management skills only							
Chadwick <i>et al.</i> (2001)	Parent training programme developed by authors.	Group or individual	Group: structured input with group discussion. Individual: functional analysis and development and implementation of management strategies.	Group: weekly; Individual: fortnightly sessions	Group: 1.5 hours; Individual: 1.5-2 hours	Group: five weeks sessions; Individual: 10-14 weeks	Group: local leisure centres; Individual: family home
Gates <i>et al.</i> (2001)	Parent training workshop developed by authors.	Single workshop	Workshop format including teaching and group discussion.	One-off	Day	One day	Not stated
Hornby and Singh (1984)	Parent training programme developed by authors.	Group	Combination of lecture, role play, problem-solving tasks and group discussion.	Weekly	Two hours	Six weeks	Special school
Quinn <i>et al.</i> (2007)	<i>Parent Plus</i>	Group	Teaching based on video-vignettes with sessions also incorporating group discussion, role play and skills rehearsal. Handouts for parents.	Weekly	Two hours	Six sessions	Clinic
Intervention on parents' behaviour management skills and parent-child relationship							
Bagner and Eyberg (2007)	<i>Parent-Child Interaction Therapy</i> (PCIT)	Individual	Individual work by therapist with parent and child to enhance the parent-child relationship, increasing positive parenting and improving child social skills. All sessions also include observation of parent-child interaction followed by coaching delivered by therapist.	One week	Approximately one hour	Continues until desired outcomes for parenting skills and child behaviour achieved. Average=12 sessions.	Not clear

Author and year	Intervention	Mode of delivery	How intervention delivered	Frequency	Duration	Period of intervention	Setting
McIntrye (2008a)	<i>The Incredible Years Parent Training</i> (modified)	Group	Teaching, group discussions, role-play, video-vignettes, homework assignments.	Weekly	2.5 hours	12 weeks	Not stated
Intervention on parents' behaviour management skills and teaching skills							
Brightman <i>et al.</i> (1982)	The 'Steps to Independence' training curriculum.	Group or individual	Group: predominantly didactic approach alongside role play, small group problem-solving and 'co-consulting'. Video-taped material used to support training. Individual: child involved and therapist observes the parent teaching the child; provides videotaped feedback, suggestions on developing skills and modelling. Video-taped material used to support training.	Sessions 1-6 weekly; Sessions 7-9: bi-weekly	Group: two hours; Individual: one hour	Nine sessions, delivered over 12 weeks, plus a preliminary orientation session.	'Community-based centres'
Intervention on parents' behaviour management skills and teaching skills							
Hudson <i>et al.</i> (2003)	'Signposts'. Parent training programme developed by authors.	Group or individual or self-directed	Group: training delivered at a group meeting facilitated by a therapist. Video vignettes used to support input. Individual: training resources received via post at set intervals with follow-up telephone call from therapist. Video vignettes used to support input. Self-directed: resources received via post at set intervals. Video vignettes used to support input.	Fortnightly	Group: two hours; Individual: 20 minutes	12 weeks	Group: community venue; Individual: home.

Chapter 3 Results

Author and year	Intervention	Mode of delivery	How intervention delivered	Frequency	Duration	Period of intervention	Setting
Plant and Sanders (2007)	<i>Stepping Stones Triple P: standard (SSTP-S) and enhanced (SSTP-E)</i>	Individual	Training from therapist using modelling, role plays, and feedback.	Weekly	60-90 minutes	SSTP-S: ten weeks; SSTP-E: 16 weeks.	Mainly at clinic with two home sessions.
Prieto-Bayard and Baker (1986)	<i>Parents as Teachers</i>	Group	Presentations, video vignettes, group discussions. The children also present at half the meetings when therapists also modelled and supervised parents as they worked with their children.	Weekly	Two hours	Ten weeks	Community-setting venue
Roberts <i>et al.</i> (2006)	<i>Stepping Stones Triple P: standard (SSTP-S) and enhanced (SSTP-E)</i>	Individual	Training from therapist using modelling, role plays and feedback. Video vignettes used to support teaching.	Weekly	Clinic: two hours; Home: 40-60 minutes	SSTP-S: ten weeks; SSTP-E: 16 weeks.	Clinic and home
Intervention on parents' behaviour management skills and understanding of their child's condition							
Sofronoff and Farbotko (2002)	Parent training programme developed by authors.	Single workshop or individual	Group: teaching, group discussion, small group tasks. Individual: as above but discussion/tasks always specific to parents own child.	Group: single day workshop; Individual: weekly	Workshop: one day; Individual: sessions: one hour	Workshop: single day; Individual: six weeks	University clinic
Sofronoff <i>et al.</i> (2004)	Parent training programme developed by authors.	Single workshop or individual	Group: teaching, group discussion, small group tasks. Individual: as above but discussion/tasks always specific to parents own child.	Group: single day workshop; Individual: weekly	Workshop: one day; Individual: sessions: one hour	Workshop: single day; Individual: six weeks	University clinic

3.4 Overview of the studies

Table 3.5 (pp 29-30) summarises the studies included in this review. These are organised according to the four types of intervention described above.

3.4.1 Research design

The studies included regarding interventions on parents' behaviour management skills include an RCT (Chadwick *et al.*, 2001) and three controlled trials (Gates *et al.*, 2001; Hornby and Singh, 1984; Quinn *et al.*, 2007). The RCT had two treatment arms. Two of the controlled trials compared outcomes of the intervention with a no-intervention group (Hornby and Singh, 1984; Quinn *et al.*, 2007). The third controlled trial had a wait list control group and two treatment arms (one of which was non-behavioural approach to addresses problem behaviour (Gates *et al.*, 2001)). Both studies (Bagner and Eyberg, 2007; McIntyre, 2008a) of interventions on parents' behaviour management skills and parent child relationship used an RCT design. Included studies of interventions on parents' behaviour management skills and teaching skills include four RCTs, two with one treatment arm (Prieto-Bayard and Baker, 1986; Roberts *et al.*, 2006) and two with two treatment arms (Brightman *et al.*, 1982; Plant and Sanders, 2007). The fifth study (Hudson *et al.*, 2003) was a controlled trial with three treatment arms and no control group. Two studies (Sofronoff and Farbotko, 2002; Sofronoff *et al.*, 2004), an RCT and a controlled trial, looked at the effectiveness of interventions on parents' behaviour management skills and understanding of the child's condition. Conducted by the same research team, both had two treatment arms and a wait list control

3.4.2 Type of disability or impairment

Studies concerning the first three types of intervention were concerned with the effectiveness of the interventions for parents of children with learning difficulties. However, differences between studies in the level of detail reported about their samples means it is not possible to ascertain how similar or dissimilar the studies are either in terms of the level (or range) of learning difficulties.

The two studies of the intervention which sought to improve parents' behaviour management skills and understanding of their child's condition (Sofronoff and Farbotko, 2002; Sofronoff *et al.*, 2004) are different. Here the parents all had children aged six to 12 years recently diagnosed with Asperger Syndrome. Children with Asperger Syndrome do not generally have learning difficulties, instead their impairments lie in areas of social and emotional skills and understanding.

3.4.3 Severity of the behaviour problem

Studies varied as to whether the severity of the child's behaviour problems was used as an inclusion criteria or as a factor by which the sample was described. In only four of the 13 studies (Chadwick *et al.*, 2001; Plant and Sanders, 2007; Quinn *et al.*, 2007; Bagner and Eyberg, 2007) was an indicator of the severity or frequency of the child's problem behaviours used to select families to the study. In two studies, parent-report assessment tools were used. One study only selected children with a diagnosis of Oppositional Defiant Disorder, and another was concerned with children referred to a service for behaviour problem management (which can be taken to suggest some degree of severity).

3.4.4 Child's age

The studies covered children between the ages of two and 19 years old. Not all studies report age range: some only provide a mean age.

3.4.5 Country

Just two of the studies were carried out in the UK (Chadwick *et al.*, 2001; Gates *et al.*, 2001), and a further one in Ireland (Quinn *et al.*, 2007). All these were studies of interventions on parents' behaviour management skills only. The other study of this intervention type included

in the review was carried out in New Zealand (Hornby and Singh, 1984). Five studies (covering four interventions) were carried out in Australia and included investigations into interventions on parents' behaviour management skills and teaching skills (Hudson *et al.*, 2003; Plant and Sanders, 2007; Roberts *et al.*, 2006) and parents' behaviour management skills and understanding of the child's condition (Sofronoff and Farbotko, 2002; Sofronoff *et al.*, 2004). Four are US studies and these cover both the interventions included in the review on parents' behaviour management's skills and parent-child relationship (Bagner and Eyberg, 2007; McIntyre, 2008a), and two of the studies of interventions on parents' behaviour management skills and teaching skills (Brightman *et al.*, 1982; Prieto-Bayard and Baker, 1986).

3.4.6 Outcome measures used

Table C.1 (see Appendix C) details the outcome measures used by the intervention studies which, in the case of multi-faceted interventions, were pertinent to assessing the effectiveness of the behaviour management aspect of the intervention. All used child behaviour as an outcomes measure and, aside from one study (Sofronoff *et al.*, 2004), used at least one other measure. The second most common outcome measure was of parental stress or mental health which was used by seven studies. Six studies used a measure or assessment of parent-child interaction. Other outcome measures used include: parenting skills (n=3); parent knowledge of behaviour modification principles (n=3); extent to which parent is implementing these principles (n=3); parent attitude to child (n=1); parent sense of competence/self-efficacy (n=2); parenting hassles (n=1); child's impact on family life (n=1); family stress (n=1) and quality of the marital relationship (n=1). Eleven of the studies also used some sort of measure of consumer satisfaction.

Table 3.5 Overview of the studies

Author and year	Design	Child's age (years)	Recruitment/sampling	Disability/impairment	Type/severity of behaviour problem	Country
Intervention on parents' behaviour management skills only						
Chadwick <i>et al.</i> (2001)	RCT Mode1 versus Mode2 versus WLC	4-11 (Not pre-existing intervention)	Self-selection via special schools followed by screening (learning difficulty diagnosis and parent reported level of behaviour problems).	Formal diagnosis of severe learning disabilities.	Assessed as having one or more (major or minor) behavioural problems.	UK
Gates <i>et al.</i> (2001)	CT NonBM versus BM versus WLC	3-18 (Not pre-existing intervention)	Recruited from caseloads of Community Learning Difficulty Nurses and other professional and voluntary organisations.	Diagnosed as having learning disabilities.	Parents reported child had behavioural difficulties.	UK
Hornby and Singh (1984)	CT Int versus No Int	7-14 (Not pre-existing intervention)	Self-selection via a school.	IQ within the moderately retarded range.	Type or severity of behaviour problem not an inclusion criteria.	New Zealand
Quinn <i>et al.</i> (2007)	CT Int versus No Int	4-7	Consecutive referrals to four early intervention clinics for behaviour problem intervention.	Developmental disabilities.	'Significant behaviour problems'.	Ireland
Intervention on parents' behaviour management skills and parent child relationship						
Bagner and Eyberg (2007)	RCT Int versus WLC	3-6 (Not stated)	Referred by health professionals, teachers or self-referral, followed by screening (diagnosis of learning difficulties and behaviour problem).	Children had received a formal diagnosis of mild or moderate mental retardation.	Children had a diagnosis of Oppositional Defiant Disorder.	US
McIntyre (2008a)	RCT Int versus No Int	2-5 (Modified version of 0-3 years programme)	Self-selection via early intervention and pre-school services, followed by a screening (IQ).	Developmental functioning score within pre-set range.	Type or severity of behaviour problem not an inclusion criteria.	US
Intervention on parents' behaviour management skills and teaching skills						
Brightman <i>et al.</i> (1982)	RCT Mode1 versus Mode2 versus WLC	2-15	Self-selection via schools, services and local media.	Children were moderately to severely retarded.	Type or severity of behaviour problem not an inclusion criteria.	US

Author and year	Design	Child's age (years)	Recruitment/sampling	Disability/impairment	Type/severity of behaviour problem	Country
Hudson <i>et al.</i> (2003)	CT Mode1 versus Mode 2 versus Mode3	4.6-19.4 (Not pre-existing intervention)	Self-selection via schools and local media.	Children assessed as having intellectual disability.	Type or severity of behaviour problem not an inclusion criteria.	Australia
Plant and Sanders (2007)	RCT Mode1 versus Mode 2 versus Mode3	<6	Self-selection via early intervention services followed by screening (mos rating of behaviour problems).	Identified developmental disability or 'at risk' due to a diagnosed condition.	Mos rated child's behaviour in the elevated range on behaviour inventory.	Australia
Prieto-Bayard and Baker (1986)	RCT Int versus WLC	3.5-6	Self-selection via disability services.	One child 'mildly retarded', the remainder reported to be 'moderately to severely retarded'.	Type or severity of behaviour problem not an inclusion criteria.	US
Roberts <i>et al.</i> (2006)	RCT Int versus WLC	Mean: 4.95	Self-selection via disability services.	Mild developmental delays.	Type or severity of behaviour problem not reported an inclusion criteria.	Australia
Intervention on parents' behaviour management skills and understanding of their child's condition						
Sofronoff and Farbotko (2002)	CT Mode1 versus Mode 2 versus WLC	6-12.	Self-selection via clinic lists.	Diagnosed with Asperger Syndrome.	Type or severity of behaviour problem not an inclusion criteria.	Australia
Sofronoff <i>et al</i> (2004)	RCT Mode1 versus Mode 2 versus WLC	6-12	Self-selection via clinic lists.	Diagnosed with Asperger Syndrome.	Type or severity of behaviour problem not an inclusion criteria.	Australia

Key:

RCT = randomised controlled trial

CT = controlled trial

WLC = waiting list control

BM = behaviour modification

Int = intervention

Chapter 4 Findings on Intervention Outcomes

This chapter reports findings from the included studies on the outcomes of the interventions. Detailed reports of each study's results can be found in Table D.1 (Appendix D), tables summarising the findings are used here.

4.1 Interventions on behaviour management skills only

Four studies evaluated the effectiveness of interventions on parents' behaviour management skills: three controlled trials and one RCT. One of the studies (Quinn *et al.*, 2007) was investigating the effectiveness of a pre-existing parenting programme called *Parent Plus*. The research quality of three of these studies was assessed to be weak, and the fourth assessed as being of moderate research quality (Quinn *et al.*, 2007). One of the weak-rated studies (Hornby and Singh, 1984) had a very small sample (n=11). Three of the studies used self-selected samples whilst Quinn *et al.* used consecutive referrals to an early intervention service for behaviour problems. Three studies (Chadwick *et al.*, 2001; Hornby and Singh, 1984; Quinn *et al.*, 2007) used parent groups (5-6 sessions) as the delivery mode with one study (Chadwick *et al.*, 2001) comparing this to individual delivery mode (5-6 sessions). In Gates *et al.*'s (2001) study the delivery mode was a single day workshop. The four interventions were being delivered to different groups in terms of the child's age. One intervention included children age 3-18 years (Gates *et al.*, 2001), in others the age range was 7-14 years (Hornby and Singh, 1984); 4-11 years (Chadwick *et al.*, 2001) and 4-7 years (Quinn *et al.*, 2007). The findings from these studies are summarised in Table 4.1 (pp 34-37).

4.1.1 Child behaviour outcomes

All studies measured changes in child behaviour. Three used standardised, though different, measures. In addition, all used a child behaviour measure developed specifically for the study.

Chadwick *et al.*'s (2001) study compared group treatment versus individual treatment versus no treatment. They found no differences post-treatment or at six month follow-up between the groups on Disability Assessment Schedule (DAS) (Holmes *et al.*, 1982; Wing, 1989) scores. However, they did find clinically significant effects in terms of the magnitude of the reduction in the severity of the behaviour problems as measured by the DAS, for the individual treatment group compared to the other two groups. Chadwick *et al.* (2001) also developed a measure of parent reported change with respect to all the child's problem behaviours and to target problem behaviours (that is, problem behaviours identified and addressed on by the parent during the intervention). On this measure at post-treatment, no statistically significant improvements between groups were found in the frequency of occurrence of behaviour problems, or the number of behaviour problems posing greater management difficulties. However, at post-treatment, parents in the intervention groups were significantly more likely than control group parents to report a reduction in one or more problem behaviour, and also a reduction in the management difficulty posed by one or more problem behaviour. Parents receiving the individual treatment intervention also provided information about changes to target behaviours. There were statistically significant improvements in the number and severity of target behaviours at post-treatment compared to pre-treatment reported by parents. However, these improvements were not sustained at follow-up.

Neither Gates *et al.* (2001) or Hornby and Singh (1984) report statistically significant improvements in child behaviour scores among parents receiving the intervention compared

to the control group or, in Gates *et al.*'s (2001) study, parents receiving training in a non-behavioural approach to behaviour management.

Quinn *et al.* (2007) reports statistically significant improvements in child behaviour as assessed by the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) at post intervention among parents receiving the *Parent Plus* intervention compared to a waiting list control group. However, in terms of the clinical significance of this finding, a test of reliable improvement did not reveal significant differences in improvement between the intervention and control group. Looking just at intervention group scores, Quinn *et al.* did find statistically significant improvements in the total SDQ score and on the conduct problem sub-scale score, which were both sustained at ten month follow-up. These changes in the SDQ scores were found to be clinically significant. In addition to the SDQ, a tool to assess the child achieving parent set goals for behaviour change was developed for the study. On this measure statistically significant improvements were found in children achieving these targets from pre-treatment to post-treatment, and between post-treatment and follow-up. Quinn *et al.* also used Child Behaviour Checklist (Achenbach, 1991) as an outcome measure, here scores for the intervention and control groups did not differ at post-treatment.

4.1.2 Parental stress and mental health

Both Chadwick *et al.* (2001) and Quinn *et al.* (2007) used the Parenting Stress Index (PSI) as an outcome measure. Neither found significant differences in PSI scores between intervention and control groups, nor, in Chadwick's case, between treatment formats. Quinn *et al.* also used the General Health Questionnaire (GHQ) as a parent mental health outcome measure. Again, the intervention was not found to effect scores on this measure.

4.1.3 Knowledge and implementation of behaviour modification principles

Two studies assessed changes in knowledge and implementation of behaviour modification principles. Hornby and Singh (1984) report statistically significant improvements in parents' scores on a measure of parental knowledge of behaviour modification principles compared to parents who did not receive the intervention. Gates *et al.* (2001) found that parents who received training in behaviour modification principles were statistically more likely to report implementing behaviour management strategies based on behaviour modification principles after training compared to parents who had been trained in non-behavioural behaviour management strategies.

4.1.4 Other outcome measures

Quinn *et al.* (2007) used a number of other outcome measures including individual parent-centred goals, parent satisfaction and family stress. They report statistically significant improvements in *parenting satisfaction* from pre- to post-treatment among the intervention group compared to the control group, with this improvement being sustained at follow-up. In terms of *family stress*, no differences were found between the intervention group and control group at post-treatment on the Family Inventory of Life Events and Changes (McCubbin *et al.*, 1982). However, on the *parent and family problems scale* of the Questionnaire on Resources and Stress (Friedrich *et al.*, 1983), a statistically significant improvement in scores (indicating a reduction in sources of stress) was found for the intervention group but not the control group, with this improvement being sustained at ten month follow-up. Finally, ratings of the extent to which *individually set parental outcomes* of the intervention were achieved showed that statistically significant changes occurred for these outcomes, and that these changes were maintained at ten month follow-up.

Table 4.1 Outcomes of interventions on behaviour management skills only

Author and year	Design	Research quality	Sample size	Treatment completion rates	Outcomes ⁴
Intervention on parents' behaviour management skills only					
Chadwick <i>et al.</i> (2001)	RCT. Group treatment format (GTF) vs individual treatment format (ITF) vs no treatment control (NT). 6 month follow-up (T3).	Weak	GTF=16 ITF=24 NT=28	92%	<p>CHILD BEHAVIOUR Disability Assessment Schedule (DAS) (Holmes <i>et al.</i>, 1982; Wing 1989):</p> <p>Mean no. of DAS behaviour problems: GTF=ITF=NTC</p> <p>Posing severe management difficulties: GTF=ITF=NTC</p> <p>Frequency of occurrence: GTF=ITF=NTC</p> <p><i>Treatment effect⁵</i> Severity of behaviour problems: ITF>GTF=NTC Followup: ITF=GTF=NTC</p> <p>Parent reported change: all problem behaviours (developed for the study): No. beh. problems occurring more frequently: ITF=GTF=NT; Follow-up: ITF=GTF=NTC</p> <p>No, beh. probs. posing greater management difficulties: ITF=GTF=NT; Follow-up: ITF=GTF=NTC</p> <p>No. beh. probs. occurring less frequently: ITF<GTF=NTC Mean no. beh. probs. posing less of a management problem: ITF>GTF=NTC</p> <p>Parent reported change: target problem behaviours (developed for the study) (ITF only): Severity of problem posed by target behaviours: T1 > T2; T1=T3 Mean number of target behaviours posing a problem: T1 > T3; T1=T3</p> <p>PARENTAL STRESS</p>

⁴ All changes found were in a positive direction.⁵ Magnitude of the reduction in severity of behaviour problems.

Author and year	Design	Research quality	Sample size	Treatment completion rates	Outcomes ⁴
					Parenting stress index (Abidin, 1995): GTF=ITF=NTC Follow-up: GTF=ITF=NTC
Gates, Newell and Wray (2001)	Controlled trial. Gentle teaching (GT) vs behaviour modification training (BM) vs control group (CG). Used mean of post treatment scores at 3, 6 and 12 mos.	Weak	GT=41 BM=36 CG=26	n/a ⁶	CHILD BEHAVIOUR Problem and target scales (Marks et al., 1977) (severity of identified prob, beh's.): GT=BM=CG Behaviour checklist (designed for study): GT=BM=CG IMPLEMENTATION OF BEHAVIOUR MODIFICATION PRINCIPLES Parent reported implementation of skills: Overall implementation: BM>GT Implementing a strategy: BM>GT Identify reinforcers: BM>GT Identifying outcomes and targets: BM>GT.

⁶ Single day workshop.

Author and year	Design	Research quality	Sample size	Treatment completion rates	Outcomes ⁴
Hornby and Singh (1984)	Controlled trial. Treatment group (TG) vs control group (CG). No follow-up.	Weak	TG=7 CG=4	Unclear ⁷	<p>CHILD BEHAVIOUR Behaviour checklist (developed for study): TG=CG</p> <p>PARENTAL KNOWLEDGE OF BEHAVIOUR MODIFICATION PRINCIPLES Vignette test (Heifetz, 1977): TG>CG</p>
Quinn et al. (2007)	Controlled trial. Intervention (IG) vs Waiting list control (WLC). 10 mos follow-up (T3) (IG only)	Moderate	I=23 WLC=19	96%	<p>CHILD BEHAVIOUR Strengths and Difficulties Questionnaire (Goodman 1997): Total score: IG<WLC <i>Clinical significance:</i> reliable improvement rates⁸: IG=WLC Follow up: Total score: T1>T2=T3 (IG: clinical → non-clinical range); Conduct problem scale: T1>T2=T3.</p> <p>Child Behaviour Checklist (Achenbach, 1991): IG=WLC</p> <p>Child centred goal attainment: parent set targets: IG only (developed for study): T1<T2<T3</p> <p>PARENTAL STRESS/MENTAL HEALTH General Health Questionnaire 12 (Goldberg and Williams, 1988): IG=WLC</p> <p>Parental distress scale (Parenting stress index) (Abidin, 1995): IG=WLC</p>

⁷ Eighty-three per cent attendance across all sessions.

⁸ Reliable change index, Jacobson and Truax, 1991.

Author and year	Design	Research quality	Sample size	Treatment completion rates	Outcomes ⁴
					<p>PARENT SATISFACTION Kansas parental satisfaction scale (James et al., 1985) IG>WLC Follow-up: T1<T2=T3</p> <p>FAMILY STRESS Family Inventory of life events and changes (McCubbin et a., 1982): IG=WLC</p> <p>Parent and family problems scale of the Questionnaire on Resources and Stress (Friedrich et al., 1983): IG<WLC Follow-up: T1<T2=T3</p> <p>PARENT CENTRED GOAL ATTAINMENT (INDIVIDUALISED) Parent set targets (developed for study) T1<T2=T3</p>

4.2 Interventions on behaviour management skills and the parent-child relationship

Two included studies evaluated the effectiveness of interventions which seek to improve parents' behaviour management skills and the parent-child relationship. Both were randomised controlled trials evaluating of existing interventions – Parent Child Interaction Therapy (PCIT) (Bagner and Eyberg, 2007) and a modified version of the Incredible Years Parent Training programme (IYPT) (McIntyre, 2008a). PCIT is delivered individually and IYPT through parent groups. The quality of both the studies was assessed as moderate. The PCIT evaluation used a waiting list control group, and the IYPT study had a usual care control group. Neither study had a follow-up element. The evaluations involved children in a similar age range (PCIT: 3-6 years; IYPT: 2-5 years). Table 4.2 (pp 40-41) summarises the findings of these studies.

4.2.1 Child behaviour outcomes

Both studies used the Child Behaviour Checklist (CBCL) (Achenbach, 2000) to assess child behaviour outcomes. Both report statistically significant improvements in total scale scores on the CBCL from pre- to post treatment in the intervention groups which were not found in the control groups. In addition, the IYPT (McIntyre, 2008a) evaluation reports a similar effect for scores on the externalising sub-scale of the CBCL, but not the internalising sub-scale. In contrast, the PCIT evaluation (Bagner and Eyberg, 2007) found statistically significant improvements on the externalising subscale for the intervention group at post-treatment but not the control group. Both studies report these improvements in scores to be clinically significant.

The PCIT evaluation (Bagner and Eyberg, 2007) also used the Eyberg Child Behaviour Inventory (ECBI) (Eyberg and Pincus, 1999) to measure changes in problem behaviour. On this measure, statistically significant improvements in problem intensity scores (that is, the frequency at which the problem occurs) at post-treatment were found for the intervention group but not the control group, and this difference was confirmed by an intent to treat analysis. However, the study did not find that the intervention resulted in parents finding behaviours less problematic (as indicated by the problem scale of the ECBI).

4.2.2 Parent-child interaction

Both studies used observational data to explore changes in parent-child interaction. Bagner and Eyberg (2007) found a statistically significant increase in positive parent behaviour ('Do skills') during parent-child interactions at post-treatment in the intervention group but not the control group. No intervention effects were found for parents' 'Don't skills' or child compliance. McIntyre (2008a) report a significant decrease in negative or inappropriate parental behaviour among the intervention group at post-treatment compared to the control group. No intervention effect was found, however, for positive parent behaviour (child-directed praise).

4.2.3 Parental stress

Bagner and Eyberg (2007) used parental stress as another outcome, with the Parenting Stress Index (PSI) (Abidin, 1995) as their measure. Here they found that scores on the parental distress and parent-child dysfunctional interaction sub-scales did not differ between the intervention and control groups across time. However, on the difficult child subscale, significantly improved scores were found post-treatment among the intervention group compared to control group.

4.2.4 Child's impact on family life

McIntyre *et al.* (2008) used the Family Impact Questionnaire (Donenberg and Baker, 1993) to measure changes in the child's impact on family life. No significant intervention effects were found.

Table 4.2 Outcomes of interventions on behaviour management skills and the parent-child relationship

Author and year	Design	Research quality	Sample size	Treatment completion rates	Outcomes ⁹
Bagner and Eyberg (2007)	RCT. Immediate treat (IT) vs Waiting list control (WLC). No follow-up.	Moderate	IT=15 WLC=15	47%	<p>CHILD BEHAVIOUR Child Behaviour Checklist (Achenbach and Rescorla, 2000): Externalising scale: IT<WLC Total scale: IT<WLC</p> <p>Eyberg Child Behaviour Inventory (Eyberg and Pincus, 1999): ECBI Intensity scale: IT<WLC (confirmed by intent-to-treat analysis). ECBI Problem Scale: IT=WLC</p> <p><i>Clinical significance¹⁰</i> CBCL externalising :70% (IT) vs 17% (WL): ECBI Intensity: 50% (IT); 8% (WL).</p> <p>PARENT-CHILD INTERACTION Dyadic Parent-Child Interaction Coding system (incl. child compliance) Eyberg et al., 2004): “Do skills”: IT>WLC “Don’t skills”: IT=WLC Child compliance: IT=WLC</p> <p>PARENTAL STRESS Parenting Stress Index – Short form (Abidin, 1995): Parental distress: IT=WL Parent-Child Dysfunctional Interaction: IT=WL Difficult Child sub-scale: IT<WL</p>

⁹ All changes found were in a positive direction.¹⁰ Jacobson et al.’s (1999) Reliable Change Index.

Author and year	Design	Research quality	Sample size	Treatment completion rates	Outcomes ⁹
McIntyre (2008a)	RCT Intervention (IG) vs usual care control CG). No follow-up.	Moderate	I=21 C=23	Unclear ¹¹	<p>CHILD BEHAVIOUR Child Behaviour Checklist (ages 1.5-5 yrs) (Achenbach, 2000): Total problems: IG<CG; Internalising problems: IG<CG. Externalising behaviours: IG=CG. (Attendance significantly correlated with CBCL total problems change scores: better attendance was associated with decreases in children's problem behaviour.)</p> <p><i>Clinical significance:</i> No. children with stable scores¹²: IG<CG</p> <p>CHILD'S IMPACT ON FAMILY LIFE Family Impact Questionnaire –FIQ (Donenberg and Baker, 1993): Negative impact composite score: IG=CG Positive impact composite score: IG=CG</p> <p>PARENT-CHILD INTERACTION Parent-child interaction observation: (developed for the study): Parent inappropriate behaviour index: IG<CG Positive parent behaviour index: IG=CG Child directed praise: IG=CG</p> <p>CONSUMER SATISFACTION Consumer Satisfaction Questionnaire (Forehand and McMahon, 1981): Parents rated the program as somewhat to very useful. Parents who attended with someone else rated sessions more useful than those who went alone.</p>

¹¹ Average attendance rate reported as 88 per cent.¹² Scores not changing by five or more points.

4.3 Interventions on behaviour management and teaching skills

Five included studies evaluated the effectiveness of interventions which sought to improve parents' behavioural problem behaviour management skills and teaching skills (for example, self-care, life skills, supporting language and development). Three investigated pre-existing parent training programmes: *Steps to Independence Programme* (Brightman *et al.*, 1982); *Stepping Stones Triple P* (Roberts *et al.*, 2006; Plant and Sanders, 2007) and *Parents as Teachers* (Prieto-Bayard and Baker, 1986). The fourth intervention, *Signposts for Building Better Behaviour*, had been developed by the authors as part of the study (Hudson *et al.*, 2003). Two studies were concerned only with the effectiveness of the intervention, one in its standard form (Roberts *et al.*, 2006), and the other once it had been modified for use with a particular group of parents (low income, Spanish speaking) (Prieto-Bayard and Baker, 1986). All the others also investigated the effectiveness of the intervention but, in addition, tested whether effectiveness differed according to the mode of delivery (Brightman *et al.*, 1982; Hudson *et al.*, 2003; Plant and Sanders, 2007). All but one (Hudson *et al.*, 2003) of the studies was a randomised controlled trial. All the RCTs were assessed as being of moderate research quality, and the quality of the controlled trial was assessed as weak.

Three of the interventions (*Steps to Independence Programme*, *Parents as Teachers*, *Signposts for Building Better Behaviour*) were delivered to parents with a wide age range of children. The fourth intervention, *Stepping Stones Triple P*, was delivered only to young children (less than 6 years).

Table 4.3 (pp 47-51) summarises the findings regarding outcomes of the interventions reported by these studies.

4.3.1 Child behaviour

Looking first at the three studies which investigated 'all-age' interventions. All the studies report positive changes on at least one measure of child behaviour at post-treatment in the intervention group which were not found in the control group.

Brightman *et al.* (1982), using a behaviour problem checklist developed for the study, found statistically significant improvements in checklist scores from pre- to post-treatment for both intervention groups (individual sessions, parent group) which were not found in the waiting list control group. Hudson *et al.* (2003) used the child behaviour subscale of the Parenting Hassles Scale (Gavidia-Payne *et al.*, 1997) and found no significant changes in scores pre- and post-treatment for any of the study groups (group delivery, individual telephone support, self-directed or waiting list control). However, on the antisocial behaviour sub-scale of the Developmental Behaviour Checklist (Einfield and Tonge, 1989) significant improvements in scores from before treatment to follow-up were found in all the intervention groups but not the control group. This was not found for the disruptive behaviour sub-scale, however. Finally, Prieto-Bayard and Baker (1986) report a statistically significant improvement in intervention group scores at post-treatment on the child behaviour checklist developed for their study which was not found in the waiting list control sample. Neither the Brightman *et al.* (1982) study nor the Hudson *et al.* (2003) study report differences in effectiveness, in terms of improving child behaviour, between different delivery modes.

In terms of the intervention delivered only to young children, Roberts *et al.* (2006) and Plant and Sanders (2007) both investigated the effectiveness of *Stepping Stones Triple P* (SSTP-S) parent training programme. Plant and Sanders (2007) had two treatment arms – the standard programme (SSTP-S) and the enhanced programme (SSTP-E), which includes additional sessions on improving parental coping skills and resources. All parents in the intervention group in Roberts *et al.* (2006)'s study received SSTP-S with some families, at the clinician's judgement, also receiving additional sessions from the enhanced curriculum.

Both studies used the Developmental Behaviour Checklist (DBC) (Rinfield and Tonge, 1991) to investigate the effectiveness of the intervention in alleviating child behaviour problems. Roberts *et al.* (2006) report significant improvements in DBC scores among mothers in the intervention group which were not found among mothers in the control group. These improvements were found at post-treatment and at 6 month follow-up. Intention to treat analyses confirmed these significant effects which were also reported to be approaching clinical significance. In contrast, no significant differences in scores were found between fathers in the treatment and control groups. Plant and Sanders (2007) found that DBC scores improved significantly for the SSTP-S group only, with this improvement being maintained at follow-up. In terms of testing for clinical significance, significantly more children in both the intervention groups had reliably improved compared to children in the control group (with no difference found between parents receiving SSTP-S or SSTP-E). However, there were no significant differences in the number of children moving from clinical to normal range DBC scores between the two treatment arms and the control group.

Both studies also used an observational measure (Revised Family Observation Schedule (rFOS), Sanders *et al.*, 1996) to assess child behaviour in 'target' and 'generalisation' settings. Roberts *et al.* (2006) did not find the intervention changed levels of the child's appropriate behaviour or non-compliance as assessed by the rFOS, but statistically significant improvements were found in terms of oppositional behaviour in target settings among the intervention group but not the control group, with these improvements being maintained at six month follow-up and confirmed by intent to treat analysis. In generalisation settings, a different effect was found, with statistically significant improvements in non-compliance (but not oppositional behaviour) being observed in the intervention group but not the control group. This improvement was maintained at six month follow-up and confirmed by intent to treat analysis. Plant and Sanders (2007) also found the intervention significantly improved observed child behaviour between pre- and post treatment, further statistically significant improvements being found at follow-up. They did not find differences in rFOS scores between the SSTP-S and SSTP-E groups. Tests confirmed the intervention effects found by Plant and Sanders (2007) were clinically significant.

Plant and Sanders (2007) developed a further measure of child behaviour which focused on care-giving activities and had two sub-scales: difficult child behaviour and problematic care-giving tasks. On these scales, statistically significant improvements were found for children in both the SSTP-S and SSTP-E groups, but not the control group, with these improvements being maintained at follow-up. In addition, on the 'difficult child behaviour subscale', the SSTP-E group had significantly better scores at post-treatment and follow-up than the SSTP-S group.

4.3.2 Parenting stress and mental health

Among the 'all-age' interventions, Hudson *et al.* (2003) was the only study to look at the impact of the intervention on parental stress (as measured on the stress subscale of Lovibond and Lovibond's (1995) Depression, Anxiety and Stress Scale (DASS)) and the Parenting Hassles Scale (PHS), Gavidia-Payne *et al.*, 1997). They found that the intervention, in whatever delivery mode, had a significant effect on parents' scores on the DAS and PHS which were not found in the control group, and that these improvements were maintained at 4-6 month follow-up.

The two evaluations of SSTP (REFS) also used the DASS but found no effect of the intervention on parental stress apart from a clinically significant positive effect on mothers receiving the intervention in Roberts *et al.*'s (2006) study.

4.3.3 Parental knowledge and implementation of behaviour modification principles

Two of the 'all-age' intervention studies (Brightman *et al.*, 1982; Prieto-Bayard and Baker, 1986) used parental knowledge (as measured using Heifetz *et al.*'s (1981) Vignettes Test) and implementation of (ascertained using a structured interview) behaviour modification principles as outcome measures. Both found a statistically significant improvement in parental knowledge of behaviour modification principles among the intervention groups which was not found in the control groups. In addition, Brightman *et al.* (1982) found intervention delivery mode (group vs individual format) did not effect parental knowledge. Similarly, Brightman *et al.* (1982) found no differences in the extent to which behaviour modification principles were being implemented between parents who had received the group intervention compared to those who had received the individual intervention. Prieto-Bayard and Baker (1986) report a statistically significant improvement on the sophistication of behaviour management strategies employed by parents in the intervention group compared to the control group, but no statistically significant improvement in the extent to which behaviour modification strategies were being used. Looking at the intervention group only, the authors report statistically significant improvements in both the extent of use and sophistication of behaviour management strategies from pre- to post treatment, with these improvements being maintained to some extent at 6 month follow-up.

4.3.4 Parenting skills

The SSTP (Roberts *et al.*, 2006; Plant and Sanders, 2007) evaluations did not look specifically at changes in parental knowledge and implementation of behaviour modification principles, but instead used a generic measure of parenting skills (Parenting Scale, Arnold *et al.*, 1993) and an observational tool (rFOS (negative parent behaviour score), Sanders *et al.*, 1996) to explore the effect of the intervention on parenting behaviours.

Plant and Sanders (2007) report a statistically significant improvement in parenting skills as measured by the Parenting Scale within the intervention groups which was not found in the control group. Roberts *et al.* (2006) also found statistically significant improvements in parenting skills in the intervention group but not the control group. Specifically, statistically and clinically significant improvements were found in mothers' over-reactivity (though this effect was not confirmed by intent to treat analysis), and fathers' laxness and verbosity (confirmed by intent to treat analysis). In all instances, these improvements were maintained at six month follow-up. However, in terms of observational data on negative parent behaviour, neither study found significant intervention effects. In addition, Roberts *et al.* (2006) reports a statistically significant improvement in parental use of praise in target (but not generalisation) settings among the intervention group that was not found in the control group. This improvement was maintained at six month follow-up and confirmed by intent to treat analysis.

4.3.5 Parental sense of competence

Two studies (one looking at an 'all-age' intervention (Hudson *et al.*, 2003)), and one of the SSTP evaluations (Plant and Sanders, 2007)) used a measure of parental sense of competence as an outcome measure (Parenting Sense of Competence Scale (PSOC), Johnson and Mash, 1989; Gibaud-Wallston and Wandersman, 1978). Hudson *et al.* (2003) used the efficacy subscale only and found a statistically significant improvement in efficacy scores for the intervention group but not the control group which was maintained at 4-6 month follow-up. The mode of delivery of the intervention was not found to affect changes in parenting efficacy scores. Plant and Sanders (2007) used the PSOC total score and found statistically significant improvements in scores both intervention groups compared to the control group. There was, however, no statistical difference between the scores of parents in the SSTP-S group and those in the SSTP-E group. The improvements found in parental competence in the intervention groups were maintained at 12 month follow-up.

Table 4.3 Outcomes of interventions on behaviour management and teaching skills

Author and year	Design	Research quality	Sample size	Treatment completion rates	Outcomes ¹³
Brightman <i>et al.</i> (1982)	RCT. Individual treatment format (ITF) vs Group treatment format (GTF) vs Wait list control (WLC). 6 month follow up (T3) (ITF and GTF only)	Moderate	ITF=16 GTF=37 WLC=13	ITF=87% GTF=86%	<p>CHILD BEHAVIOUR Behaviour Problem Checklist (developed for the study): ITF=GTF<WLC</p> <p>PARENTAL KNOWLEDGE OF BEHAVIOUR MODIFICATION PRINCIPLES Behavioural Vignettes Test (Heifetz <i>et al.</i>, 1981): ITF=GTF>WLC</p> <p>IMPLEMENTATION OF BEHAVIOUR MODIFICATION PRINCIPLES Researcher rated interview at 6 month follow-up (developed for study): Extent of continued use of behaviour management: ITF=GTF Appropriateness of behavioural techniques employed ITF=GTF.</p>
Hudson <i>et al.</i> (2003)	Controlled trial. Group support (GS) vs telephone support (TS) vs self-directed (SD) vs wait list control (WLC) 4-6 month follow-up (GS, TS and SD only).	Weak	GS=46 TS=13 SD=29	57% ¹⁴	<p>CHILD BEHAVIOUR Parenting Hassles Scale (PHS, Gavidia-Payne <i>et al.</i>, 1997): child behaviour subscale: GS=TS=SD=WLC</p> <p>Developmental Behaviour Checklist (DBS, Einfield and Tonge, 1989): disruptive and anti-social subscales only: Follow-up (T3): Antisocial behaviour sub-scale: T1>T3 (GS=TS= SD). Follow-up (T3): Disruptive subscale: T1=T3 (GS=TS= SD).</p> <p>PARENTAL STRESS Depression Anxiety and Stress Scale (DASS, Lovibond and Lovibond, 1995): stress subscale only: GS=TS=SD<WLC Follow-up (GS, TS, SD only): changes in scores maintained</p>

¹³ All changes found were in a positive direction.¹⁴ The study does not report separate treatment and study completion rates.

Author and year	Design	Research quality	Sample size	Treatment completion rates	Outcomes ¹³
					<p>PARENTAL SENSE OF COMPETENCY Parenting Sense of Competence Scale (PSOC) (Johnson and Mash, 1989) efficacy subscale only: $GS=TS=SD>WLC$ Follow-up: changes in scores maintained</p> <p>PARENTING HASSLES Parenting Hassles Scale (PHS, Gavidia-Payne et al., 1997): parental needs subscale only: $GS=TS=SD<WLC$ Follow-up : changes in scores maintained</p>
Plant and Sanders (2007)	RCT SSTP-S vs SSTP-E vs Waiting list control (WLC). 12 month follow-up (SSTP-S and SSTP-E only)	Moderate	SSTP-S=24 SSTP-E=16 WLC=28	Unclear. SSTP-S: 40% 5 sessions; 60%; 4 or fewer sessions. SSTP-E: 22% 7 sessions; 96% >5 sessions	<p>CHILD BEHAVIOUR: Developmental Behaviour Checklist – Parent Version (DBC, Rinfield and Tonge, 1991): $SSTP-S < SSTP-E = WLC$ Follow-up (T3): T3=T2 <i>Clinical significance</i>¹⁵: i) RCI at post-intervention: significantly greater proportion of children in the SSTP-E and SSTP-S conditions behaviour had reliably improved when compared to the WL condition. NS between SSTP-S and SSTP-E. ii) Movement from clinical to normal range on DBC total score: ns between groups.</p> <p>Care-giving problem checklist (CPC): difficult child behaviour (developed for study): $SSTP-E < SSTP-S < WLC$ Follow-up (T3): T3=T2; SSTP-E < SSTP-S</p> <p>Care-giving problem checklist (CPC): problematic care-giving tasks (dev. for study): $SSTP-E = SSTP-S < WLC$ Follow-up (T3): T3=T2</p> <p>Revised Family Observation Schedule (Sanders et al., 1996): negative child behaviour composite score: $SSTP-E = SSTP-C < WLC$ Follow-up (T3): T3 < T2</p>

¹⁵ Used the *reliable change index* (RCI, Jacobson and Truax, 1991).

Author and year	Design	Research quality	Sample size	Treatment completion rates	Outcomes ¹³
Plant and Sanders (2007) (cont'd)					<p><i>Clinical significance</i>¹⁶ A greater proportion of children in SSTP-S and SSTP-E showed significant change in the FOS-NCB score compared to children in the WL condition. NS between SSTP-S and SSTP-E. Follow-up: 72% of children across the two intervention conditions had achieved 30% reduction in negative behaviour</p> <p>PARENTING SKILLS Parenting Scale (Arnold et al., 1993): SSTP-S>SSTP-E=WLC</p> <p>Revised Family Observation Schedule (Sanders et al., 1996): negative parent behaviour composite score: SSTP-S=SSTP-E=WLC Follow-up: T3=T2</p> <p>PARENTAL SENSE OF COMPETENCE Parenting Sense of Competence Scale (PSOC) (Gibaud-Wallston and Wandersman, 1978): SSTP-S=SSTP-E>WLC Follow-up: T3=T2</p> <p>PARENTAL STRESS/MENTAL HEALTH Depression, anxiety, and stress scales (DASS) (Lovibond and Lovibond, 1995). SSTP-E=SSTP-S=WLC Follow-up: T3=T2</p>

¹⁶ Thirty per cent reduction in score used as criteria for significant change (Webster-Stratton et al., 1989).

Author and year	Design	Research quality	Sample size	Treatment completion rates	Outcomes ¹³
Prieto-Bayard and Baker, 1986	RCT Intervention Group (IG) vs Waiting List Control (WLC) 6 month follow-up (T3) (IG only).	Moderate	I=9 WLC=11	78%	<p>CHILD BEHAVIOUR Child Behaviour Checklist (CBC) (developed for the study): IG<WLC</p> <p>PARENTAL KNOWLEDGE OF BEHAVIOUR MODIFICATION PRINCIPLES Verbal Behavioural Vignettes Test (Baker and Heifetz, 1976): IG>WLC</p> <p>IMPLEMENTATION OF BEHAVIOUR MODIFICATION PRINCIPLES Structured interview (developed for study): Extent of teaching and behaviour problem management: IG=WLC Sophistication of behaviour methods employed: IG>WLC Follow-up (T3): Extent of teaching and behaviour problem management: T2>T3>T1 Sophistication of behaviour methods employed T2>T3>T1.</p>
Roberts et al. (2006)	RCT. Intervention (IG) vs Wait List Control (WLC). 6 month follow-up (T3) (IG only)	Moderate	I=24 families; WLC=20 families.	67%	<p>CHILD BEHAVIOUR Developmental Behaviour Checklist Parent Version (Einfield and Tonge, 1992): <i>Mothers:</i> IG<WLC; T1>T2; T1>T3. (Both confirmed by intent to treat analysis). Reliable change¹⁷ :IG<WLC (approaching significance p<0.05¹⁸). <i>Fathers:</i> IG=WLC</p> <p>Family Observation Schedule – Revised III: (Sanders et al., 1996): <i>Target setting:</i> Non-compliance: IG=WLC Oppositional behaviour: IG<WLC; T1>T2; T1>T3. (Both confirmed by intent to treat analysis). Appropriate behaviour: IG=WLC <i>‘Generalisation’ setting:</i> Non-compliance: IG<WLC (confirmed by intent to treat analysis); T1>T2, T1>T3. Oppositional behaviour: IG=WLC Appropriate behaviour: IG=WLC</p>

¹⁷ A change score of 17 or more used to assess reliable change.

¹⁸ Authors using conservative p<0.01.

Author and year	Design	Research quality	Sample size	Treatment completion rates	Outcomes ¹³
Roberts et al. (2006) (cont'd)					<p>PARENTING Family Observation Schedule – Revised III: (Sanders et al., 1996): <i>Target setting</i> Negative behaviours: IG=WLC Positive antecedent behaviours: IG=WLC Social attention: IG=WLC Praise:: I>WLC; T1<T2, T1<T3 (both confirmed by intent to treat analysis) <i>'Generalisation' setting</i> Negative behaviours: IG=WLC Positive antecedent behaviours: IG=WLC Social attention: IG=WLC Praise IG=WLC</p> <p>Parenting Scale (Arnold et al., 1993): <i>Mothers</i> Laxness: I=WLC Over-reactivity: I<WLC (Not confirmed by intent to treat analysis) Verbosity: I=WLC <i>Clinical significance:</i> Reliable change¹⁹: Over-reactivity: I<WLC (maintained at T3) <i>Fathers</i> Laxness: I<WLC; T1<T2, T<T3 (Confirmed by intent to treat analysis) Over-reactivity: I=WLC Verbosity: I<WLC; T1<T2, T<T3 (Confirmed by intent to treat analysis) <i>Clinical significance:</i> Reliable change: Laxness: I<WLC (maintained at T3); verbosity: I>WLC; (maintained at T3)</p> <p>PARENTAL STRESS/MENTAL HEALTH Depression-anxiety-stress scale (Lovibond and Lovibond, 1995) Mothers: IG=WLC Fathers: IG=WLC <i>Clinical significance:</i> Nos. reporting reliable reductions (mothers only): I>WLC. (T2=T3)</p>

¹⁹ Used the Reliable Change Index (Jacobson and Truax, 1991).

4.4 Interventions on behaviour management skills and understanding of the condition

Two of the included studies were evaluations of an intervention designed for parents of primary school aged children recently diagnosed with Asperger's syndrome (Sofronoff and Farbotko, 2002; Sofronoff *et al.*, 2004). The purpose of the intervention is two-fold: to improve parents' understanding of Asperger's syndrome, and to improve their skills in managing problem behaviour. Both studies were comparing different modes of delivering the intervention (a single day workshop versus six individual weekly sessions) and also had a waiting list control group. One study was an RCT, the other a controlled trial; both were assessed to be of moderate research quality. Table 4.4 (p 53) provides an overview of findings on the outcomes of these interventions.

4.4.1 Child behaviour outcomes

Both studies used Eyberg's Child Behaviour Inventory (ECBI) (Eyberg and Pincus, 1999) to measure child behaviour outcomes. Sofronoff and Farbotko (2002) report statistically significant improvements in total score on the ECBI in the intervention groups compared to the control group, with these improvements being maintained at three month follow-up. There were no significant differences between different delivery modes. Sofronoff *et al.* (2004) also report statistically significant improvements in terms of the number of problem behaviours reported by parents in the intervention groups compared to the control group. These effects were maintained at three month follow-up and no differences were found between delivery modes. However, in terms of ECBI's measure of frequency of problem behaviours (intensity sub-scale), it was only parents in the individual treatment group where a statistically significant improvement was found at post-treatment, and this was also found at follow-up.

4.4.2 Parents' self-efficacy in managing Asperger's syndrome

Sofronoff and Farbutko (2002) developed a measure of parental self-efficacy in managing Asperger's syndrome which included managing problem behaviour. Statistically significant improvement in scores on this measure were found for the intervention groups which were not found in the control group. Further analysis revealed the source of this effect lay in significant changes in mothers' self-efficacy scores but not fathers' self-efficacy scores. (The authors also report that at pre-treatment mothers scores were lower than fathers' scores but at post-treatment mothers' scores were higher than fathers' scores.) No significant differences were found between delivery modes.

Table 4.4 Outcomes of interventions on behaviour management skills and understanding of the child's condition

Author and year	Design	Research quality	Sample size	Treatment completion rates	Outcomes ²⁰
Sofronoff and Farbotko, (2002)	<p>Controlled trial.</p> <p>Workshop (WTF) vs individual treatment format (ITF) vs waiting list control (WLC)</p> <p>3 month follow-up (T3) (W and I only) (WLC T2 scores carried forward to Time 3 in an intention to treat analysis)</p>	Moderate	<p>WTF=32 (17 mos; 16 fas);</p> <p>ITF=36 (18 mos, 18 fas);</p> <p>WLC=20 (10 mos; 10 fas)</p>	100%	<p>CHILD BEHAVIOUR Eyberg Child Behaviour Inventory (Eyberg and Pincus, 1999): T2: WTF=ITF<WLC Follow-up (T3): WTF=ITF<WLC</p> <p>PARENT SENSE OF COMPETENCE/SELF-EFFICACY 'Parental Efficacy in the management of Asperger Syndrome' (developed for project): WTF=ITF>WLC <i>Mothers:</i> sig. increase; <i>Fathers:</i> little change. (Mos scores started with lower scores but ended higher than fas).</p>
Sofronoff et al. (2004)	<p>RCT.</p> <p>Workshop (WTF) vs individual treatment format (ITF) vs waiting list control (WLC)</p> <p>3 month follow-up (T3).</p>	Moderate	<p>WTF=18;</p> <p>ITF=18</p> <p>WLC=</p>	Unclear	<p>CHILD BEHAVIOUR Eyberg Child Behaviour Inventory (Eyberg and Pincus, 1999): Number of problem behaviours: WTF=ITF<WLC Follow-up (T3): WTF=ITF<WLC Intensity of problem behaviours: ITF<GTF=WLC Follow-up (T3): ITF<GTF=WLC</p>

²⁰ All changes found were in a positive direction.

Chapter 5 Discussion

5.1 The evidence on effectiveness

Table 5.1 provides a summary of the findings from the included studies. Only outcomes measured in at least two studies are displayed in the table.

Overall, this table shows that in 11 of the 13 included studies at least one positive effect on child behaviour was found. Four studies used a measure of parental self-competence or self-efficacy and all report positive effects on this outcome. Three studies assessed parental knowledge of behaviour modification principles and all report positive changes in the intervention group(s) when tested post-intervention. Two studies explored parents' implementation of behavioural problem behaviour strategies. One study found significant improvements for the intervention group. The findings from the other study are less clear as this outcome was only compared between parents receiving behaviour modification or non-behaviour modification training. Here, parents who had received behaviour modification training were significantly more likely to be implementing behaviour modification principles compared to the other training group. Two studies measured changes in parenting skills and both report positive effects of the intervention on this outcome. Finally, two studies looked for changes in parent-child interaction as a result of an intervention. In both cases, the intervention resulted in improvements in one or more aspects of parent-child interaction. Two out of the six studies which used parental stress or mental health as a treatment outcome found the intervention significantly impacted on this outcome. This was the outcome area where findings across the included studies are most equivocal.

A key issue which needs to be considered when reviewing the findings of these studies is that most studies only used parents' reports of child behaviour or parenting as outcome measures. Parents undertaking these interventions, as well as learning about behavioural principles of managing difficult behaviour, are likely to improve their understanding of their child's behaviour, their child's condition and/or parenting *per se*. This change in understanding alone may affect how parents report their child's behaviour or their parenting. Collecting observational data, ideally by someone blind to the treatment arm, is one way to address this issue. Just two studies (Plant and Sanders, 2007; Roberts *et al.*, 2006) used observational data on child behaviour and parenting skills as well as parent-completed measures and, typically, observational data corroborated parent-completed measures. In addition, observational data collected by Bagner and Eyberg (2007) and McIntyre (2008a) on parent-child interaction can be taken to support parent-reported changes in child behaviour.

Table 5.1 Overview of significant effects for each intervention

	Intervention	Mode ²¹	Res. qual ²²	Child b'viour	Stress/ MH	Parenting skills	Self - efficacy /competence	Knowledge BM	Implement BM	Par.- chi. i'action
Chadwick <i>et al.</i> (2001)	Developed by authors	G / I	W	• ²³ Mode	X ²⁴					
Gates <i>et al.</i> (2001)	Developed by authors	WS	W	X						
Hornby and Singh (1984)	Developed by authors	G	W	X				•		
Quinn <i>et al.</i> (2007)	Parent Plus (not modified)	G	M	•	X		•			
Bagner and Eyberg (2007)	PCIT(not modified)	I	M	•	•					♦ ²⁵
McIntyre (2008a)	IYPT (modified)	G	M	•						♦
Brightman <i>et al.</i> (1982)	Steps to Ind'ence (for LD)	G / I	M	•-Mode ²⁶				• Mode	Mode ²⁷	
Hudson <i>et al.</i> (2003)	Developed by authors	G / I / SD	W	•-Mode	•-Mode		•-Mode			
Plant and Sanders (2007)	SSTP (for LD)	I S / E	M	• Mode ♦	X	• ◇	• Mode			
Prieto-Bayard and Baker (1986)	Parents as Teachers (for LD)	G	M	•				•	•	
Roberts <i>et al.</i> (2006)	SSTP (for LD)	I	M	•mos ²⁸ ♦	X	•mos/fas ²⁹ ♦				

²¹ G=group; I=individual; WS=single day workshop; SD=self-directed (information only; S=standard; E=enhanced.²² S=strong (not achieved by any included study); M=moderate; W=weak.²³ •=significant effect(s) for intervention found on parent-report outcome measure.²⁴ X=no significant effect(s) for intervention found on parent-report outcome measure.²⁵ ♦=significant effect(s) for intervention found on observational outcome measure; ◇= significant effect(s) for intervention not found on observational outcome measure.²⁶ Mode = significant effect for mode of delivery found; mode = mode of delivery did not differentially effect outcome.²⁷ Mode effect only reported as this outcome only measured in intervention groups.²⁸ The significant intervention effect found only for mothers.²⁹ Significant intervention effect for mother and fathers but specific effects different.

Chapter 5 Discussion

Sofronoff and Farbotko (2002)	Developed by authors	WS / I	M	• Mode			• Mode				
Sofronoff <i>et al.</i> (2004)	Developed by authors	WS / I	M	• Mode			• Mode				

Taken together, and bearing in mind the various weaknesses of study design and research quality, these findings suggest that interventions to improve parents' skills in managing problem behaviours using principles of behaviour modification appear to be a promising intervention approach. The evidence reviewed shows they can have a positive impact on child behaviour and parent outcomes for at some parents of children with learning difficulties.

The current state of the evidence about behavioural interventions for families with a disabled children with problem behaviours is not only limited by the quality of the evidence but also by the fact that the behaviour management interventions have usually been investigated within the context of wider interventions (for example, improving parents' teaching skills, parent-child interaction or parental understanding of the condition). These may, or may not, have an indirect impact on the effectiveness of the behaviour management aspect of the intervention. For this reason it is not possible to treat the included studies as a single group.

The included studies in this review were therefore grouped according to the overall focus of the intervention. The evidence is weakest and most equivocal with respect to interventions on behaviour management skills only. Quinn *et al.*'s (2007) study of a pre-existing parent training programme (*Parent Plus*) is the best quality study. Here the findings suggest *Parent Plus* looks promising as an intervention which would improve the behaviour management skills of, at least, some parents of children with learning difficulties. The fact that statistically significant changes in scores were found to be clinically significant supports this view. Chadwick *et al.*'s (2001) findings with respect to delivery mode, specifically that the individual treatment mode was associated with better child behaviour outcomes than group treatment mode are of interest (though it is impossible to gauge the extent of their significance).

Two included studies (Bagner and Eyberg, 2007; McIntyre, 2008a) concerned interventions which seek to improve the parent-child relationship and the parents' behaviour management skills. The studies investigated *Parent Child Interaction Therapy (PCIT)* and a modified version of the *Incredible Years Training Programme (IYPT)*. Both studies report significant positive intervention effects on child behaviour and parent-child interaction, with the effects on child behaviour reaching clinical significance in both studies. Both these studies were RCT's of moderate quality. However, high treatment drop rates not only compromise the strength of the data in the Bagner and Eyberg (2007) study but also call into question the acceptability of the intervention and its suitability for all parents of young children with learning disabilities. The main weakness in the McIntyre (2008a) study is that the sample was self-selected which means the ability to generalise the findings is highly limited.

The set of interventions where there is most evidence concerns interventions on parents' behaviour management and teaching skills. The included studies here concern four interventions, three of which were pre-existing manual or curriculum based interventions (*Steps to Independence*, *Stepping Stones Triple P* and *Parents as Teachers*). All the interventions were developed specifically for use with children with learning disabilities or, in the case of *Stepping Stones Triple P (SSTP)* had previously been modified from a generic parent training intervention (*Triple P – Positive Parenting Programme*). Four of the studies were assessed to be of moderate research quality and one of weak quality. The common key area of design weakness was that samples were self-selected. The only area where hypothesised positive outcomes were not achieved was with respect to parental stress. Only two of the studies (both evaluating *SSTP*) report the clinical significance of statistically significant results. Here changes in scores on child behaviour measures were found to be clinically significant (Plant and Sanders, 2007) or approaching clinical significance (Roberts *et al.*, 2006). Roberts *et al.* (2006) also report clinically significant changes in parenting skills. This set of evidence suggests that, at least among some parents of children with learning difficulties, interventions which are developed specifically for parents of children with learning difficulties and which incorporate training on behaviour management and teaching skills can be effective in improving child behaviour and various parent outcomes.

A different and very specific intervention was the focus of the final set of included studies (Sofronoff and Farbotko, 2002; Sofronoff *et al.*, 2004). Here an intervention developed parents of primary school aged children recently diagnosed with Asperger's syndrome was tested for its effectiveness. Both the studies were of moderate research quality with, again, the fact that the samples were self-selected being the key area of design weakness. In addition, the authors do not report clinical significance. The findings, though promising, are therefore limited in terms of their generalisability and extent to which conclusions can be drawn about effectiveness.

Table 5.1 can also be examined for evidence about the effectiveness of different modes of delivering parent training interventions. Six studies compared two or more intervention delivery modes. In terms of child behaviour outcomes, three report an effect for delivery mode and three do not. A similar pattern is found with respect to two other outcomes: parental self-competence/self-efficacy and knowledge of behaviour modification principles. Hudson *et al.*'s (2003) finding that self-directed training (in this case, providing written and video information in a staged process) was found to be as effective in their study as group training or individual, telephone support is interesting. Understanding the differential impacts of receiving a group intervention versus an individual intervention is complicated because in all cases the delivery of the intervention in the two modes was quite different. Group training tends to be more didactic but has the known benefit (Solomon, Pistrang, and Barker, 2001) of working in and being supported by a group of parents. In contrast, delivering the intervention individually meant the focus can be much more on the specific behavioural issues faced by each parent. Thus, although intervention adherence rates are typically reported as being very high across the included studies, the extent to which the intervention was individualised will differ across different delivery modes. This means it is not possible, on the basis of the studies included in this review, to draw any conclusions about the impact of delivery mode on effectiveness.

Two of the included studies (Quinn *et al.*, 2007; Bagner and Eyberg, 2007) investigated the effectiveness of generic parent training interventions (*Parent Plus; Parent Child Interaction Therapy*) which had not been modified for use with parents of children with a learning disability. Both found evidence for their effectiveness in improving child behaviour and, in both cases, the improvements were of clinical significance. Taking account of both studies moderate research quality, these studies provide evidence which suggests that the content and structure of generic parent training interventions may be appropriate for using with some parents of some children with learning difficulties. However, no studies comparing generic and specific interventions were identified for inclusion in the review and, thus, there is no evidence on the *relative* effectiveness of generic compared to interventions modified or developed for parents of children with learning difficulties.

An important issue to draw from this synthesis of the research evidence concerns the effectiveness of these interventions for mothers and fathers. Just one study (Roberts *et al.*, 2006) explores mothers' and fathers' outcomes separately. The main reason for this is because in most studies mothers were the sole recipients of the intervention. What is interesting in the Roberts *et al.* (2006) study is the findings suggest that the intervention affected parents' parenting skills differently and, in addition, at pre-intervention mothers' levels of parenting self-efficacy are poorer than fathers. This, in itself may impact on the effectiveness of a parent training intervention.

5.2 Gaps in the evidence and implications for future research

More UK research on the effectiveness of behavioural approaches to managing behaviour problems among disabled children is needed. In order to improve the evidence base a

number of different issues need to be addressed. These concern both research design and research topic or research questions.

1. All studies should explore and report the clinical significance of the research findings. It should be remembered that evidence is needed on interventions which make a difference to families. Including a measure of the extent to which parent-set targets for behavioural change have been achieved is also important.
2. Studies should seek to incorporate within their designs some means of triangulating evidence with regard to changes in child behaviour and, ideally, parenting skills. This would help to overcome the limitation noted above concerning possible confounding effects of the intervention on parents' perceptions and understanding of their child's behaviour and hence their reports of behaviour and parenting.
3. The key difficulty with much of the research reviewed in this report is that the samples were self-selected. This imposes severe restrictions on the generalisability of the research findings. Future research should therefore look for ways by which the issue of selection bias can be addressed.
4. Mode of delivery is a key factor in costs of service delivery. Evidence to date on the impact on mode of delivery on effectiveness is unclear and studies are needed which will allow this issue to be investigated. More generally, where future research takes place in service settings, collecting data on costs should be part of the project.
5. An issue linked to mode of delivery and costs is that the interventions typically include a number of different ways both to train parents in behaviour modification principles and techniques, and to support them as they implement these skills. There is extremely limited evidence, however, on which elements of the interventions are necessary to achieving positive changes.
6. From the evidence reviewed, it would seem that generic parenting interventions can be effective in addressing behaviour problems for some families with a child with learning difficulties. What is not clear is whether they are more or less effective than interventions which are modified or developed specifically for children with learning difficulties. Research which explores this, and which also identifies ways in which generic parenting programmes need to be adapted to make them effective when used with families with a child with learning difficulties, is therefore required.
7. Most of the studies were not concerned with children with behavioural difficulties who had already been referred to a secondary or tertiary service for intervention. This may be an indication of a lack of services as opposed to severity of the behaviour problem. Alternatively, it may be that parents do not play an active role in modifying very severe behaviour problems, in which case such evaluations would have been excluded from this review. Thus this apparent gap in the evidence may be spurious. However, a clearer understanding of this issue would be helpful.
8. A number of studies highlight the difficulty of maintaining change in child behaviour and/or parenting strategies. Including a follow-up stage in research in this field is highly desirable. Research which, in addition, identifies the most effective ways to support or maintain improvements gained from an intervention would be extremely valuable.

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Appendix A

Search Strategy

Search strategies

The search strategies used to search the databases are described in detail below.

Cochrane Database of Systematic Reviews (CDSR), DARE and CENTRAL

```

#1 (infant* or baby or babies or toddler* or child* or preschool* or adolescen*):ti,ab,kw
#2 MeSH descriptor Disabled Persons explode all trees
#3 MeSH descriptor Child Development Disorders, Pervasive explode all trees
#4 MeSH descriptor Communication Disorders explode all trees
#5 MeSH descriptor Developmental Disabilities explode all trees
#6 MeSH descriptor Learning Disorders explode all trees
#7 MeSH descriptor Mental Retardation explode all trees
#8 MeSH descriptor Motor Skills Disorders explode all trees
#9 (#2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8)
#10 ((disabled or disability or disabilities or handicap* or retard*) near/3 (infant* or baby or babies or toddler* or child or children or preschool* or teenager* or adolescent* or pupil* or "school student*")):ti,ab
#11 (intellectual* impair* near/3 (infant* or baby or babies or toddler* or child or children or preschool* or teenager* or adolescent* or pupil* or "school student*")):ti,ab
#12 ((complex or special) near/3 needs near (infant* or baby or babies or toddler* or child or children or preschool* or teenager* or adolescent* or pupil* or "school student*")):ti,ab
#13 ("life limit*" or "life threaten*") near (infant* or baby or babies or toddler* or child or children or preschool* or teenager* or adolescent* or pupil* or "school student*")):ti,ab
#14 (learning near/2 disorder* near/3 (infant* or baby or babies or toddler* or child or children or preschool* or teenager* or adolescent* or pupil* or "school student*")):ti,ab
#15 (learning near/2 difficult* near/3 (infant* or baby or babies or toddler* or child or children or preschool* or teenager* or adolescent* or pupil* or "school student*")):ti,ab
#16 (development* near/5 (disorder* or delay*) near/5 (infant* or baby or babies or toddler* or child or children or preschool* or teenager* or adolescent* or pupil* or "school student*")):ti,ab
#17 (technolog* depend* near/3 (infant* or baby or babies or toddler* or child or children or preschool* or teenager* or adolescent* or pupil* or "school student*")):ti,ab
#18 ((cerebral palsy or down*2 syndrome) near/3 (infant* or baby or babies or toddler* or child or children or preschool* or teenager* or adolescent* or pupil* or "school student*")):ti,ab
#19 ((autist* or asperger* or blindness or deaf or deafness or adhd or attention deficit) near/3 (infant* or baby or babies or toddler* or child or children or preschool* or teenager* or adolescent* or pupil* or "school student*")):ti,ab
#20 (blind near/1 (infant* or baby or babies or toddler* or child or children or preschool* or teenager* or adolescent* or "school student*")):ti,ab
#21 (#10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20)
#22 (( #1 AND #9 ) OR #21)
#23 MeSH descriptor Behavior Therapy explode all trees
#24 MeSH descriptor Reinforcement (Psychology) explode all trees
#25 MeSH descriptor Relaxation Techniques explode all trees
#26 MeSH descriptor Relaxation explode all trees
#27 (antecedent or abc or punishment* or punishing or punitive or "early intervention*"):ti,ab
#28 "applied behav* analysis":ti,ab
#29 (negative near/3 (technique* or consequence* or reinforcement)):ti,ab
#30 (behav* near/3 (approach* or intervention* or program* or therap* or treatment* or skills or modification or prompt*)):ti,ab

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Appendix A Search Strategy

#31 (behav* near/3 (shaping or strateg* or technique* or support or observation or function* or training or management or managing)):ti,ab
#32 (biofeedback or chaining or “contingency management” or desensiti* or extinction or faded or fading or fct):ti,ab
#33 (communication near/3 intervention*):ti,ab
#34 (“functional analysis” or “functional communication training”):ti,ab
#35 (negative near/3 (technique* or consequence* or reinforcement)):ti,ab
#36 (“non aversive” or nonaversive or “omission training”):ti,ab
#37 (parent* near/3 (management or training or skill*)):ti,ab
#38 (“positive behav*” or “positive intervention*” or “positive programming” or “positive reinforcement”):ti,ab
#39 (“psychological methods” or reinforce* or relaxation or “response cost*” or seclusion):ti,ab
#40 (skills near/3 (training or teaching or program*)):ti,ab
#41 (“social learning”) near/3 (intervention* or therap* or treatment* or program* or approach* or technique* or strateg*):ti,ab
#42 (snoezelen or “social problem solving” or “time out*” or timeout*):ti,ab
#43 (#23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42)
#44 (#22 AND #43)
#45 MeSH descriptor Anxiety, Separation explode all trees
#46 MeSH descriptor Impulse Control Disorders explode all trees
#47 MeSH descriptor Personality Disorders explode all trees
#48 MeSH descriptor Impulsive Behavior explode all trees
#49 MeSH descriptor Aggression explode all trees
#50 MeSH descriptor Anger explode all trees
#51 MeSH descriptor Attention Deficit and Disruptive Behavior Disorders explode all trees
#52 MeSH descriptor Child Behavior Disorders explode all trees
#53 MeSH descriptor Elimination Disorders explode all trees
#54 MeSH descriptor Feeding and Eating Disorders of Childhood explode all trees
#55 MeSH descriptor Mutism explode all trees
#56 (noncompliant* or “non compliant*”):ti,ab
#57 ((challenging* or problem* or destructive or maladaptive or inappropriate or disorder*) near/3 (behav* or conduct)):ti,ab
#58 (anger or aggressi* or oppositional):ti,ab
#59 (#45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57 OR #58)
#60 (#44 AND #59)
#61 (disabled or disability or disabilities or handicap* or retard*):ti,ab
#62 “intellectual* impair*”:ti,ab
#63 ((complex or special) near/3 needs):ti,ab
#64 (“life limit*” or “life threaten*”):ti,ab
#65 (“learning disorder*” or “learning difficult*”):ti,ab
#66 (development* near/5 (disorder* or delay*)):ti,ab
#67 (technolog* near/2 depend*):ti,ab
#68 (“cerebral palsy” or “down* syndrome”):ti,ab
#69 (autist* or asperger* or blindness or deaf or deafness or adhd or “attention deficit”):ti,ab
#70 (blind) near/1 (people or person or persons or individual or individuals):ti,ab
#71 (#61 OR #62 OR #63 OR #64 OR #65 OR #66 OR #67 OR #68 OR #69 OR #70)
#72 (#43 AND #59 AND #71)
#73 (#72 AND NOT #60)
#74 (#72 AND NOT #60)
#75 review*:ti
#76 (#73 AND #75)

The results of set 60 (disabled children) and set 76 (disabled people) were downloaded.

MEDLINE, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1950 to Present>

- 1 adolescent/ or exp child/ or infant/ (2121808)
- 2 exp disabled persons/ (36004)
- 3 exp child development disorders, pervasive/ (14392)
- 4 exp communication disorders/ (43636)
- 5 developmental disabilities/ (10336)
- 6 exp learning disorders/ (15633)
- 7 mental retardation/ (42249)
- 8 motor skills disorder/ (1207)
- 9 ((disabled or disability or disabilities or handicap\$ or retard\$) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (14958)
- 10 (intellectual\$ impair\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (52)
- 11 ((complex or special) adj3 needs adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (1171)
- 12 (life adj (limit\$ or threaten\$) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (690)
- 13 (learning disorder\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (122)
- 14 (learning difficult\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (234)
- 15 (development\$ adj5 (disorder\$ or delay\$) adj5 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (3222)
- 16 (technolog\$ depend\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (89)
- 17 ((cerebral palsy or down\$2 syndrome) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (6702)
- 18 ((autist\$ or asperger\$ or blindness or deaf or deafness or adhd or attention deficit) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (9770)
- 19 (blind adj (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or high school student\$)).ti,ab. (459)
- 20 or/9-19 (35613)
- 21 (1 and (2 or 3 or 4 or 5 or 6 or 7 or 8)) or 20 (93759)
- 22 abc.ti,ab. (12033)
- 23 antecedent.ti,ab. (5249)
- 24 early intervention\$.ti,ab. (6373)
- 25 (punishment\$ or punishing or punitive).ti,ab. (4091)
- 26 Applied behav\$ analysis.ti,ab. (121)
- 27 (Aversive adj3 (consequence\$ or intervention\$ or technique\$ or therap\$ or treatment\$)).ti,ab. (272)
- 28 (Behav\$ adj3 (approach\$ or intervention\$ or program\$ or therap\$ or treatment\$ or Skills or modification or prompt\$)).ti,ab. (29353)
- 29 exp Behavior Therapy/ (37634)
- 30 (Behav\$ adj3 (shaping or strateg\$ or technique\$ or support or observation or function\$ or training or management or managing)).ti,ab. (19628)

Appendix A Search Strategy

31 biofeedback.ti,ab. (4050)
32 exp "Reinforcement (Psychology)"/ (30025)
33 chaining.ti,ab. (246)
34 (Communication adj3 intervention\$).ti,ab. (473)
35 contingency management.ti,ab. (386)
36 desensiti\$.ti,ab. (20498)
37 extinction.ti,ab. (12570)
38 (faded or fading).ti,ab. (2705)
39 fct.ti,ab. (232)
40 Functional analysis.ti,ab. (10488)
41 Functional communication training.ti,ab. (54)
42 (Negative adj3 (technique\$ or consequence\$ or reinforcement)).ti,ab. (4481)
43 Non aversive.ti,ab. (81)
44 nonaversive.ti,ab. (107)
45 Omission training.ti,ab. (11)
46 (Parent\$ adj3 (management or training or skill\$)).ti,ab. (1886)
47 Positive behav\$.ti,ab. (480)
48 Positive intervention\$.ti,ab. (90)
49 Positive programming.ti,ab. (6)
50 Positive reinforcement.ti,ab. (858)
51 Psychological methods.ti,ab. (263)
52 (Reinforcement or reinforcing or reinforcer\$).ti,ab. (24141)
53 Relaxation Techniques/ (5011)
54 Relaxation/ (1531)
55 relaxation.ti,ab. (66385)
56 Response cost\$.ti,ab. (177)
57 Seclusion.ti,ab. (661)
58 (skills adj3 (training or teaching or program\$)).ti,ab. (5732)
59 Snoezelen.ti,ab. (59)
60 (Social learning adj3 (intervention\$ or therap\$ or treatment\$ or program\$ or approach\$ or technique\$ or strateg\$)).ti,ab. (112)
61 Social problem solving.ti,ab. (252)
62 (Time out or time outs or timeout\$ or stimulat\$).ti,ab. (751029)
63 or/22-62 (981483)
64 21 and 63 (7496)
65 limit 64 to (english language and yr="1980 - 2008") (5685)
66 Case Reports/ (1417431)
67 (letter or note or editorial or comment).pt. (995913)
68 65 not (66 or 67) (4798)
69 anxiety, separation/ (1605)
70 exp impulse control disorders/ (3697)
71 exp personality disorders/ (26442)
72 exp impulsive behavior/ (6634)
73 aggression/ or exp anger/ (25236)
74 exp "attention deficit and disruptive behavior disorders"/ (14488)
75 child behavior disorders/ (15648)
76 exp elimination disorders/ (4427)
77 exp "feeding and eating disorders of childhood"/ (972)
78 mutism/ (759)
79 (noncomplian\$ or non complian\$).ti,ab. (7626)
80 ((challenging\$ or problem\$ or destructive or maladaptive or inappropriate) adj3 behav\$).ti,ab. (14723)
81 ((challenging\$ or problem\$ or destructive or maladaptive or inappropriate) adj3 conduct).ti,ab. (1252)
82 (anger or aggressi\$).ti,ab. (97360)

Appendix A Search Strategy

83 ((conduct or behav\$) adj3 disorder\$).ti,ab. (9990)
84 oppositional.ti,ab. (1386)
85 or/69-84 (194499)
86 68 and 85 (1511)
87 ((disabled or disability or disabilities or handicap\$ or retard\$) adj3 (people or person or persons or individual or individuals)).ti,ab. (10779)
88 (intellectual\$ impair\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (24)
89 ((complex or special) adj3 needs adj3 (people or person or persons or individual or individuals)).ti,ab. (277)
90 (life adj (limit\$ or threaten\$) adj3 (people or person or persons or individual or individuals)).ti,ab. (218)
91 (learning disorder\$ adj3 (people or person or persons or individual or individuals)).ti,ab.
(1)
92 (learning difficult\$ adj3 (people or person or persons or individual or individuals)).ti,ab.
(85)
93 (development\$ adj5 (disorder\$ or delay\$) adj5 (people or person or persons or individual or individuals)).ti,ab. (299)
94 (technolog\$ depend\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (6)
95 ((cerebral palsy or down\$2 syndrome) adj3 (people or person or persons or individual or individuals)).ti,ab. (1229)
96 ((autist\$ or asperger\$ or blindness or deaf or deafness or adhd or attention deficit) adj3 (people or person or persons or individual or individuals)).ti,ab. (1796)
97 (blind adj (people or person or persons or individual or individuals)).ti,ab. (565)
98 or/87-97 (14897)
99 review.ti. or review.pt. (1505874)
100 98 and 99 (1886)
101 limit 100 to (english language and yr="1980 - 2008") (1703)
102 101 and 63 and 85 (79)

Records from set 86 and set 103 were downloaded.

EMBASE, OvidSP, <1980 to 2008 Week 38>

1 exp adolescent/ or exp child/ or exp infant/ (832347)
2 exp autism/ or exp behavior disorder/ or exp learning disorder/ or exp mental deficiency/ or exp developmental disorder/ or exp disabled person/ or exp handicapped child/ (251930)
3 ((disabled or disability or disabilities or handicap\$ or retard\$) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (8390)
4 (intellectual\$ impair\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (43)
5 ((complex or special) adj3 needs adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab.
(701)
6 (life adj (limit\$ or threaten\$) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab.
(573)
7 (learning disorder\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (82)
8 (learning difficult\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (184)

Appendix A Search Strategy

9 (development\$ adj5 (disorder\$ or delay\$) adj5 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (2598)

10 (technolog\$ depend\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (31)

11 ((cerebral palsy or down\$2 syndrome) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (4920)

12 ((autist\$ or asperger\$ or blindness or deaf or deafness or adhd or attention deficit) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (6933)

13 (blind adj (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or high school student\$)).ti,ab. (325)

14 or/3-13 (23380)

15 (1 and 2) or 14 (86977)

16 abc.ti,ab. (9175)

17 antecedent.ti,ab. (3942)

18 early intervention\$.ti,ab. (5309)

19 (punishment\$ or punishing or punitive).ti,ab. (2615)

20 applied behav\$.analysis.ti,ab. (91)

21 (aversive adj3 (consequence\$ or intervention\$ or technique\$ or therap\$ or treatment\$)).ti,ab. (222)

22 (behav\$ adj3 (approach\$ or intervention\$ or program\$ or therap\$ or treatment\$ or Skills or modification or prompt\$)).ti,ab. (25530)

23 exp aversion therapy/ or exp behavior therapy/ or exp cognitive behavioral stress management/ or exp cognitive rehabilitation/ or exp cognitive therapy/ or exp relaxation training/ (28761)

24 (behav\$ adj3 (shaping or strateg\$ or technique\$ or support or observation or function\$ or training or management or managing)).ti,ab. (15141)

25 biofeedback.ti,ab. (3317)

26 exp reinforcement/ (9628)

27 chaining.ti,ab. (155)

28 (Communication adj3 intervention\$).ti,ab. (325)

29 contingency management.ti,ab. (316)

30 (desensiti\$ or extinction or faded or fading or fct).ti,ab. (27385)

31 functional analysis.ti,ab. (7901)

32 functional communication training.ti,ab. (19)

33 (Negative adj3 (technique\$ or consequence\$ or reinforcement)).ti,ab. (3257)

34 (non aversive or nonaversive).ti,ab. (157)

35 omission training.ti,ab. (11)

36 (parent\$ adj3 (management or training or skill\$)).ti,ab. (1377)

37 positive behav\$.ti,ab. (324)

38 positive intervention\$.ti,ab. (72)

39 positive programming.ti,ab. (5)

40 positive reinforcement.ti,ab. (534)

41 psychological methods.ti,ab. (147)

42 (reinforcement or reinforcing or reinforcer\$).ti,ab. (15898)

43 relaxation/ (6575)

44 relaxation.ti,ab. (50427)

45 response cost\$.ti,ab. (137)

46 Seclusion.ti,ab. (382)

47 (skills adj3 (training or teaching or program\$)).ti,ab. (4292)

48 Snoezelen.ti,ab. (33)

49 (social learning adj3 (intervention\$ or therap\$ or treatment\$ or program\$ or approach\$ or technique\$ or strateg\$)).ti,ab. (102)

Appendix A Search Strategy

50 social problem solving.ti,ab. (247)
51 (time out or time outs or timeout\$ or stimulat\$).ti,ab. (599007)
52 or/16-51 (767484)
53 exp attention deficit disorder/ or exp disruptive behavior/ or exp oppositional defiant disorder/ or exp eating disorder/ or exp impulse control disorder/ or exp psychomotor disorder/ (56641)
54 exp Separation Anxiety/ (1370)
55 exp Impulsiveness/ (4528)
56 aggression/ or exp anger/ (20643)
57 exp Incontinence/ (28884)
58 mutism/ (824)
59 (noncomplian\$ or non complian\$).ti,ab. (6496)
60 ((challenging\$ or problem\$ or destructive or maladaptive or inappropriate) adj3 behav\$).ti,ab. (11458)
61 ((challenging\$ or problem\$ or destructive or maladaptive or inappropriate) adj3 conduct).ti,ab. (911)
62 (anger or aggressi\$).ti,ab. (77094)
63 ((conduct or behav\$) adj3 disorder\$).ti,ab. (8362)
64 oppositional.ti,ab. (1135)
65 or/53-64 (189720)
66 ((disabled or disability or disabilities or handicap\$ or retard\$) adj3 (people or person or persons or individual or individuals)).ti,ab. (9150)
67 (intellectual\$ impair\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (22)
68 ((complex or special) adj3 needs adj3 (people or person or persons or individual or individuals)).ti,ab. (151)
69 (life adj (limit\$ or threaten\$) adj3 (people or person or persons or individual or individuals)).ti,ab. (159)
70 (learning disorder\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (2)
71 (learning difficult\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (77)
72 (development\$ adj5 (disorder\$ or delay\$) adj5 (people or person or persons or individual or individuals)).ti,ab. (260)
73 (technolog\$ depend\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (6)
74 ((cerebral palsy or down\$2 syndrome) adj3 (people or person or persons or individual or individuals)).ti,ab. (1030)
75 ((autist\$ or asperger\$ or blindness or deaf or deafness or adhd or attention deficit) adj3 (people or person or persons or individual or individuals)).ti,ab. (1372)
76 (blind adj (people or person or persons or individual or individuals)).ti,ab. (548)
77 or/66-76 (12420)
78 review.ti. or review.pt. (957656)
79 77 and 78 (2035)
80 15 and 52 and 65 (3510)
81 Case Report/ (1006507)
82 (letter or note or editorial or comment).pt. (877963)
83 80 not (81 or 82) (2957)
84 limit 83 to (english language and yr="1980 - 2008") (2668)
85 52 and 65 and 79 (90)
86 limit 85 to (english language and yr="1980 - 2008") (88)
87 86 not 84 (75)

Records from set 84 and set 87 were downloaded.

PsycINFO, OvidSP, <1806 to September Week 2 2008>

- 1 ("180" or "120" or "160" or "100" or "140" or "200").ag. (467558)
- 2 exp movement disorders/ or exp neuromuscular disorders/ or exp paralysis/ or paraplegia/ or poliomyelitis/ or quadriplegia/ or exp hearing disorders/ or exp vision disorders/ or chronic pain/ or exp head injuries/ or exp spinal cord injuries/ (47571)
- 3 exp communication disorders/ or exp congenital disorders/ or exp learning disorders/ or exp autism/ or exp brain damage/ or exp mental retardation/ or exp special needs/ or exp developmental disabilities/ or exp disabilities/ (134917)
- 4 1 and (2 or 3) (62854)
- 5 ((disabled or disability or disabilities or handicap\$ or retard\$) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (25267)
- 6 (intellectual\$ impair\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (50)
- 7 (life adj (limit\$ or threaten\$) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (136)
- 8 (learning disorder\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (206)
- 9 (learning difficult\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (610)
- 10 (development\$ adj5 (disorder\$ or delay\$) adj5 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (3213)
- 11 (technolog\$ depend\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (32)
- 12 ((cerebral palsy or down\$2 syndrome) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (2930)
- 13 ((autist\$ or asperger\$ or blindness or deaf or deafness or adhd or attention deficit) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (12830)
- 14 (blind adj (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or high school student\$)).ti,ab. (1107)
- 15 or/5-14 (44019)
- 16 4 or 15 (85555)
- 17 exp reinforcement/ (36237)
- 18 exp behavior analysis/ (7584)
- 19 stimulation/ or aversive stimulation/ (4883)
- 20 aversion/ or exp aversion conditioning/ or exp aversion therapy/ (4805)
- 21 exp behavior therapy/ (15635)
- 22 behavior modification/ (9998)
- 23 cognitive behavior therapy/ (4687)
- 24 parent training/ (4612)
- 25 biofeedback/ or biofeedback training/ (4335)
- 26 communication skills training/ (1728)
- 27 contingency management/ (1467)
- 28 "extinction (learning)"/ (5469)
- 29 functional analysis/ (526)
- 30 "fading (conditioning)"/ (167)
- 31 omission training/ (24)
- 32 progressive relaxation therapy/ or exp relaxation therapy/ (3402)
- 33 exp skill learning/ (3665)
- 34 exp social learning/ (8412)

Appendix A Search Strategy

35 social skills training/ (3388)
36 time out/ (223)
37 abc.ti,ab. (1058)
38 antecedent.ti,ab. (4213)
39 early intervention\$.ti,ab. (5411)
40 (punishment\$ or punishing or punitive).ti,ab. (13711)
41 Applied behav\$ analysis.ti,ab. (872)
42 (Aversive adj3 (consequence\$ or intervention\$ or technique\$ or therap\$ or treatment\$)).ti,ab. (650)
43 (Behav\$ adj3 (approach\$ or intervention\$ or program\$ or therap\$ or treatment\$ or Skills or modification or prompt\$)).ti,ab. (51855)
44 (Behav\$ adj3 (shaping or strateg\$ or technique\$ or support or observation or function\$ or training or management or managing)).ti,ab. (29618)
45 biofeedback.ti,ab. (4273)
46 chaining.ti,ab. (540)
47 (Communication adj3 intervention\$).ti,ab. (603)
48 contingency management.ti,ab. (852)
49 desensiti\$.ti,ab. (4644)
50 extinction.ti,ab. (12954)
51 (faded or fading).ti,ab. (1655)
52 fct.ti,ab. (77)
53 Functional analysis.ti,ab. (1609)
54 Functional communication training.ti,ab. (125)
55 (Negative adj3 (technique\$ or consequence\$ or reinforcement)).ti,ab. (5261)
56 Non aversive.ti,ab. (72)
57 nonaversive.ti,ab. (275)
58 Omission training.ti,ab. (83)
59 (Parent\$ adj3 (management or training or skill\$)).ti,ab. (4890)
60 Positive behav\$.ti,ab. (1559)
61 Positive intervention\$.ti,ab. (111)
62 Positive programming.ti,ab. (14)
63 Positive reinforcement.ti,ab. (2115)
64 Psychological methods.ti,ab. (715)
65 (Reinforcement or reinforcing or reinforcer\$).ti,ab. (41195)
66 relaxation.ti,ab. (10865)
67 Response cost\$.ti,ab. (502)
68 Seclusion.ti,ab. (697)
69 (skills adj3 (training or teaching or program\$)).ti,ab. (10526)
70 Snoezelen.ti,ab. (49)
71 (Social learning adj3 (intervention\$ or therap\$ or treatment\$ or program\$ or approach\$ or technique\$ or strateg\$)).ti,ab. (546)
72 Social problem solving.ti,ab. (1050)
73 (Time out or time outs or timeout\$ or stimulat\$).ti,ab. (73072)
74 or/17-73 (282634)
75 16 and 74 (13428)
76 limit 75 to (english language and yr="1980 - 2009") (10525)
77 clinical case study.md. (45481)
78 letter.dt. (8041)
79 editorial.dt. (13212)
80 or/77-79 (63735)
81 76 not 80 (9803)
82 exp anger/ or exp anxiety/ (47894)
83 anxiety disorders/ or separation anxiety/ (10947)
84 exp impulse control disorders/ or exp conduct disorder/ or exp impulsiveness/ (6903)
85 exp personality disorders/ (16788)

Appendix A Search Strategy

86 aggressive behavior/ (17249)
87 violence/ (16547)
88 aggressiveness/ (2908)
89 exp behavior problems/ (19096)
90 behavior disorders/ (7149)
91 exp eating disorders/ (17707)
92 (noncomplian\$ or non complian\$).ti,ab. (3148)
93 ((challenging\$ or problem\$ or destructive or maladaptive or inappropriate) adj3 behav\$).ti,ab. (31505)
94 ((challenging\$ or problem\$ or destructive or maladaptive or inappropriate) adj3 conduct).ti,ab. (2205)
95 (anger or aggressi\$).ti,ab. (63916)
96 ((conduct or behav\$) adj3 disorder\$).ti,ab. (15567)
97 oppositional.ti,ab. (2653)
98 exp mutism/ (638)
99 or/82-98 (212366)
100 81 and 99 (2190)
101 ((disabled or disability or disabilities or handicap\$ or retard\$) adj3 (people or person or persons or individual or individuals)).ti,ab. (17418)
102 (intellectual\$ impair\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (38)
103 ((complex or special) adj3 needs adj3 (people or person or persons or individual or individuals)).ti,ab. (253)
104 (life adj (limit\$ or threaten\$) adj3 (people or person or persons or individual or individuals)).ti,ab. (101)
105 (learning disorder\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (12)
106 (learning difficult\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (275)
107 (development\$ adj5 (disorder\$ or delay\$) adj5 (people or person or persons or individual or individuals)).ti,ab. (366)
108 (technolog\$ depend\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (0)
109 ((cerebral palsy or down\$2 syndrome) adj3 (people or person or persons or individual or individuals)).ti,ab. (899)
110 ((autist\$ or asperger\$ or blindness or deaf or deafness or adhd or attention deficit) adj3 (people or person or persons or individual or individuals)).ti,ab. (2548)
111 (blind adj (people or person or persons or individual or individuals)).ti,ab. (853)
112 or/101-111 (22165)
113 (2 or 3) and (people or person or persons or individual or individuals).ti,ab. (39203)
114 112 or 113 (46509)
115 from 100 keep 1-2000 (2000)
116 from 100 keep 2001-2190 (190)
117 114 and 74 and 99 (1544)
118 limit 117 to (english language and yr="1980 - 2009") (1422)
119 "literature review"/ (24189)
120 ("800" or "830" or "1200").md. (7526)
121 review.ti. (76863)
122 or/119-121 (101078)
123 118 and 122 (114)
124 from 123 keep 1-114 (114)

Records from set 100 and set 124 were downloaded.

CINAHL, OvidSP, <1982 to September Week 3 2008>

- 1 exp adolescent/ or exp child/ or exp infant/ (241149)
- 2 exp Mental Disorders Diagnosed in Childhood/ (20793)
- 3 exp Mental Retardation/ (7952)
- 4 exp Developmental Disabilities/ (2337)
- 5 exp Communicative Disorders/ (11110)
- 6 exp Child, Disabled/ (4146)
- 7 ((disabled or disability or disabilities or handicap\$ or retard\$) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (2899)
- 8 (intellectual\$ impair\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (19)
- 9 ((complex or special) adj3 needs adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (1077)
- 10 (life adj (limit\$ or threaten\$) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (171)
- 11 (learning disorder\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (17)
- 12 (learning difficult\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (65)
- 13 (development\$ adj5 (disorder\$ or delay\$) adj5 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (788)
- 14 (technolog\$ depend\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (89)
- 15 ((cerebral palsy or down\$2 syndrome) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (1692)
- 16 ((autist\$ or asperger\$ or blindness or deaf or deafness or adhd or attention deficit) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (1839)
- 17 (blind adj (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or high school student\$)).ti,ab. (67)
- 18 or/7-17 (8222)
- 19 (1 and (or/2-6)) or 18 (22758)
- 20 (abc or antecedent).ti,ab. (1410)
- 21 early intervention\$.ti,ab. (2362)
- 22 (punishment\$ or punishing or punitive).ti,ab. (759)
- 23 applied behav\$ analysis.ti,ab. (40)
- 24 (aversive adj3 (consequence\$ or intervention\$ or technique\$ or therap\$ or treatment\$)).ti,ab. (26)
- 25 (behav\$ adj3 (approach\$ or intervention\$ or program\$ or therap\$ or treatment\$ or Skills or modification or prompt\$)).ti,ab. (6633)
- 26 (behav\$ adj3 (shaping or strateg\$ or technique\$ or support or observation or function\$ or training or management or managing)).ti,ab. (3850)
- 27 (biofeedback or chaining).ti,ab. (788)
- 28 (Communication adj3 intervention\$).ti,ab. (296)
- 29 contingency management.ti,ab. (101)
- 30 (desensiti\$ or extinction or faded or fading or fct).ti,ab. (712)
- 31 functional analysis.ti,ab. (110)
- 32 functional communication training.ti,ab. (7)
- 33 (Negative adj3 (technique\$ or consequence\$ or reinforcement)).ti,ab. (871)

Appendix A Search Strategy

34 (non aversive or nonaversive).ti,ab. (15)
35 omission training.ti,ab. (0)
36 (parent\$ adj3 (management or training or skill\$)).ti,ab. (808)
37 positive behav\$.ti,ab. (205)
38 positive intervention\$.ti,ab. (32)
39 positive programming.ti,ab. (1)
40 positive reinforcement.ti,ab. (113)
41 psychological methods.ti,ab. (11)
42 (reinforcement or reinforcing or reinforcer\$).ti,ab. (1555)
43 relaxation.ti,ab. (2702)
44 response cost\$.ti,ab. (15)
45 seclusion.ti,ab. (342)
46 (skills adj3 (training or teaching or program\$)).ti,ab. (2143)
47 Snoezelen.ti,ab. (55)
48 (social learning adj3 (intervention\$ or therap\$ or treatment\$ or program\$ or approach\$ or technique\$ or strateg\$)).ti,ab. (29)
49 social problem solving.ti,ab. (82)
50 (time out or time outs or timeout\$ or stimulat\$).ti,ab. (14230)
51 exp Behavior Modification/ (11430)
52 exp "Reinforcement (Psychology)"/ (1263)
53 or/20-52 (44655)
54 exp attention deficit hyperactivity disorder/ or exp child behavior disorders/ (5053)
55 exp Separation Anxiety/ (198)
56 exp Eating Disorders/ (5004)
57 exp Impulse Control Disorders/ (677)
58 exp Social Behavior Disorders/ (26602)
59 exp Incontinence/ (5358)
60 exp mutism/ (77)
61 (noncomplian\$ or non complian\$).ti,ab. (1421)
62 ((challenging\$ or problem\$ or destructive or maladaptive or inappropriate) adj3 behav\$).ti,ab. (3720)
63 ((challenging\$ or problem\$ or destructive or maladaptive or inappropriate) adj3 conduct).ti,ab. (207)
64 (anger or aggressi\$).ti,ab. (9263)
65 ((conduct or behav\$) adj3 disorder\$).ti,ab. (1283)
66 oppositional.ti,ab. (196)
67 or/54-66 (53483)
68 ((disabled or disability or disabilities or handicap\$ or retard\$) adj3 (people or person or persons or individual or individuals)).ti,ab. (6314)
69 (intellectual\$ impair\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (17)
70 ((complex or special) adj3 needs adj3 (people or person or persons or individual or individuals)).ti,ab. (225)
71 (life adj (limit\$ or threaten\$) adj3 (people or person or persons or individual or individuals)).ti,ab. (88)
72 (learning disorder\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (1)
73 (learning difficult\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (183)
74 (development\$ adj5 (disorder\$ or delay\$) adj5 (people or person or persons or individual or individuals)).ti,ab. (63)
75 (technolog\$ depend\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (4)
76 ((cerebral palsy or down\$2 syndrome) adj3 (people or person or persons or individual or individuals)).ti,ab. (323)

77 ((autist\$ or asperger\$ or blindness or deaf or deafness or adhd or attention deficit) adj3 (people or person or persons or individual or individuals)).ti,ab. (500)
78 (blind adj (people or person or persons or individual or individuals)).ti,ab. (88)
79 or/68-78 (7639)
80 limit 79 to "review articles" (493)
81 review.ti. or review.pt. (85821)
82 (79 and 81) or 80 (550)
83 19 and 53 and 67 (880)
84 limit 83 to (anecdote or case study or editorial or letter) (126)
85 83 not 84 (754)
86 limit 85 to (english and yr="1980 - 2008") (744)
87 53 and 67 and 82 (17)
88 limit 87 to (english and yr="1980 - 2008") (17)
89 from 86 keep 1-744 (744)
90 from 88 keep 1-17 (17)

Records from set 86 and set 88 were downloaded.

SPECTR and C2-RIPE (Campbell Collaboration),
http://www.campbellcollaboration.org/campbell_library/index.php

The Campbell Library was searched using the following terms:

'Behav aggress challen' (any) in C2 domains 'education' and 'social justice'

SPECTR was searched at <http://geb9101.gse.upenn.edu/RIS/RISWEB.ISA>

Search terms (automatically truncated) :

disab or handicap or retard (in all indexed fields)

HMIC, OvidSP, <September 2008 >

1 (abc or antecedent).ti,ab. (120)
2 early intervention\$.ti,ab. (239)
3 (punishment\$ or punishing or punitive).ti,ab. (271)
4 applied behav\$ analysis.ti,ab. (3)
5 (aversive adj3 (consequence\$ or intervention\$ or technique\$ or therap\$ or treatment\$)).ti,ab. (7)
6 (behav\$ adj3 (approach\$ or intervention\$ or program\$ or therap\$ or treatment\$ or Skills or modification or prompt\$)).ti,ab. (1048)
7 (behav\$ adj3 (shaping or strateg\$ or technique\$ or support or observation or function\$ or training or management or managing)).ti,ab. (616)
8 (biofeedback or chaining).ti,ab. (7)
9 (Communication adj3 intervention\$).ti,ab. (45)
10 contingency management.ti,ab. (5)
11 (desensiti\$ or extinction or faded or fading or fct).ti,ab. (46)
12 functional analysis.ti,ab. (12)
13 functional communication training.ti,ab. (1)
14 (Negative adj3 (technique\$ or consequence\$ or reinforcement)).ti,ab. (132)
15 (non aversive or nonaversive).ti,ab. (0)
16 omission training.ti,ab. (1)
17 (parent\$ adj3 (management or training or skill\$)).ti,ab. (229)

Appendix A Search Strategy

18 positive behav\$.ti,ab. (15)
19 positive intervention\$.ti,ab. (15)
20 positive programming.ti,ab. (0)
21 positive reinforcement.ti,ab. (9)
22 psychological methods.ti,ab. (6)
23 (reinforcement or reinforcing or reinforcer\$).ti,ab. (254)
24 relaxation.ti,ab. (141)
25 response cost\$.ti,ab. (4)
26 seclusion.ti,ab. (58)
27 (skills adj3 (training or teaching or program\$)).ti,ab. (808)
28 Snoezelen.ti,ab. (12)
29 (social learning adj3 (intervention\$ or therap\$ or treatment\$ or program\$ or approach\$ or technique\$ or strateg\$)).ti,ab. (9)
30 social problem solving.ti,ab. (2)
31 (time out or time outs or timeout\$ or stimulat\$).ti,ab. (17495)
32 exp behavioural control/ (441)
33 exp psychotherapy/ (1962)
34 or/1-33 (22564)
35 exp behaviour disorders/ (6026)
36 exp impulse disorders/ (10)
37 exp aggressive behaviour/ or exp anger/ (182)
38 exp Incontinence/ (313)
39 exp mutism/ (2)
40 (noncomplian\$ or non complian\$).ti,ab. (170)
41 ((challenging\$ or problem\$ or destructive or maladaptive or inappropriate) adj3 behav\$).ti,ab. (810)
42 ((challenging\$ or problem\$ or destructive or maladaptive or inappropriate) adj3 conduct).ti,ab. (40)
43 (anger or aggressi\$).ti,ab. (694)
44 ((conduct or behav\$) adj3 disorder\$).ti,ab. (192)
45 oppositional.ti,ab. (16)
46 ((disabled or disability or disabilities or handicap\$ or retard\$) adj3 (people or person or persons or individual or individuals)).ti,ab. (5119)
47 (intellectual\$ impair\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (2)
48 ((complex or special) adj3 needs adj3 (people or person or persons or individual or individuals)).ti,ab. (191)
49 (life adj (limit\$ or threaten\$) adj3 (people or person or persons or individual or individuals)).ti,ab. (20)
50 (learning disorder\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (0)
51 (learning difficult\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (906)
52 (development\$ adj5 (disorder\$ or delay\$) adj5 (people or person or persons or individual or individuals)).ti,ab. (20)
53 (technolog\$ depend\$ adj3 (people or person or persons or individual or individuals)).ti,ab. (1)
54 ((cerebral palsy or down\$2 syndrome) adj3 (people or person or persons or individual or individuals)).ti,ab. (35)
55 ((autist\$ or asperger\$ or blindness or deaf or deafness or adhd or attention deficit) adj3 (people or person or persons or individual or individuals)).ti,ab. (248)
56 (blind adj (people or person or persons or individual or individuals)).ti,ab. (52)
57 or/46-56 (6284)
58 exp children/ (12926)
59 exp disabilities/ (27335)

60 ((disabled or disability or disabilities or handicap\$ or retard\$) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (1262)

61 (intellectual\$ impair\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (4)

62 ((complex or special) adj3 needs adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (280)

63 (life adj (limit\$ or threaten\$) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (45)

64 (learning disorder\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (0)

65 (learning difficult\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (94)

66 (development\$ adj5 (disorder\$ or delay\$) adj5 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (31)

67 (technolog\$ depend\$ adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (5)

68 ((cerebral palsy or down\$2 syndrome) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (70)

69 ((autist\$ or asperger\$ or blindness or deaf or deafness or adhd or attention deficit) adj3 (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or pupil\$ or high school student\$)).ti,ab. (180)

70 (blind adj (infant\$ or baby or babies or toddler\$ or child or children or preschool\$ or teenager\$ or adolescent\$ or high school student\$)).ti,ab. (20)

71 (58 and 59) or (or/60-70) (3603)

72 or/35-45 (7962)

73 71 and 34 and 72 (146)

74 57 and 34 and 72 (62)

75 review.mp. [mp=title, other title, abstract, heading words] (17540)

76 (74 and 75) not 73 (6)

Records from set 73 and set 76 were downloaded.

NNR archive, <https://portal.nihr.ac.uk/Pages/NRRArchiveSearch.aspx>.

This is a difficult interface to search. Searches have to be constructed with the most general concept first and then more specific concepts used to narrow down the retrieved set. There is no facility to record the search history or to export the results.

(searching in “all fields”):

(1) “child*” or “infant*” or “adolescent*” or “teenage*”

AND

(2) “disab*” or “disorder*” or “handicap*” or “retard*” or “impair*” or special or palsy or syndrome or “autis*” or “asperger*” or “blind*” or “deaf*” or adhd

AND

(3) “behav*” or “challeng*” or “disturb*” or “problem*” or “destruct*” or maladaptive or inappropriate or anger or “aggressi*”

Appendix A Search Strategy

This produced 143 records which were assessed onscreen. 13 potentially relevant records were downloaded.

CERUK, <http://www.ceruk.ac.uk/>

Search terms were entered one by one.

Title-word search for:

disab* or disord* or retard* or handicap* or impair* or adhd or autis* or cerebral or asperger* or blind* or deaf*

AND

psychotherap* or interv* or therap* or relax* or train*

ERIC, Dialog/Datastar

Two search approaches were used:

“A” search = (1) AND (2) AND (3) AND (4)

“B” search = ((2) AND (3) AND (4) AND review) NOT “A”

Searches were limited to English language and publications in the period 1980–2008

(1) CHILDREN

Adolescents.W..DE. OR Children#.W..DE. OR Young-Children#.DE. OR Early-Adolescents.DE. OR Late-Adolescents.DE. OR Secondary-School-Students#.DE. OR Special-Needs-Students.DE. OR Elementary-School-Students.DE.
(infant\$ OR baby OR babies OR toddler\$ OR child OR children OR preschool\$ OR adolescen\$ OR teenage\$).ti,ab.

(2) DISABILITIES

Attention-Deficit-Disorders.DE. OR Behavior-Disorders.DE. OR Communication-Disorders.DE. OR Congenital-Impairments#.DE. OR Developmental-Disabilities.DE. OR Language-Impairments#.DE. OR Learning-Disabilities.DE. OR Pervasive-Developmental-Disorders#.DE. OR Mental-Retardation#.DE. OR Multiple-Disabilities#.DE. OR Physical-Disabilities#.DE. OR Severe-Disabilities#.DE. OR Speech-Impairments#.DE. OR Visual-Impairments#.DE.

(disabled OR disability OR disabilities OR handicap\$ OR retard\$).ti,ab.

(intellectual\$ impair\$).ti,ab.

((complex OR special) ADJ needs).ti,ab.

(life ADJ (limit\$ OR threaten\$)).ti,ab.

(learning ADJ (disorder\$ OR disab\$)).ti,ab.

(technolog\$ ADJ depend\$).ti,ab.

(cerebral ADJ palsy OR down\$2 ADJ syndrome OR autis\$ OR asperger\$ OR blind OR blindness OR deaf OR deafness OR adhd OR attention ADJ deficit).ti,ab.

(3) BEHAVIOURAL PROBLEMS

Separation-Anxiety.W..DE. OR Attention-Deficit-Disorders#.W..DE. OR Behavior-Disorders#.W..DE. OR Antisocial-Behavior#.W..DE. OR Eating-Disorders#.W..DE.
((challenging\$ OR problem\$ OR destructive OR maladaptive OR inappropriate OR disorder\$) NEAR (behav\$ OR conduct)).TI,AB.

(anger OR aggressi\$ OR noncomplian\$ OR (non ADJ complian\$).TI,AB.

(mutism OR incontinen\$ OR eating ADJ disorder\$ OR antisocial ADJ behav\$).TI,AB.

(personality ADJ disorder\$ OR impulsive ADJ behav\$ OR attention ADJ deficit OR ADHD OR impuls\$ NEAR control OR separation ADJ anxiety).TI,AB.

(4) BEHAVIOURAL INTERVENTIONS

Behavior-Modification#.DE. OR Psychotherapy#.W..DE. OR Reinforcement#.W..DE.
(behav\$ ADJ therapy) OR (psychotherapy OR reinforcement).ti,ab.
(abc OR antecedent OR early ADJ intervention\$ OR punish\$ OR punitive).ti,ab.
(applied ADJ behav\$ OR biofeedback OR chaining OR extinction OR desensiti\$ OR faded OR fading).ti,ab.
(aversive NEAR (consequence\$ OR intervention\$ OR technique\$ OR therap\$ OR treatment\$)).ti,ab.
(behav\$ NEAR (approach\$ OR intervention\$ OR program\$ OR therap\$ OR treatment\$ OR Skills OR modification OR prompt\$)).ti,ab.
(behav\$ NEAR (shaping OR strateg\$ OR technique\$ OR support OR observation OR function\$ OR training OR manag\$)).ti,ab.
(communication NEAR intervention\$ OR contingency ADJ management).ti,ab.
(fct OR functional ADJ analysis OR functional ADJ communication).ti,ab.
(negative NEAR (technique\$ OR consequence\$ OR reinforcement)).ti,ab.
(non ADJ aversive OR nonaversive OR omission ADJ train\$).ti,ab.
(parent\$ NEAR (management OR training OR skill\$)).ti,ab.
(positive NEAR (behav\$ OR intervention\$ OR programming)).ti,ab.
(psychologic\$ ADJ method\$ OR reinforce\$ OR relaxation OR response ADJ cost\$ OR seclusion).ti,ab.
(skills NEAR (training OR teaching OR program\$)).ti,ab.
Snoezelen.ti,ab.
(social ADJ learning NEAR (intervention\$ OR therap\$ OR treatment\$ OR program\$ OR approach\$ OR technique\$ OR strateg\$)).ti,ab.
(social ADJ problem ADJ solving OR time ADJ out\$ OR timeout\$ OR stimulat\$).ti,ab.

Childdata

The search interface does not allow complex searches so a series of searches was undertaken in the title:

(disab*/disord*/retard*/handicap*/(intellectual &
impair*)/adhd/autis*/cerebral/asperger*/blind*/deaf*)
&
((behav* & therap*)/psychotherap*/interv*/therap*/relax*/train*

British Education Index, Dialog/Datastar, 1975 to date (BREI) and Australian Education Index (AUEI)

Two search approaches were used:

“A” search = (1) AND (2) AND (3) AND (4)
“B” search = ((2) AND (3) AND (4) AND review) NOT “A”

Records were not limited by year or language.

(1) CHILDREN

Adolescents.W..DE. OR Children#.W..DE. OR Young-Children#.DE. OR Early-Adolescents.DE. OR Late-Adolescents.DE.

infant\$ OR baby OR babies OR toddler\$ OR child OR children OR preschool\$ OR adolescen\$ OR teenage\$

(2) DISABILITIES

Disabilities#.W..DE.

(disabled OR disability OR disabilities OR handicap\$ OR retard\$).ti,ab.

(intellectual\$ NEAR impair\$).ti,ab.

((complex OR special) NEAR needs).ti,ab.

(life ADJ (limit\$ OR threaten\$)).ti,ab.

(learning ADJ (disorder\$ OR disab\$)).ti,ab.

(technolog\$ ADJ depend\$).ti,ab.

(cerebral ADJ palsy OR down\$2 ADJ syndrome OR autis\$ OR asperger\$ OR blind OR blindness OR deaf OR deafness OR adhd OR attention ADJ deficit).ti,ab.

(3) BEHAVIOURAL PROBLEMS

Separation-Anxiety.W..DE. OR Attention-Deficit-Disorders#.W..DE. OR Behaviour-

Disorders#.W..DE. OR Antisocial-Behaviour#.W..DE. OR Eating-Disorders#.W..DE.

((challenging\$ OR problem\$ OR destructive OR maladaptive OR inappropriate OR disorder\$) NEAR (behav\$ OR conduct)).TI,AB.

(anger OR aggressi\$ OR noncomplian\$ OR (non ADJ complian\$).TI,AB.

(mutism OR incontinen\$ OR eating ADJ disorder\$ OR antisocial ADJ behav\$).TI,AB.

(personality ADJ disorder\$ OR impulsive ADJ behav\$ OR attention ADJ deficit OR ADHD OR impuls\$ NEAR control OR separation ADJ anxiety).TI,AB.

(4) BEHAVIOURAL INTERVENTIONS

Behaviour-Modification#.DE. OR Psychotherapy#.W..DE. OR Reinforcement#.W..DE.

(behave\$ ADJ therapy) OR (psychotherapy OR reinforcement).ti,ab.

(abc OR antecedent OR early ADJ intervention\$ OR punish\$ OR punitive).ti,ab.

(applied ADJ behav\$ OR biofeedback OR chaining OR extinction OR desensiti\$ OR faded OR fading).ti,ab.

(aversive NEAR (consequence\$ OR intervention\$ OR technique\$ OR therap\$ OR treatment\$)).ti,ab.

(behav\$ NEAR (approach\$ OR intervention\$ OR program\$ OR therap\$ OR treatment\$ OR Skills OR modification OR prompt\$)).ti,ab.

(behav\$ NEAR (shaping OR strateg\$ OR technique\$ OR support OR observation OR function\$ OR training OR manag\$)).ti,ab.

(communication NEAR intervention\$ OR contingency ADJ management).ti,ab.

(fct OR functional ADJ analysis OR functional ADJ communication).ti,ab.

(negative NEAR (technique\$ OR consequence\$ OR reinforcement)).ti,ab.

(non ADJ aversive OR nonaversive OR omission ADJ train\$).ti,ab.

(parent\$ NEAR (management OR training OR skill\$)).ti,ab.

(positive NEAR (behav\$ OR intervention\$ OR programming)).ti,ab.

(psychologic\$ ADJ method\$ OR reinforce\$ OR relaxation OR response ADJ cost\$ OR seclusion).ti,ab.

(skills NEAR (training OR teaching OR program\$)).ti,ab.

Snoezelen.ti,ab.

(social ADJ learning NEAR (intervention\$ OR therap\$ OR treatment\$ OR program\$ OR approach\$ OR technique\$ OR strateg\$)).ti,ab.

(social ADJ problem ADJ solving OR time ADJ out\$ OR timeout\$ OR stimulat\$).ti,ab.

Appendix B

Quality Assessments

Table B.1 Quality of randomised controlled trials

	<i>Bagner and Eyberg</i>	<i>Brightman et al</i>	<i>Chadwick et al</i>	<i>McIntyre</i>	<i>Plant and Sanders</i>	<i>Preito-Bayard and Baker</i>	<i>Roberts et al</i>	<i>Sofronoff et al</i>
a) Selection bias								
Are the individuals selected to participate likely to be representative of the target population?	Somewhat likely	Not likely	Not likely	Not likely	Not likely	Not likely	Not likely	Not likely
What percentage of selected individuals agreed to participate?	Unclear	Unclear	47%	100%	Unclear	100%	94%	Unclear
<i>Rate this section</i>	<i>Moderate</i>	<i>Weak</i>	<i>Weak</i>	<i>Weak</i>	<i>Weak</i>	<i>Weak</i>	<i>Weak</i>	<i>Weak</i>
b) Study design								
Was the study described as randomised?	Yes	Yes ³⁰	Yes ³¹	Yes	Yes	Partial ³²	Yes	Yes
If yes, was the method described?	Yes	No	Yes	Yes	No	No	No	Yes
If yes, was the method appropriate?	Yes	---	Unclear	Yes	---	---	---	No
<i>Rate this section</i>	<i>Strong</i>	<i>Strong</i>	<i>Strong</i>	<i>Strong</i>	<i>Strong</i>	<i>Strong</i>	<i>Strong</i>	<i>Strong</i>
c) Confounders								
Were there important differences between groups prior to the intervention?	No	No	Yes	No	No	Yes	No	No
If yes, indicate the percentage of relevant confounders that were controlled in the design or analysis?	n/a	n/a	0%	n/a	n/a	100%	n/a	n/a
<i>Rate this section</i>	<i>Strong</i>	<i>Strong</i>	<i>Weak</i>	<i>Strong</i>	<i>Strong</i>	<i>Strong</i>	<i>Strong</i>	<i>Strong</i>

³⁰ Except for three control families who applied for parent training shortly after the programme began.³¹ Randomisation via borough: two boroughs were treatment groups, one borough control group.³² One parent switched condition.

Appendix B Quality Assessments

	<i>Bagner and Eyberg</i>	<i>Brightman et al</i>	<i>Chadwick et al</i>	<i>McIntyre</i>	<i>Plant and Sanders</i>	<i>Preito-Bayard and Baker</i>	<i>Roberts et al</i>	<i>Sofronoff et al</i>
d) Blinding								
Were the assessors blind to the participants' group assignments? ³³	Yes	n/a	Unclear ("independent evaluator")	Yes	Yes	Yes	Yes	n/a
Were the study participants unaware of the research question? ³⁴	---	---	---	---	---	---	---	---
<i>Rate this section</i>	Strong	---	Moderate	Strong	Strong	Strong	Strong	---
e) Data collection methods								
Were data collection tools shown to be valid?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Were data collection tools shown to be reliable?	Yes	Partial	Partial	Partial	Yes	Partial	Yes	Yes
<i>Rate this section</i>	Strong	Moderate	Moderate	Moderate	Strong	Moderate	Strong	Strong
f) Withdrawals and dropouts								
Were withdrawals and dropouts reported in terms of numbers and reasons per group?	Reported but reasons not given	Reported but reasons not given	Reported but reasons not given	Yes	Reported but reasons not given	Reported but reasons not given	Yes	No dropouts
Indicate the percentage of participants completing the study.	47%	87%	Post 94%; follow-up 75%	90%	Post 100%; follow-up 89% (int. gps only; control gp not follow-up)	89%	Post 67%; follow-up 56% (int. gp only; control gp not follow-up)	---
<i>Rate this section</i>	Weak	Moderate	Moderate	Strong	Moderate	Moderate	Moderate	Strong
Global rating³⁵	Moderate	Moderate	Weak	Moderate	Moderate	Moderate	Moderate	Moderate

³³ This question only completed if non-parent completed measures completed or observational data collected as part of the study.

³⁴ This question deemed inappropriate as parents responsible or partially responsible for delivering the intervention.

³⁵ **Strong** = 4 **strong** ratings with no **weak** ratings; **Moderate** = less than four **strong** ratings and one **weak** rating; **Weak** = 2 or more **weak** ratings).

Appendix B Quality Assessments

	<i>Bagner and Eyberg</i>	<i>Brightman et al</i>	<i>Chadwick et al</i>	<i>McIntyre</i>	<i>Plant and Sanders</i>	<i>Preito-Bayard and Baker</i>	<i>Roberts et al</i>	<i>Sofronoff et al</i>
g) Analyses								
Are the statistical methods appropriate for the study design?	Yes	Partial	Yes	Yes	Yes	No	Yes	Yes
Is the analysis on an intention to treat basis?	Yes	Unclear	No	Unclear	Yes (at post treatment, not follow-up)	No	Yes	Unclear

Intervention integrity								
No. of participants	15 int 15 control	37 int 1 16 int 2 13 control	16 int 1 24 int 2 28 control	21 int 23 control	26 int 1 24 int 2 24 control	9 int 11 control	24 int 20 control	18 int 1 18 int 2 15 control
Treatment completion rates		87%	Int 1: 22% 7 sessions; 96% >5 sessions Int 2: 40% 5 sessions; 40% 4 sessions; 20% 2-4 sessions	89%	100%	78%	67%	Unclear
Consistency of treatment delivery checked?	All sessions videotaped, 50% randomly selected and checked for integrity by two individuals (one independent of the study). 97% adherence (97% inter-observer agreement).	Unclear	Unclear	Protocol adherence checklist completed by therapist and an independent observer collected treatment integrity data during 33% of sessions. 100% adherence	Protocol adherence checklist completed by therapist and 33% sessions videotaped and analysed. 100% adherence	Unclear	Protocol adherence checklist completed by therapist. Programme content covered 67%-98%	Protocol adherence checklist completed by therapist used to indicate all components completed. Adherence rates not reported.

Table B.2 Quality of non-randomised controlled trials

	Gates <i>et al.</i>	Hornby and Singh	Hudson <i>et al.</i>	Quinn <i>et al.</i>	Sofronoff <i>et al.</i>
a) Selection bias					
Are the individuals selected to participate likely to be representative of the target population?	Not likely	Not likely	Not likely	Somewhat likely	Somewhat likely
What percentage of selected individuals agreed to participate?	Unclear	Unclear	Unclear	100%	Unclear
<i>Rate this section</i>	<i>Weak</i>	<i>Weak</i>	<i>Weak</i>	<i>Moderate</i>	<i>Moderate</i>
b) Study design					
Was the study described as randomised?	Controlled clinical trial				
If yes, was the method described?	n/a	n/a	n/a	n/a	n/a
If yes, was the method appropriate?	---	---	---	---	---
<i>Rate this section</i>	<i>Strong</i>	<i>Strong</i>	<i>Strong</i>	<i>Strong</i>	<i>Strong</i>
c) Confounders					
Were there important differences between groups prior to the intervention?	No	No	Unclear	No	Unclear
If yes, indicate the percentage of relevant confounders that were controlled in the design or analysis?	---	---	Unclear	---	Unclear
<i>Rate this section</i>	<i>Strong</i>	<i>Strong</i>	<i>Weak</i>	<i>Strong</i>	<i>Weak</i>

	Gates <i>et al.</i>	Hornby and Singh	Hudson <i>et al.</i>	Quinn <i>et al.</i>	Sofronoff <i>et al.</i>
d) Blinding					
Were the assessors blind to the participants' group assignments? ³⁶	n/a – parent report measures only	Unclear	n/a - parent report measures only	n/a – parent report measures only	n/a – parent
Were the study participants unaware of the research question? ³⁷	---	---	---	---	---
Rate this section					
e) Data collection methods					
Were data collection tools shown to be valid?	No	Partial (Vignette Test ³⁸ and home behaviour observations only)	Yes	Yes	Yes
Were data collection tools shown to be reliable?	No	Partial (Vignette Test and home behaviour observations only)	Yes	Yes	No ³⁹
Rate this section	Weak	Strong (partial)	Strong	Strong	Moderate
f) Withdrawals and dropouts					
Were withdrawals and dropouts reported in terms of numbers and reasons per group?	n/a – one day workshop	Reasons not given	Reasons not given	Reasons not given	Yes
Indicate the percentage of participants completing the study.	Unclear	54%	57% completed treatment and/or study at post treatment (figures)	92%	100% post-treatment 78% follow-up

³⁶ This question only completed if non-parent completed measures completed or observational data collected as part of the study.

³⁷ This question deemed inappropriate as parents responsible or partially responsible for delivering the intervention.

³⁸ Vignette Test (Heifetz, 1997) measure of parents' ability to apply behavioural principles and techniques.

³⁹ SDQ conduct problems subscale only had moderate reliability based on baseline data.

Appendix B Quality Assessments

	Gates <i>et al.</i>	Hornby and Singh	Hudson <i>et al.</i>	Quinn <i>et al.</i>	Sofronoff <i>et al.</i>
			combined) 28% follow-up (treatment groups only)		
Rate this section	Weak	Weak	Weak	Moderate	Moderate
Global rating ⁴⁰	Weak	Weak	Weak	Moderate	Moderate
g) Analyses					
Are the statistical methods appropriate for the study design?	Yes	No ⁴¹	Yes	Yes	Yes
Is the analysis on an intention to treat basis?	Yes	No	No	Unclear	Yes

⁴⁰ **Strong** = 4 **strong** ratings with no **weak** ratings; **Moderate** = less than four **strong** ratings and one **weak** rating; **Weak** = 2 or more **weak** ratings).

⁴¹ Parametric test used despite very small sample size.

Appendix B Quality Assessments

Intervention integrity					
No. of participants	intervention 1 = 41 intervention 2 = 36 control = 26	intervention = 7 control = 4	intervention 1 = 46 intervention 2 = 13 intervention 3 = 29 control = 27	intervention 1 = 22 control = 19	intervention 1 = 33 parents (17 children) intervention 2 = 36 parents (18 children) control = 20 parents (10 children)
Treatment completion rates	n/a – single day workshop	Unclear (attendance rates across the six sessions reported @ 83%)	57% completed treatment and/or study to post-measure completion.	96% completed five/six sessions	100%
Consistency of treatment delivery checked?	n/a	n/a	Completed adherence checklists. Adherence rates not reported.	Sample of audio-recordings of sessions rated for programme integrity (does not specify who did the rating). All rated as 100% adherence.	Not clear

Appendix C

Outcome Measures

Table C.1 Outcome measures⁺ used by included studies

Author and year	Child behaviour	Parent-child interaction	Parental stress/mental health	Parenting skills	Parenting hassles	Parent attitude to child	Parent sense of competence / self-efficacy	Parent knowledge of behaviour modification (BM) principles	Implementation of BM skills	Child's impact on family life	Family stress	Quality of marital relationship	Consumer satisfaction
Intervention on parents' behaviour management skills only													
Chadwick et al. (2001)	✓✓			✓									✓
Gates, B.; Newell, R. and Wray, J. (2001)	✓✓									✓			
Hornby and Singh (1984)	✓					✓		✓					✓
Quinn et al. (2007)	✓✓✓			✓✓							✓✓		✓
Intervention on parents' behaviour management skills and parent-child relationship													
Bagner and Eyberg (2007)	✓✓	✓	✓										✓
McIntyre (2008)	✓	✓								✓			✓
Intervention on parents' behaviour management skills and teaching skills													
Brightman et al. (1982)	✓							✓	✓				

Appendix C Outcome Measures

Author and year	Child behaviour	Parent-child interaction	Parental stress/mental health	Parenting skills	Parenting hassles	Parent attitude to child	Parent sense of competence / self-efficacy	Parent knowledge of behaviour modification (BM) principles	Implementation of BM skills	Child's impact on family life	Family stress	Quality of marital relationship	Consumer satisfaction
Hudson <i>et al.</i> (2003)	✓		✓		✓		✓						✓
McIntyre (2008)	✓	✓								✓			✓
Plant and Sanders (2007)	✓✓	✓	✓	✓			✓					✓	✓
Prieto-Bayard and Baker (1986)	✓							✓	✓				
Roberts <i>et al.</i> (2006)	✓	✓	✓	✓									✓
Intervention on parents' behaviour management skills and understanding of their child's condition													
Sofronoff and Farbotko (2002)	✓	✓	✓	✓									✓
Sofronoff <i>et al.</i> (2004)	✓												✓

⁺ Where intervention covered more than behaviour problems, only outcomes relevant to behaviour problem aspect of intervention reported.

Appendix D
Results of Studies

Table D.1 Results of studies

Author and year	Quantitative outcome measures and findings
Bagner and Eyberg (2007)	<p>Child Behaviour Checklist (1.5 – 5 yrs) (Achenbach and Rescorla, 2000) Externalising scale and the total scale mos in IT group reported sig fewer child behaviour problems at T2 compared to WL group.</p> <p><i>Externalising scale</i> IT (n=10): T1: mean=34.60 (sd 7.73); T2: mean=20.28. (sd 10.72); WL (n=12): T1: mean=36.25 (sd 6.25); T2: mean=30.69 (sd 8.56), $f(1,19)=8.56$, $p=0.009$</p> <p><i>Total scale</i> IT (n=10): T1: mean=89.70 (sd 29.45); T2: mean=51.90. (sd 27.87); WL (n=12): T1: mean=95.17 (sd 16.41); T2: mean=83.83 (sd 20.44), $f(1,19)=11.62$, $p=0.003$</p> <p>Dyadic Parent-Child Interaction Coding system (Eyberg et al., 2004) (Includes child compliance.) Children's compliance to maternal commands was significantly higher in the IT than the WL group at T2. IT (n=10): T1: mean=63.88 (sd 19.22); T2: mean=85.20 (sd 9.44); WL (n=11): T1: mean=68.89 (sd 19.71); T2: mean=59.72 (sd 25.68), $f(1,18)=9.68$, $p=0.006$</p> <p>Eyberg Child Behaviour Inventory (Eyberg and Pincus. 1999) Sig diffs on the ECBI intensity scale but not the Problem Scale.</p> <p><i>Intensity scale:</i> IT (n=10): T1: mean=156.40 (sd 34.30); T2: mean=100.63. (sd 26.22); WL (n=12): T1: mean=170.92 (sd 19.47); T2: mean=148.14 (sd 30.33), $f(1,19)=13.00$, $p=0.002$.</p> <p>Parenting Stress Index – Short form (Abidin, 1995) No sig diffs between IT and WL on Parental distress and Parent-Child Dysfunctional Interaction subscales but on the Difficult Child sub-scale, IT mos reported sig. fewer child behaviour problems than WL mos.</p> <p>IT (n=10): T1: mean=42.60 (sd 8.40); T2: mean=33.97. (sd 8.87); WL (n=12): T1: mean=43.67 (sd 7.79); T2: mean=38.61 (sd 6.80), $f(1,19)=4.80$, $p=0.041$</p> <p>Mediating role of changes in parenting behaviour Found that changes in positive parenting behaviours and negative parenting behaviours both contributed to child behaviour change during treatment.</p> <p>Intent-to-treat Analyses For those who did not start or dropped out of treatment, last ECBI intensity score before dropping out was taken as post-treatment score. Sig. difference between intervention group and non-intervention group remained ($F(1,29)=5.79$, $p=0.23$, $d=0.67$).</p>

Author and year	Quantitative outcome measures and findings
	<p>Clinical significance Applied Joacbson et al's (1999) Reliable Change Index: found a 'relatively high percentage of mos in the IT group reported clinically significant behaviour change' CBCL externalising :70% (IT) vs 17% (WL): ECBI Intensity: 50% (IT) vs 8% (WL).</p>
Brightman <i>et al.</i> (1982)	<p>Behavioural Vigenettes Test (Heifetz et al., 1981) Parents (all but two mos): knowledge of behavioural principles (Behavioural Vignettes) Mos BVT scores: showed significant condition ($F(2,55)=4.00$, $p=0.002$), time ($F(1,55)=46.96$, $p<0.001$) and conditionxtime effects ($F(2,55)=4.08$, $p=0.02$). Trained mos showed a significant BVT gain ($t(45)=8.62$, $P<0.001$). The gain for trained mos was significantly greater than the gain for control mothers ($t(57)=2.91$, $p=0.003$). BVT gain scores for group vs individual did not differ.</p> <p>Behaviour Problems Checklist (developed by authors) Significant main effect for time ($F(1,42)=18.93$, $p<0.001$). No conditions effect and the conditionxtime interaction did not reach significance ($F(2,42)=2.41$, $p=0.10$). Since the interaction approached significance, t-tests were conducted. Children in trained families showed a highly significant decrease in behaviour problems ($t(37)=6.32$, $p<0.001$) and decreased significantly more than controls ($t(43)=2.12$, $p=0.04$). Behaviour improvement for group vs individual formats did not differ ($t(36)=0.59$, ns).</p> <p>6 month follow-up interviews: Structured interview in home 6 months after to 'assess the extent and quality of follow-through teaching. Interviews later 'scored' on two dimensions: extent of continued programming and appropriateness of behavioural techniques employed. (Inter-rater reliabilities for a subsample of 14 interviews were $r=0.87$ and 0.90.) Interviews with 41/46 families. No difference found in extent of continued programming between the two formats ($t(39)=0.71$, ns) or the quality of behavioural techniques employed ($G>I$, $t(39)=1.57$, ns). Fams were characterised as high, medium or low follow-through based upon a combination of the programming and technique dimensions. Families above the mean for the sample on both dimensions had productively continued the programs they began during training and initiated some new teaching and/or behaviour problem management following training. Fams at least one SD below the mean on either dimension constituted the low group: these families ($n=10$) reported little or no continued teaching or demonstrated inadequate behavioural technique. The remaining 16 fams constituted the medium group: these had continued some degree of useful teaching. Group and individually trained families did not differ by follow-through category (chi-square (2)=1.21 ns).</p>
Chadwick <i>et al.</i> (2001)	<p>Disability Assessment Schedule (Holmes et al., 1982; Wing, 1989): ratings of severity and frequency of behaviour (only for those where basline and immed. post intervention data avail.) Mean no. of DAS behaviour problems.... Posing severe management difficulties: NS across time or between groups</p>

Author and year	Quantitative outcome measures and findings
	<p><i>Occurring more than once/week:</i> NS across time or between groups.</p> <p><i>Magnitude of the reduction in severity</i> between baseline and post-intervention assessments between the three groups was significant ($F[59,2]=8.76$: $p=0.005$), and post hoc tests showed significantly greater magnitude of improvement ($p<0.05$) in the ind int group vs the other two groups (both of which showed a slight deterioration). (Reductions in the severity of the behav. problems between baseline and 6 months were greatest in the ind. int but fell short of statistical significance ($p=0.78$)).</p> <p>Parent reported change:</p> <p>In terms of mean no of behaviour problems posing <i>severe management difficulties or occurring more often than once a week</i>: no sig diffs between groups or across time (though authors report result were consistent in terms of improvement being more likely in the ind. int gp, and little diff. Between then group and control groups).</p> <p>At immediate follow up: no of problems <i>occurring less frequently and less severe</i>: sig diff between groups, with that difference lying between in ind int gp and the other two groups ($p<0.05$). Diffs between groups in the number of behav. problems occurring more frequently or resulting in greater management difficulties were ns.</p> <p><i>Parents' ratings of change in behaviours targeted in the intervention vs those not targeted (ind int only):</i> at immediate follow-up targeted behaviour probs were sig. More likely to pose less of a management problem ($\chi^2=20.73$, 2 df, $p<0.001$) and were more likely to occur less frequently ($\chi^2=8.49$, 2 df, $p<0.001$). AT 6 month, the change was in the same direction but fell short of sig..</p> <p>Parenting stress index – short form (Abidin, 1995) No sig diffs in PD scale between groups on any of the assessment occasions.</p>
Gates, B., Newell, R. and Wray, J. (2001)	<p>Child behaviour measures:</p> <p><i>American Association on Mental Retardation Adaptive Behaviour Scale (Sparrow et al., 1984): note designed for 18-80 yr olds: findings not reported</i> <i>Problem and target scales (Marks et al., 1977):</i> a record of identified problem behaviours measured by the parent on a 9 pt. scale. <i>Behaviour checklist developed by authors:</i> 7 day record of the child's behaviour, recorded prior to each assessment point.</p> <p>Outcomes: no sig diffs between the groups in terms of the children's behaviours following treatment (a mean of the three post-treatment data pts.) on any of these measures.</p> <p>BM participants more likely than GT participants to report using the intervention they were taught in general ((Fisher's exact) $P=0.03416$), and to use the following interventions: implementing a strategy, identifying reinforcers, identifying outcomes and targets. Other interventions (BM or GT): no sig diffs between groups.</p>

Author and year	Quantitative outcome measures and findings
Hornby and Singh (1984)	<p>Home Observations: Observers were 10 undergrad students/ 3 x 30 min obs (one per day). Completed in interval between arriving home from school and completion of evening meal. Behav. coding sheets using a modified version of Peed et al. (1977) coding system: parent behaviour (rewards, punishments, demands, talks) and child behaviour (appropriate, inappropriate, undesirable, non-compliance). At end of each 15 sec interval, observer recorded one (or the first) parent and one child behaviour. Interobserver reliability checked in 33% of obs.: mean IO agreement = 87% (range: 67-100%). Data only available for 4 treatment and 2 controls: not used.</p> <p>Hereford parent attitude survey (Hereford, 1963): attitudes to child rearing. 77 items, 5 pt scale. TG: statistically significant ($p < 0.05$) positive change in parental attitude during the pre-training period, but the change in attitudes over the treatment period was not significant. CG: no sig. changes.</p> <p>Behaviour checklist: to assess changes in parents' perceptions of their child's behaviour covering: problem behaviours, learning difficulties and difficult situations (34 items, 3 pt scale). TG and CG: No sig changes on the behaviour checklist found over baseline or treatment periods.</p> <p>Vignette test (Heifetz, 1977): 'used to test parents' ability to apply behavioural principles and techniques to written problems involving mentally retarded children'. 20, mc questions (5 options). Mean score on Vignette test showed a statistically significant increase ($p < 0.001$) over the treatment period, with no change over the pre-training baseline. NS for CG.</p>
Hudson et al. (2003)	<p>Parenting Sense of Competence Scale (PSOC) (Johnson and Mash, 1989): 16 item scale with 2 subscales: satisfaction with role as parent; efficacy (measuring extent to which parents feel they are managing the role of being a parent). Here interested in the efficacy subscale.</p> <p>Depression Anxiety and Stress Scale (DASS, Lovibond and Lovibond, 1995): 3 subscales: dep., anx., and stress. Here interested in the stress subscale.</p> <p>Parenting Hassles Scale (PHS, Gavidia-Payne et al., 1997): 87 item scale to assess daily hassles. 12 subscales, two of which of interest to this evaluation: child behaviour subscale, parent needs subscale.</p> <p>Developmental Behaviour Checklist (DBS, Einfield and Tonge, 1989): 95 item scale assessing difficult behaviour of children with disabilities. Six subscales: disruptive, self-absorbed, communication disturbance, anxiety, autistic and anti-social. Plus a total problems score.</p> <p>Outcomes data DASS stress subscale, PSOC efficacy sub scale, PHS child behav. subscale and PHS parental needs sub-scale.</p>

Author and year	Quantitative outcome measures and findings
	<p>At post-test: Compared to control gp., mothers in the experimental groups had more positive scores on the DASS stress subscale ($F(1,60)=5.75$, $p=0.02$); the PSOC efficacy subscale ($F(1,60)=4.10$, $p=0.06$); and the PHS Parental Needs subscale ($F(1,60)=4.21$, $p=0.07$); but not on the PHS Child Behaviour subscale. NO differences were found among the experimental groups.</p> <p><i>Follow-up data</i></p> <p>Of the 88 who began in one of the experimental groups, 25 (28%) completed all measures at pre-, post- and follow up. Changes in pre- to post- scores for the PSOC efficacy subscale, the DASS stress subscale, and the PSOC parental needs subscale 'were maintained at follow-up' (means presented: Table 3).</p> <p>For the DBC Disruptive Behaviour subscale: sig diff between pre- and follow-up scores ($t=2.69$, $p=0.013$). But no diffs between groups.</p> <p>For the DBC Antisocial Behaviour subscale: sig diff between pre- and follow-up scores ($t=2.31$, $p=0.028$). But no diffs between groups.</p>
McIntyre (2008)	<p>Child Behaviour Checklist (ages 1.5-5 yrs) (Achenbach, 2000).</p> <p>Sig group/time interaction effect for CBCL Total problems, post-treatment children in the treatment group sug. Lower parent-reported behaviour problems/ Also a sig. time effect for both groups.</p> <p>Sig. group x time for CBCL broad-band internalising problems, also a sig time effect for both groups.</p> <p>Externalizing behaviours: no groupxtime effect, but sig effect for time. Behavioural stability (pre and post scores on the CBCL within four points of each other) lower in the experimental group compared to the control group ($\chi^2=7.14$, $p=0.03$).</p> <p>Family Impact Questionnaire –FIQ (Donenberg and Baker, 1993): five scales measure neg impact, one measures pos impact. Used three scales: Neg impact on feelings about parenting and neg impact on social relationships (combined to form a negative impact composite score; and positive feelings about parenting formed the positive impact composite).</p> <p><i>Outcomes:</i> main effect for time on the pos and neg impact scales, but not a significant time x group effect</p> <p>Parent/child interactions:</p> <p>Observation system (using partial interval coding) developed based on IYPT core content areas:</p> <p>7 parent inappropriate behaviour categories and Child Directed Praise. Observed for 15 mins doing a standardised activity (10 mins free play, 2 mins clean up, 3 mins structured activity). Used the combined Inappropriate Behaviour Index (% of intervals containing an inappropriate behaviour) and the rate of Child-Directed Praise (rate/10 min). Obs carried out within 2 weeks before and within 2 weeks after. Two (blind) independent observers coded 50% videotaped parent-child interaction data. Mean interobserver agreement 99.2% for Inappropriate Behaviour Index, and 97.4% for Inappropriate Behaviour Index. Also checked integrity by which standardised activity was carried out: 100% accuracy.</p> <p><i>Outcomes:</i> Sig. group x time interaction for the parent combined Inappropriate Behaviour Index: sig reduced for the exp. gp but not the control group ($F(2,44)=21.35$, $p<0.001$). Also a trend approaching significance ($p=0.08$) for increased rates of child-directed praise in the treatment group, though both groups increased rate of CDP.</p>

Author and year	Quantitative outcome measures and findings
	<p><i>Outcomes by child diagnosis</i> 50% of the treatment group had autism, so looked at response to the treatment as a function of diagnosis. No sig diffs found.</p> <p><i>Outcomes by presence of support person</i> 8/21 parents in treatment group attended with a spouse (n=7) or other support person (n=1). Looked at FIQ scores: no sig diffs when controlled for pre-treatment FIQ scores.</p>
Plant and Sanders (2007)	<p>Parent child interaction: assessed using a 30 min recorded home observation session following a set format. Observed and coded using the Revised Family Observation Schedule (Sanders et al., 1996). Two composite scores: negative parent behaviour and negative child behaviour. 3 trained observers coded the interactions. Coders were blind to the intervention conditions of participants and stage in intervention. Interrater reliability checked (0.77 parent behaviour; 0.74: child behaviour).</p> <p>Child behaviour: <i>Developmental Behaviour Checklist – Parent Version</i> (DBC, Rinfield and Tonge, 1991). Total problem behaviour score plus six subscales: disruptive, self-absorbed. Communication disturbance, anxiety-relating, autistic-relating, anti-social. Used the total score and the disruptive sub scale scores.</p> <p><i>Care-giving problem checklist (CPC) – difficult child behaviour:</i> assessed the frequency of difficult child behaviour when completing care-giving tasks. Total score, higher scores indicative of higher frequency of problem behaviour.</p> <p><i>Care-giving problem checklist (CPC) – problematic care-giving tasks:</i> presence or absence of problem behaviours across 22 different care giving tasks over a one week period.</p> <p>Parenting skills and ability: <i>Parenting Scale</i> (Arnold et al., 1993): 30 items, measuring dysfunctional discipline styles in parents. Total score based on 3 factors: laxness, over-reactivity, verbosity.</p> <p><i>Parenting Sense of Competence Scale (PSOC)</i> (Gibaud-Wallston and Wandersman, 1978). 16 items: two dimensions: satisfaction with parenting role and feels of efficacy. Get total score and the two dimension sub scores.</p> <p>Parental adjustment <i>Depression, anxiety, and stress scales (DASS)</i> (Lovibond and Lovibond, 1995). 42 items. Get total score, plus depression, anxiety and stress subscores.</p>

Author and year	Quantitative outcome measures and findings
	<p>Short-term intervention effects</p> <p>ANCOVA scores were significant for the four child behaviour measures (FOS-NCB: $F(3,732)=6.92$; $p=0.002$; DBC-D: $F(3,732)=4.62$; $p=0.013$; CPC-B: $F(3,732)=8.18$; $p=0.001$; CPC-T: $F(3,732)=18.62$; $p=0.000$). At post-intervention, the Sstp-E resulted in significant reductions in child behaviour on three of the four measures as compared to the WL condition: FOS-NCB; CPC-T; CPC-B, but not DBC-D. At post-intervention, the Sstp-S resulted in significant reductions in child behaviour on three of the four measures as compared to the WL condition: FOS-NCB; CPC-T; DBC-D, but not CPC-B. Of the four measures, one sig diff. between Sstp-E and Sstp-S : CPC-B (Sstp-E produced better outcomes).</p> <p>ANCOVA scores were significant for parenting skills (PS: $F(3,73)=5.72$, $p=0.005$) and competence ((PSOC: $F(3,73)=5.59$, $p=0.006$). Found a significant effect for treatment condition: compared to the WL condition, mothers in the Sstp-S gp. reported significantly higher (better) scores for PS and PSOC; and mothers in the Sstp-E gp. reported significantly higher (better) scores for PSOC only. No diffs observed between Sstp-S and Sstp-E. ANCOVA scores not significant for negative parent behaviour (FOS-NPB). ANCOVA scores for maternal distress or relationship adjustment not significant.</p> <p>Long-term intervention effects</p> <p><i>Child behaviour:</i> sig. main effect for time on FOS-NCB ($F(1,43)=4.22$, $p=0.04$), with negative behaviour decreasing significantly from post-intervention to 1 year follow-up for Sstp-S and Sstp-E groups. No main effects for time on the other child behaviour measures (DBC-D; CPC-B; CPC-T). Also a significant conditionXtime interaction for DBC-D ($F(1,39)=5.10$, $p=0.03$), which revealed significantly lower rates of difficult child behaviour at 1 yr f-up for children in the Sstp-E group as compared to the Sstp-S group.</p> <p><i>Parenting skills/competence:</i> significant conditionXtime interaction for parenting skills (PS)($F(1,39)=4.99$, $p=0.03$), but pairwise comparisons did not reveal any sig diffs between conditions and no sig time effect. No sig main effects or interactions for the other measures (PSOC, FOS-NPB).</p> <p><i>Maternal distress:</i> no significant main effects or conditionxtime interactions for measures of maternal distress.</p> <p><i>Clinical significance of changes in children's problem behaviour</i></p> <p>Used the <i>reliable change index</i> (RCI, Jacobson and Truax, 1991) and a <i>30% reduction in observed disruptive child behaviour</i> (Webster-Stratton et al., 1989).</p> <p>Used DBC scores to calculate RCI at post-intervention: a sig. greater proportion of children in the Sstp-E and Sstp-S conditions behaviour had reliably improved when compared to the WL condition. No sig diffs between Sstp-S and Sstp-E.</p> <p>Scores showing movement from clinical to normal range on DBC total score did not reveal significant differences between the 3 groups. Using the 30% reduction criteria, a greater proportion of children in Sstp-S and Sstp-E showed sig. change in the FOS-NCB compared to children in the WL condition. NO sig. diffs between Sstp-S and Sstp-E.</p>

Author and year	Quantitative outcome measures and findings
	Follow-up: no sig diffs in reliable change, movement from clinical to normal range or 30% reduction between the SSTP-S and SSTP-E conditions. ON FOS-NCB: 72% of children across the two intervention conditions had achieved 30% reduction in negative behaviour.
Prieto-Bayard and Baker (1986)	<p>Verbal Behavioural Vignettes Test (VVT): assesses parental knowledge of behaviour modification principles. Verbally administered. Coders rated audiotaped responses for effective use of behavioural principles. Inter-rater reliability=0.91. (pre and post only)</p> <p><i>Outcomes:</i></p> <p>VVT: trained mothers gained significantly ($t(5)=3.86$, $p<0.01$). ANOVA: a significant Condition x Testing interaction ($F(1,13)=15.85$, $p<0.01$).</p> <p>Teaching Interview (TI): home teaching and behaviour problem management assessed through a 'detailed audio-taped interview'. Audiotapes rated on: a) extent of teaching and behaviour problem management reported; and b) the sophistication of behaviour methods employed. Inter-rater reliability=0.94. (pre, post and f-up)</p> <p><i>Outcomes:</i></p> <p>TI: trained families gained significantly ($t(4)=6.00$, $p<0.01$). ANOVA yielded a significant Condition x Testing interaction ($F(1,13)=4.90$, $p<0.05$). No Condition x Testing effect for extent of teaching, but a significant effect for sophistication of teaching ($F(1,13)=12.04$, $p<0.01$).</p> <p>Child Behaviour Checklist (CBC): a simplified version of a more detailed performance inventory (Baker and Heifetz, 1976): the authors report the CBC had not been validated. (pre and post only)</p> <p><i>Post-intervention:</i></p> <p>CBC: children improved significantly in behaviour problems ($t(6)=3.41$, $p<0.01$). ANOVA yielded a significant Condition x Testing interaction ($F(1,15)=4.85$, $p<0.05$).</p> <p>Follow-up</p> <p>(n=9). TI scores at follow-up significantly higher than before training, they did not maintain their post-training level in terms of extent and sophistication (5 showed a gain, 3 remained unchanged, one had a poorer rating).</p>
Quinn et al. (2007)	<p>[Paper provides detail of psychometric properties of all the measures.]</p> <p>Strengths and Difficulties Questionnaire (Goodman 1997): yields total difficulties score and five subscale scores: conduct problems, hyperactivity, emotional symptoms, peer problems and pro-social behaviour. (Psychometric properties re use with adolescents with intellectual disabilities found to be adequate, Emerson, 2005).</p> <p>Child Behaviour Checklist (Achenbach, 1991): 113 item inventory: 3 main scales (total, externalising, internalising); 8 subscales (withdrawn, somatic complaints, anxious/depressed, social problems, thought problems, attention problems, delinquent behaviour, aggressive behaviour). (Norms of children with mild/mod intellectual disabilities, Dekker et al, 2002).</p> <p>Specific targets: prior to treatment, participants set at least 3 specific, measurable and achievable child- and parent-focussed goals expressed in</p>

Author and year	Quantitative outcome measures and findings
	<p>positive behavioural terms. Participants rated the frequency of the target behaviour in the previous month.</p> <p>General Health Questionnaire 12 (Goldberg and Williams, 1988) (assesses psychological distress)</p> <p>Kansas parental satisfaction scale (James et al., 1985).</p> <p>Family Assessment devise (Kabacoff et al., 1990): yields a total score and subscale scores for family problem-solving, communication, roles, affective responsiveness, affective involvement, behaviour control and general functioning.</p> <p>Family Inventory of life events and changes (McCubbin et a., 1982): Sources of family stress: total score and subscales: intra-familial strain, work strains, illness and family care strains, family transitions, pregnancy and child strains, financial strains and losses.</p> <p>Parental distress scale from the short form of the parenting stress index (PSI, Abidin, 1995). (Used in past evaluations of Parent Plus)</p> <p>Parent and family problems scale of the Questionnaire on Resources and Stress (Friedrich et al., 1983). (Widely used to assess the stress processes in families of children with intellectual disability.)</p> <p>[Internal consistency of scales checked based on data collected at Time 1: all scales used had good reliability ($\alpha > 0.7$) except SDQ conduct subscale (0.42).]</p> <p>Impact of treatment on group mean post-treatment scores ANCOVAs conducted revealed: the treatment and control groups only differed significantly on: the total difficulties scale of the SDQ only ($F = 6.402$, $p < 0.01$). Also, the mean for the treatment group moved from the clinical to the non-clinical range.</p> <p>Improvement in treatment group mean scores at follow-up Sig improvement on SDQ total difficulties ($F = 11.25$, $p < 0.001$: T1 > T2 = T3; mean scores at post treatment and f/up below the clinical cut-off score, pre treatment mean score was above clinical cut off) and SDQ conduct problems scales of SDQ ($F = 11.34$, $p < 0.01$: T1 > T2 = T3), the Kansas Parental Satisfaction Scale ($F = 5.542$, $p < 0.01$: T1 < T2 = T3; mean scores at post treatment and f/up in the non-clinical range, pre treatment mean score was in clinical range), and the Questionnaire on Resource and Stress Parent and Family Problems Scale ($F = 3.42$, $p < 0.01$: T1 < T2 = T3). Post treatment and follow-up scores were significantly different from pre-treatment scores but not significantly different from each other. Thus gains made at Time 2 were maintained at Time 3.</p> <p>Clinical improvement rates Cases classified as clinically improved if they moved from the clinical to the non-clinical range on the SDQ total diff. The diff in clinical improvement rates was <u>not</u> statistically significant. Clinically significant improvers and non-improvers did not differ significantly ($p < 0.01$) on any baseline variable.</p>

Author and year	Quantitative outcome measures and findings
	<p>Reliable improvement rates Cases classified as reliably improved if achieved a score of >1.96 on the reliable change index (Jacobson and Truax, 1991) 3 of the cases in the treatment group and none of the cases in the control group were classified as reliably changed at T2: ns. Reliable and non-reliable improvers did not differ significantly on any baseline variables.</p> <p>Goal attainment Rated attainment of 3 child-centred and 3 parent-centred parent-set goals (10 pt scale). Mean child-centred goal attainment for treatment group increased significantly from T1 to T2, and this was improved 10 months later at follow-up ($F(2,42)=100.63$, $p<0.01$). Mean parent-centred goal attainment also increased significantly from T1 to T2 with the improvement maintained at follow-up ($F(92,40)=58.30$, $p<0.01$).</p>
Roberts et al. (2006)	<p>Blind research assistants visited parents to complete measures and carry out behavioural obs (one parent was the father).</p> <p>Developmental Behaviour Checklist Parent Version (Einfield and Tonge, 1992): assesses mos and fas perceptions of behaviour problems. Total score and six subscales (disruptive, self-absorbed, communication disturbance, anxiety, autistic relating, anti-social. Total score was used (TBPS) with clinical cut-off of 46; and a change score of 17 or more used to assess reliable change.</p> <p>Family Observation Schedule – Revised III: (Sanders et al., 1996) assessed primary caregiver-child interaction in the home and community settings. Parents nominated 3 difficult settings from a 16-setting checklist. Observations blind to child's group status. Child non-compliance and oppositional behaviours were coded plus appropriate verbal interactions and engaged activity. Five positive parental behaviours were coded: 2 antecedent and 3 consequent to child's behaviour. Parental negative behaviour also coded. 15 sec interval coding system, 20 min observation period. Research assistants coded. Reached 80% agreement.</p> <p>Parenting Scale (Arnold et al., 1993): 30 item measure of dysfunctional parenting discipline: 3 factors: laxness, overreactivity, verbosity. Clinical cutoffs used.</p> <p>Depression-anxiety-stress scale (Lovibond and Lovibond, 1995): relating to continuing difficulties in meeting the demands of life in the previous week.</p> <p>Outcomes</p> <p><i>Child behaviour: parent report:</i> Mothers' TBPS indicated significant time ($F(1,30)=4.25$, $p<0.05$) and time by group ($F(1,30)=8.51$, $p<0.01$) effects. Intervention mos reported sig. reductions in behaviour probs from pre to post intervention ($t(16)=3.67$ $p<0.01$), and pre-int to follow-up ($t(14)=3.19$, $p<0.05$). Control mos reported no sig. changes. No sig effects found for fathers. Intention to treat analyses did confirmed the time x group interaction</p> <p><i>Child behaviour: Behavioural observations:</i> no sig effects for non-compliance, but significant time ($F(1,30)=6.23$, $p<0.05$) and time by group effects ($F(1,30)=8.90$, $p<0.01$) for oppositional behaviour, with intervention group decreasing in levels of oppositional behaviour from pre to post ($t(15)=2.67$, $p<0.05$), and from pre to follow-up ($t(15)=2.98$, $p<0.05$). No changes in control group children. Sig time effects for 'appropriate'</p>

Author and year	Quantitative outcome measures and findings
	<p>behaviour' for both groups. Intention to treat analyses did confirmed the time x group interaction</p> <p>In the 'generalisation settings': sig time ($F(1,30)=5.59$, $p<0.05$) and time x group effects ($F(1,30)=7.80$, $p<0.01$) for non-compliance, with intervention group decreasing in levels of noncompliance from pre to post ($t(16)=3.69$, $p<0.01$), and from pre to follow-up ($t(15)=2.70$, $p<0.05$). No changes for the control group. For oppositional: sig time effect only, indicating both groups reduced in oppositional behaviour over time. No sig effects for appropriate child behaviour. Intention to treat analyses did confirmed the time x group interaction</p> <p><i>Parental behaviour</i></p> <p><i>Parental report: Mothers:</i> sig time x group effects for over-reactivity ($F(1,27)=7.96$, $p<0.01$) and time effects for laxness ($F(1,27)=6.24$, $p<0.05$) and over-reactivity ($F(1,27)=9.72$, $p<0.01$). Intervention mos became less over-reactive after the intervention ($t(13)=3.34$, $p<0.01$ and this was maintained at follow-up compared to preint. ($t(11)=3.97$, $p<0.01$). No changes for control group mos. However, intention to treat analyses did not confirm the time x group interaction.</p> <p><i>Parental report: Fathers:</i> sig time x group effects for laxness ($F(1,19)=9.95$, $p<0.01$), verbosity ($F(1,19)=18.82$, $p<0.01$), but not over-reactivity. Intervention fathers use of lax ($t(9)=4.47$, $p<0.01$) and verbose ($t(9)=3.24$, $p<0.01$) styles declined sig from pre- to post- and from pre- to follow-up. Control fas used more verbose discipline from pre tp post. Intention to treat analyses confirmed the group effects for verbose discipline, and declines in intervention fas use of these discipline strategies.</p> <p><i>Behavioural observations:</i> no sig effects for parental positive antecedent behaviours or parental negative behaviours in the target settings. But for parental positive consequences behaviour there was a sig. group x time interaction ($F(3,28)=3.16$, $p<0.05$) (univariate time effects for positive social attention and time x group effects for praise – pre – post, and pre- f/up)). Intention to treat analyses confirmed the time x group interaction for praise.</p> <p>In the 'generalization settings': no sig time or time by group effects.</p> <p><i>Parental stress</i></p> <p>No sig effects found.</p> <p><i>Clinical significance</i></p> <p>At post intervention, 9 (52.9%) of intervention group children experienced reliable behaviour change on the maternal TBPS compared to 3 (20%) control-group children. Chi square analysis approached significance ($p<0.05$: they used the more conservative $p<0.01$ as they had siblings within the study so wanted to take account of possibility of Type 1 errors due to data interdependence).</p> <p><i>Parenting:</i> Sig more intervention mos (50% vs 6.7%) reported reliable reductions in overactive discipline at postintervention. At follow-up, 3 (25%) showed reliable change,. Sig more intervention fas. reported reliable change in laxness (40% vs 0%) and verbosity (50%, 1%) at postintervention. At follow-up 50% showed reliable change from preintervention on laxness and verbosity.</p> <p><i>Stress:</i> sig more intervention group mothers (28.6%) compared to control group mos (0%) reported reliable reductions in stress at post-intervention.</p>

Author and year	Quantitative outcome measures and findings
Sofronoff and Farbotko (2002)	<p>None reported deteriorations at follow-up.</p> <p>'Parental Efficacy in the management of Asperger syndrome': (developed for the project) 15 items assessing the behaviours the children displayed (yes/no) and the extent to which parents believed they could manage the behaviour problems (0-5: no confidence – complete confidence). Used average self-efficacy scores as some children displayed more problem behaviours than others.</p> <p>Eyberg Child Behaviour Inventory (ECBI) (Eyberg and Pincus, 1999) (though authors note could not find any studies which use this inventory with children with Aspergers. Used the total problem score.</p>
	<p>Outcomes For control group, data at T2 were carried forward to Time 3 as in an intention to treat analysis. 3X3 repeated measures.</p> <p>Number of reported problem behaviours The no. of problem behaviours decreased significantly between Time 1 and Time 2 ($p<0.001$ for both intervention groups). Also a sig diff between Time 1 and Time 3 for the ind gp sessions ($p<0.002$). Sig effect for time x group ($F=8.28, p<0.001$): control group different to intervention groups.</p> <p>Parental self-efficacy Significant main effect for time ($F=7.37, p=0.001$), with sig diffs between T1 and T2 ($p<0.005$), and T1 and T3 ($p<0.02$). No sig main effect for group. Sig time x group interaction ($F=6.26, p<0.001$) with control group different to intervention groups.</p> <p>Parental self-efficacy: differences between mothers and fathers 2X3 repeated measures (mo; fa) (T1, T2, T3). Sig main effect for time ($F=11.62, p<0.001$). Pairwise comparisons showed the overall level of parental self-efficacy increased sig. between T1 and T2 ($p<0.001$) and between T1 and T3 ($p<0.002$). No main effect for parent, but a sig. time x parent interaction (mos scores started lower but ended higher than fas).</p> <p>Sig parent x time interaction found in the ind session group ($F(4.19, p<0.05)$ with this interaction appearing to stem from mothers showing a sig. increase in self-efficacy whilst fathers showed little change.</p> <p>Level of self-efficacy in the intervention group: mothers increased significantly after the commencement of the intervention for the workshop (ie T2) ($F=9.80, p<0.01$) and ind sessions ($F=12.98, p<0.001$) groups. Ind session group: sig diffs between T1 and T2 ($p<0.01$) and T1 and T3 ($p<0.001$). Workshop group T1 and T2 ($p<0.01$). No such changes for fathers in either group.</p>

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Sofronoff et al. (2004)	<p>Eyberg Child Behaviour Inventory (ECBI) (Eyberg and Pincus, 1999) (though authors note could not find any studies which use this inventory with children with Aspergers. Used the total problem score.</p> <p>Outcomes</p> <p><i>Number of problem behaviours:</i> sig main effect for time ($F(2,96)=26.68$, $p<0.001$) and for group ($F(2,48)=6.90$, $p<0.005$). Main effects modified by a significant time x group interaction ($F(4,96)=6.53$, $p<0.005$). Post hoc tests revealed the workshop group reported significantly fewer problems at T2 ($p<0.0001$) compared with T1, and at T3 compared with T1 ($p<0.001$). Individual sessions group: similar ($p<0.0001$; and $p<0.0001$). No sig diffs for time for the wait list group. Also, at T2, a sig diff between workshop and wait list group ($p<0.004$) and the ind session and wait list group ($p<0.0001$). At T3, sig. diff between workshop and wait list group ($p<0.01$) and between ind sessions and wait list group ($p<0.0001$). No sig diffs between the two intervention groups at any time.</p> <p><i>Reported intensity of problem behaviours:</i> sig main effect for time ($F(2,96)=24.71$, $p<0.001$) and for group ($F(2,48)=5.81$, $p<0.01$). Main effects modified by a significant time x group interaction ($F(4,96)=7.82$, $p<0.001$). Post hoc tests revealed the workshop group reported significantly lower intensity of problem behaviours at T2 ($p<0.0001$) compared with T1, and at T3 compared with T1 ($p<0.0001$). Individual sessions group: similar ($p<0.0001$; and $p<0.0001$). No sig diffs for time for the wait list group. Also at T2 a sig diff between the workshop and individual sessions groups ($p<0.05$), the individual sessions and wait list group ($p<0.0001$), but <u>not</u> the workshop and wait list groups. At T3, sig. diff between the two intervention groups ($p<0.01$), and between ind sessions and wait list group ($p<0.0001$), but not between the workshop and waiting list groups. So, across all these the ind sessions group was reporting significantly lower intensity of problem behaviours than either the workshop or wait list group at T2 and T3.</p>