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

Appendices B-S

**Bryony Beresford⁺, Lucy Stuttard⁺, Susan
Clarke⁺, Jane Maddison⁺
Jennifer Beecham^{*}**

⁺ Social Policy Research Unit, University of York

^{*} PSSRU, University of Kent

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Appendix B

Report of the Mapping Work

Appendix B

Report of the Mapping Work

The interventions were selected following a national, voluntary, mapping exercise in which practitioners working in health, education and voluntary sector services were invited to report interventions they were delivering to manage sleep or behaviour problems among disabled children, including any 'manualised'¹ parent-training interventions to help parents better manage their child's sleep or behaviour problems.

The mapping questionnaire was available for completion on-line or as a hard copy version. The content of the questionnaire can be found in Figure A.2 (placed at the end of this appendix.)

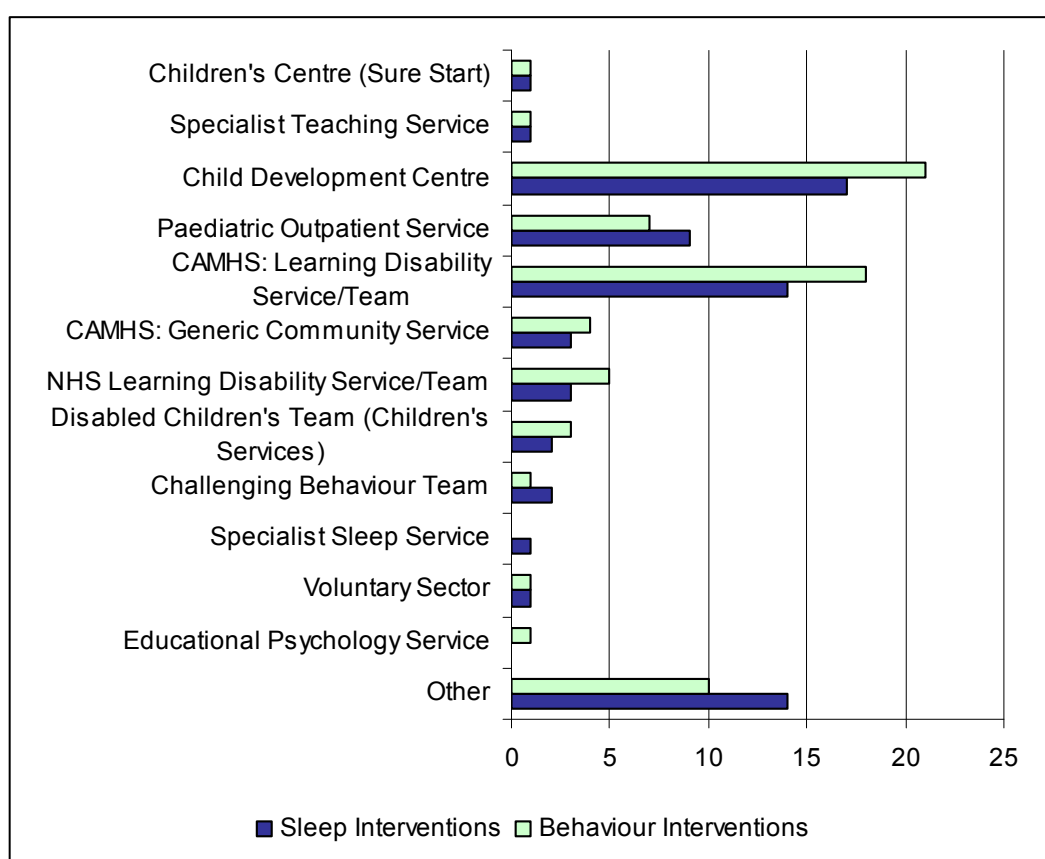
The following organisations and networks circulated the invitation via specific e-mail alerts and notices placed in e-newsletters to their members:

- Child Health Mapping (Child and Adolescent Mental Health Services (CAMHS))
- Quality Improvement Network for Multi-Agency CAMHS (QINMAC)
- The CAMHS and LD network
- British Association of Community Child Health (BACCH)
- Special Educational Needs/Learning Difficulties and Disabilities Hubs
- Royal College of Paediatrics and Child Health
- British Psychological Society special interest groups
- Local Authority disabled children's teams
- National Children's Bureau
- Interconnections

In addition, a hard copy of the mapping questionnaire was mailed to all Child Development Centres.

One hundred and twenty-one services completed the mapping questionnaire (65 behaviour interventions; 56 sleep interventions). The greatest number of submissions were received from: Child Development Centres, CAMHS LD teams and paediatric outpatient services, see Figure A.1.

¹ By this we mean the intervention had a set procedure of delivery. This was either set out in an 'intervention manual', or intervention adherence was monitored using a checklist completed by the practitioner.

Figure A.1 Services delivering sleep and/or behaviour interventions

The interventions were most likely to be focusing on children with learning difficulties and/or autistic spectrum conditions, see Table A.1. The following criteria were applied to generate a long-list of potential interventions for inclusion in the study:

- Strong behavioural element to the approach/training
- Use a manual/formalised approach
- Parent training
- Time limited
- “Early intervention” (either typically being delivered by Tier 1/2; OR for younger children; OR soon after diagnosis)

Table A.1 Target populations for the behaviour and sleep interventions

Target population	Behaviour		Sleep	
	n	%	n	%
Any child	3	5	6	11
Any child but focus on disabled children	9	14	6	11
Disabled children generally	6	9	6	11
Disabled children generally with a focus on LD and/or ASC	22	34	19	34
Children with LD only	9	14	5	9
Children with LD and/or ASC only	11	17	9	16
Children with ASC	5	8	3	2
TOTAL	65	100	56	100

Twenty of the behaviour interventions and 20 of the sleep interventions fulfilled these criteria. Telephone calls and email were used to gather additional information about these interventions. Practitioners were also asked to supply any documentation/programme manuals. The following criteria were then used to create a short-list of potential interventions:

- behavioural theory a key element of the intervention
- the intervention was embedded in routine practice
- projected potential sample size
- comparator group opportunities
- representation of generic disability and ASC-specific interventions.
- representation of different settings/services delivering the interventions.

Figure A.2 The content of the mapping questionnaire

Please note, this mapping exercise only concerns interventions which are based or draw on behavioural theory/principles of behaviour modification.

Where is the service/intervention based/delivered from?

- ☐ Children's Centre (Sure Start)
- ☐ Educational psychology team
- ☐ Specialist teaching service/team
- ☐ Child Development Centre
- ☐ Paediatric outpatient service
- ☐ CAMHS: learning disability service/team
- ☐ CAMHS: generic community service
- ☐ CAMHS: inpatient Service
- ☐ NHS Learning Disability Service/Team
- ☐ Disabled Children's Team (children's social care/social services)
- ☐ Challenging behaviour team
- ☐ Specialist sleep service
- ☐ Voluntary sector
- ☐ Private sector
- ☐ Other (*please describe*): _____

Please tell us the name and contact details for the team/service. (We will only use the contact details if we have a query about the information provided).

Name of service: _____

Address of service: _____

Contact name: _____

Email: _____

Telephone: _____

In which authority/trust(s) is the service is based?

How would you describe the stage at which the service/intervention is delivered?

- ☐ Preventive
- ☐ Early intervention
- ☐ Intervention on established problem

Which children use the service?

- ☐ Any child
- ☐ Children with learning difficulties/learning disabilities
- ☐ Disabled children generally
- ☐ Other

Where is the service delivered?

- ☐ Clinic
- ☐ Home
- ☐ Community setting

What age range is the service provided to? _____

Typically how severe is the presenting problem?

- ☐ Mild
- ☐ Moderate
- ☐ Severe

What interventions/services are delivered?

- ☐ Individual therapeutic work with child
- ☐ Individual therapeutic work with family
- ☐ Provision of information only
 - ☐ Printed booklets
 - ☐ Video/DVD
 - ☐ Other (*please describe*): _____
- ☐ Individual assessment leading to parent training on behaviour management skills
- ☐ Group parent training on behaviour management skills
- ☐ Support parents to implement behaviour management strategy
 - ☐ Delivered individually face to face
 - ☐ Delivered via phone calls
 - ☐ Delivered in group setting
 - ☐ Delivered in another way (*please describe*): _____
- ☐ Longer term follow-up support (*please describe*): _____
- ☐ Other

Does the intervention involve the use of an established manual/programme (for example, Incredible Years Parent Training, Triple P, Sleep Solutions)?

- ☐ No
- ☐ Yes (*please describe*): _____

Is medication used as part of the intervention?

- ☐ Always
- ☐ Sometimes
- ☐ Never

Would your service be interested in being involved in a research project which is evaluating sleep and behaviour interventions services for disabled children? (Please note, answering 'yes' does not commit your service in any way).

- ☐ No
- ☐ Yes

Thank you.

Appendix C

Programme Contents

C1 ASCEND (Autism Spectrum Conditions – Enhancing Nurture and Development)

Session 1: An Introduction to Autism and Mindblindness

- Introduction
- What is autism?
- Introducing the theme: mindblindness or theory of mind
- Gorilla exercise
- Group discussion/questions and answers
- Handouts and homework

Session 2: Getting the Gist

- Recap
- Introducing the theme: 'getting the gist'
- Ten-pin bowling exercise
- Group discussion/questions and answers
- Handouts and homework

Session 3: Language and Communication

- Recap
- Introducing the theme: language and communication
- Miming exercise
- Understanding difficulties with communication exercise
- Asperger Syndrome exercise
- Group discussion/questions and answers
- Handouts and homework

Session 4²: Preoccupations, Sensory Interests and Repetitive Behaviours

- Recap
- Introducing the theme: preoccupations, sensory interests and repetitive behaviours
- Sensory preoccupation exercise
- Understanding preoccupations exercise
- Group discussion/questions and answers
- Handouts and homework

Session 5: Imagination, Time Perception, Planning and Memory

- Recap
- Introducing the theme: imagination
- Exercise in understanding imagination
- Group discussion/questions and answers
- Handouts and homework

Session 6: Managing Behaviour

- Recap
- Introducing the theme: managing behaviour

² For one group (Spring 2010, York) there was an extra session between weeks 3 and 4. This was an information session run by the National Autistic Society for parents whose children were newly diagnosed.

- Exercise re applying learning about theories from previous sessions to understand some of the reasons for specific behaviours in children with ASC
- Preparation for the next session with individual therapists
- Questions and answers
- Handouts and homework

Session 7: Exploring Individual Problems and Developing Strategies for Managing Behaviour (1)

- Recap
- Introducing task
- Complete a personalised behaviour management template and FIRE wheel related to each child with individual therapists
- Handouts and homework

Session 8: Strategies for Managing Behaviour (1)

- Recap
- Introducing the theme: strategies for managing behaviour
- Group discussion exercise
- Questions and answers
- Handouts and homework

Session 9: Visual Guides/Social Stories Workshop

- Recap
- Introducing the workshop: visual guides/social stories
- Exercise for visual guides
- Exercise for social stories
- Group discussion/questions and answers
- Handouts and homework (preparation for next week)

Session 10: Exploring Individual Problems and Developing Strategies (2) for Managing Behaviour (2)

- Recap
- Introduce the task
- Exercise with individual therapists
- Group discussion
- Further teaching of strategies
- Handouts (course evaluation questionnaires)

Session 11: Consolidation, Questions and Party

- Recap
- Group feedback from individual sessions
- Final questions
- Course completion certificates and handouts on contact details/ further reading
- Party!

C2 Confident Parenting

- The Confident Parenting Programme consists of six core sessions.
- *Rating scales:* each session begins with asking parents/carers to complete simple rating scales about their child's behaviour that week and their management of that behaviour.
- *Informal discussion:* during each session, parents/carers are invited to discuss any achievements or challenges that they have faced with their child in the previous week or anything they want to share with the group.
- *Video feedback:* the group are shown films of parents carrying out a task with their child in the home and of the child carrying out a similar task in the school setting. The facilitators and parents provide feedback as to how well parents managed behaviour and what they might have done differently. Teachers' management styles and techniques are also discussed with a view to parents taking on board some of the approaches demonstrated.
- *Video clips:* Edited clips, usually taken from TV parenting programmes, are often used to illustrate specific points.
- *Directed discussion:* Facilitators guide a discussion, which usually comes from what is observed in the video or from issues that are raised in the session.
- *Tips and advice:* The facilitators offer advice about emotional matters and possible behaviour management techniques parents/carers can use with their child at home. Parents also share tips and advice about what has worked well for them with their child.
- *Handouts:* At the end of each session, parents are given a summary handout of what has been discussed in that session. Throughout the programme parents are also given pre-prepared handouts on a range of topics.
- Topics covered in the sessions typically include:
 - Parental feelings
 - Parent skills
 - New thoughts for parents
 - New behaviours from parents
 - Issues to do with the child
 - Communication with the child
 - Developing the child's skills
 - Working together with other family members
 - Going out in public

C3 Cygnet Parenting Support Programme

Session 1: Autism and Diagnosis

- Introduction to the group
- Background to the group
- Aims
- Content
- Introduction to ASC's
- What it is like to be autistic
- Experience of the diagnosis

Session 2: Communication

- Why and how do we communicate
- Communication in ASC's
- Practical strategies to aid communication
- Resources
 - Visual support
 - Social stories
 - Comic strips

Session 3: Sensory Issues

- What are the senses and how they work
- Types of sensory issues seen in ASC's
- Associated behaviours
- Practical strategies

Session 4: Understanding behaviour

- Types and functions of all human behaviour
- Behaviour and autism
- Additional factors
- Underlying difficulties behind the behaviour (Iceberg principle)

Session 5: Managing Behaviour

- Using the information (Iceberg principle)
- Analysing and managing behaviour (STAR analysis)
- Key practical strategies
- Management strategies

Session 6: Choice decided by parents/carers, e.g.

- Transitions
- Issues in adolescence/puberty
- Contacts
- Siblings
- Sleep
- Go over previous work

C4 Riding the Rapids

Session 1: *Setting Your Course*

- Introduction (welcome; icebreaker; ground rules)
- Description of children – strengths as well as difficulties
- Goal setting
- Introducing the *Riding the Rapids* kit
- Home practice

Session 2: *Building Your Boat* – Understanding Behaviour 1

- Review home practice/ take ladder and coping ratings
- What influences children's behaviour?
- Introducing and practicing the STAR approach
- Settings and triggers
- Creating a Calm Place
- Home practice and review of session

Session 3: *Making it Watertight* – Understanding Behaviour 2

- Review home practice
- Positive reinforcement, negative reinforcement and punishment
- Identifying a problem behaviour and completing a STAR (Setting, Trigger, Action, Response) analysis
- Home practice

Session 4: *Good work Captain! Encouraging new behaviours*: Praise and Rewards

- Review home practice/ take ladder and coping ratings
- Encouraging positive behaviour through praise and rewards
- Home practice

Session 5: *Enjoying the Ride* – Play

- Review home practice/ take ladder and coping ratings
- Introducing the theme play
- Play approaches with children with additional needs - small group practice (role play) and feedback to larger group
- Home practice and review of session

Session 6: *Navigating your Route* – Communication

- Review home practice/ take ladder and coping ratings
- Review individual goals
- Description of children's communication and interaction
- Strategies to support communication difficulties
- Home practice

Session 7: *Wear your Life Jacket!* – Managing Stress

- Review home practice/ take ladder and coping ratings
- Emotional and behavioural responses
- Challenging negative thinking (including exercise)
- Home practice
- Raffle (to model principle of rewards)

Session 8: *Mind the Rocks!* – Managing Unwanted Behaviour

- Review home practice/ take ladder and coping ratings
- Introduce strategies for managing unwanted behaviour (including using role plays)
 - Ignoring and time out
 - Alternatives to time out
 - Limit setting
- Home practice

Session 9: *Full Steam Ahead!* – Pulling it all together

- Review home practice/ take ladder and coping ratings
- Review how parents have used the *Riding the Rapids* kit
- Devising a behaviour plan using the kit/revisiting goals/setting new targets
- Discussion re following week's final session and party

Session 10: *Land Ahoy!* – Party, planning for the future

- Review home practice
- Using the *Riding the Rapids* kit
- Sharing information about local support agencies/groups
- Course feedback
- Handout certificates
- Discuss review date

C5 Specialist Health Visitor Sleep Support Programme

Pre-intervention:

- Sleep problems are actively enquired about in specialist paediatric appointments at the Child Development Centre. When identified, a detailed history and examination clarify whether the main issue is behavioural and if so referral to the Specialist Health Visitor Sleep Support Programme is considered.
- At the time of referral to the programme, the parent is given a sleep diary to complete before their first appointment with the Specialist Health Visitor (SHV).
- The service does not have a specific manual but gives families a range of information. They often use the *Contact a Family* leaflet. The service do not consistently give out the same material, it is dependent on individual family's needs.

Home visit:

- All parents then receive an initial home visit in which the SHV examines the sleep diary, checks out the child's bedroom and discusses at length these and other factors that might impact on child's sleep.
- They then agree a plan of action the parent feels they can manage (e.g. changes to bedroom environment, bedtime routine, gradual withdrawal, minimal night-time stimulation, controlled crying, etc.).

Ongoing support:

- As the family implements the agreed plan, the SHV provides ongoing advice and support via home visits or telephone support. This support is typically provided on a weekly basis over a period of up to six weeks.
- If initial interventions do not ameliorate the problem then a trial of melatonin may be considered alongside the behavioural advice.

Final session/further support:

- At the final session, the SHV will invite parents of pre-school children to get back in touch if they need further support.
- The family may be re-referred to the sleep service if problems recur.
- If the SHV feels she cannot resolve the problem satisfactorily the family will be referred back to the specialist paediatric clinic at the CDC.

C6 Neighbourhood Early Years (NEYS) Sleep Service

Session 1: Sleep Assessment

- Sleep Assessment interview
- Sleep diary given to parents/carers
- Sleep booklet given to parents/carers
- Pre-evaluation questionnaire completed

Session 2: Home Visit

- Sleep environment checklist completed
- Sleep diaries collected
- Sleep hygiene handout given to parents/carers

Session 3:

- Formulation shared with parents/carers
- Sleep plan devised with parents/carers
- Sleep pack given to parents

Subsequent sessions:

- Sleep plan review

Final session:

- Post Evaluation questionnaire completed

After final session:

- Closure summary written
- Closure letter sent to family, copied to GP, referrer, paediatrician
- Family feedback form sent with SAE.

C7 Managing Your Child's Behaviour To Promote Better Sleep

Session 1:

- Introduction to the sessions
- Aims of sessions
- Identifying your child's sleep problems
- Identifying past and current management strategies
- Exploring ways in which your child communicates
- Homework

Session 2:

- Recap of session 1
- Importance of sleep routines
- Using reinforcers in a bedtime schedule
- Impact of bedroom environment on sleep behaviour
- Homework

Session 3:

- Recap of session 2
- Analysing sleep problems using the Albany Sleep Scale, sleep diaries and behaviour recording charts
- Homework

Session 4:

- Recap of session 3
- Understanding and using the data collected
- Strategies to manage specific sleep behaviours

C8 Sleep Solutions One-Day Workshop

The manual is divided into 11 timed sessions.

Exemplar schedule

9am – 9.30	Arrival and Registration Ground Rules and Housekeeping Overall aim of the workshop Getting to Know You Effects On The Family
10.30	Break
10.45	Why Is Your Child Not Sleeping The Bedroom Environment Bedtime Routines
12.30	Lunch
1.10	Night Awakenings Sleep Diaries Useful Resources Conclusions and Evaluations
2.30	Finish

Appendix D

Exemplar Checklists

D1 Exemplar checklist: behaviour**Session no checklist****Group:****Start date:**

Date of meeting		
Please tick to show which sections of the manual were covered in this meeting.		
		(v)
Understanding human behaviour		
Understanding autistic behaviour		
What are the main difficulties in ASCs		
Understanding the Iceberg Principle		
Assessing behaviour		
Please list any other topics which were covered during this session but are not set out in the manual for inclusion in this session?		
How much time did you spend on these 'additional topics'?		
Please tick to show who came to the meeting.		
(Names)		(v)

D2 Exemplar checklist: sleep



Session no checklist

Group:

Start date:

The SPaR Project



The Supporting Parents Research Project

Date of meeting		
Please list who facilitated this meeting (name and job title) and also list any other staff that attended this session		
Please tick to show which sections of the manual were covered in this meeting.		
(Topics)		(V)
Introduction		
Aims of sessions		
Group rules		
Impact of Sleep Problems on the Child and the Family		
Scaling exercise – Individual and Group feedback		
Sleep Problems – Individual and Group feedback		
Solutions – Past and present/ Individual/ Group feedback		
Reinforcers		
Communication		
Please list any other topics which were covered during this session but are not set out in the manual for inclusion in this session?		

Appendix D Exemplar Checklists

How much time did you spend on these 'additional topics?
Please tell us who came to this meeting
Please list below anyone who did not come who but you were expecting to attend

Appendix E

The Quantitative Data Analysis

Appendix E

The Quantitative Data Analysis

The outcome indicators

The standardised outcome measures and attainment ratings on parent-set goals formed the quantitative dataset. The psychometric, or standardised, child outcome measures used to investigate the behaviour interventions were:

- Eyberg Child Behaviour Inventory (ECBI): ECBI-Intensity and ECBI-Problem scales
- Child's Challenging Behaviour Scale (CCBS).

The psychometric, or standardised, child outcome measure used to investigate the sleep interventions was:

- Children's Sleep Habit Questionnaire (Total Sleep Disturbance score and the following subscales.³ Night Wakenings; Bedtime Resistance and Sleep Anxiety).

The parent outcome measure used by the study for both behaviour and sleep interventions was:

- The Parenting Sense of Competency Scale (PSOC) (PSOC-Efficacy and PSOC-Satisfaction subscales).

These outcome measures were administered: pre-intervention; post-intervention; 12 weeks follow-up and 24 weeks follow-up.⁴ Where there was a comparator group, equivalent time points were used depending on the typical length of the intervention.

The parent-set goals were identified by parents receiving the intervention at the start or part way through the intervention. (Practitioners had requested that they identify the appropriate stage for the goal-setting exercise.) Parents rated progress towards each goal at the time they set the goal(s) and then at the post-intervention, 12 week follow-up and 24 week follow-up time points.

The unit of analysis

Mothers and fathers participated in this study.⁵ For the child outcome measures and goal attainment ratings, the unit of analysis was the child. Where both parents attended, mothers' data was used. The CCBS was developed for use with mothers. However, we were satisfied to widen that criterion to 'main carer'. Thus, for the CCBS, if the only respondent for a child was the father, he had to describe himself as the 'main carer' of the child to remain in the dataset. The PSOC measured parents' levels of confidence. As the parent is the unit of analysis, all parents (and other primary carers) were included in these analyses.

Missing data

Where data was missing on the standardised measures the following approach was applied.

First, the raw data were examined to see if there were any logical explanations for missing data. This was the case for some items on the ECBI (for example, items about siblings

³ These subscales represented the sleep problems areas amenable to behavioural intervention.

⁴ See Chapter 2 for deviations from this protocol.

⁵ Where a grandparent, foster carer or step-parent attended the group and identified themselves as a primary carer, they were also invited to take part in the research. Adult siblings (accompanying parents) or child-minders/nannies were not recruited.

would not be applicable to children who do not have siblings). For missing items that were clearly left out because they were not applicable, a rating of Never (1) and No (0) were inserted.

For missing items on the ECBI without any logical reason for their absence, guidelines from the manual were followed which instructed that up to three missing items on either the intensity or problem scale could be replaced with a rating of Never (1) and No (0). If more than three items were missing on either scale then a total score could not be calculated and the scale could not be included in any analysis.

For the PSOC, CCBS and CHSQ no guidance from the scale authors regarding the management of missing data is provided. The strategies we used to manage missing data on these scales were based on protocols reported in published studies.

- For the PSOC, if up to one item on either subscale was missing, this was replaced with the subscale mean score for that participant. If there were a greater number of missing items, the respondent's data for that scale was not used.
- For the CCBS if up to one item on the whole scale was missing this was replaced with the scale mean score for the participant. Again, if there were a greater number of missing items, the respondent's data for that scale was not used.
- For the CHSQ total sleep disturbance score, missing items were replaced for up to 3 items (10% of items). As with the ECBI, a conservative approach was taken and missing items were scored as Rarely (1). Any subscales (Night Wakenings; Bedtime Resistance and Sleep Anxiety) with missing data were not used.

Where a parent had not completed a goal attainment scale this was treated as missing data.

Reliability of the scales

Internal consistency alpha reliability coefficients of the scales used as outcome measures were calculated using pre-intervention data for the whole sample.

Behaviour investigations using a 'no intervention' comparator group⁶ (Programmes A-D)

Comparison of the Intervention Group and Comparator Group at baseline

The characteristics of the Intervention Group (IG) and Comparator Group (CG) were compared on a number of variables which were hypothesised to potentially have an impact on intervention effectiveness. The variables were:

- age of child (years)
- child's sex (proportion of boys)
- for those attending groups specifically for parents of children with Asperger's or Autism only: time since diagnosis (less than vs. greater than 6 months)
- schooling (predominantly in specialist⁷ vs. mainstream setting)
- respondent (mother vs. father)
- lone vs. two parent household
- ethnicity (White British vs. other)
- preferred language (English vs. other)
- employment status (working outside of home vs. not)
- school leaving qualification (no GCSE level qualifications vs. at least GCSE level qualifications)

⁶ Except Programme E where small sample sizes prohibited this analytical approach. Please see following sub-section for analytical plan for Programme E.

⁷ Including specialist unit in a mainstream school.

- pre-intervention scores on the standardised outcome measures
- number of children falling above clinical cut-off points on the Eyberg Child Behaviour Inventory (ECBI) scales: ECBI-Intensity and ECBI-problem⁸.

T-test or chi-square statistics were used to test how well matched the two samples were. Where a significant difference was found between the IG and CG with respect to a variable, this variable was then entered as a co-variate in the main analyses.

Parent-set goals

Parents in the IG set specific goals regarding their own child's behaviour. The Intervention Group (IG) mean goal attainment ratings were calculated for baseline,⁹ post-intervention,¹⁰ 12 week and 24 week follow-up time points. A one-way repeated measures ANOVA was used to examine changes in mean goal attainment ratings from baseline to the three follow-up time points. When statistically significant, paired t-tests would further explore where the significant change had occurred.

We also looked at direction of change. At each follow-up point, counts were made of the number of goals where ratings had improved, deteriorated, or not changed compared to baseline ratings.¹¹ Similar counts of the direction of change were made between 12 and 24 week follow-up time points.

Standardised outcome measures

Analysis of covariance (ANCOVA) was used to examine the impact of the intervention on scores on the child and parent outcome measures. Pre-intervention scores were entered as co-variables in these analyses in order to control for any pre-treatment intergroup differences in the dependent variables.

Short-term intervention effects were explored by comparing changes in group mean scores of the Intervention Group (IG) and Comparator Group (CG) from pre- to post-intervention. Longer-term intervention effects, or maintenance of intervention effects, were examined by comparing changes in group mean scores of the IG and CG from pre-intervention to 12 week follow-up.

Data on longer-term outcomes, measured at 24 weeks post-intervention, was only collected from the IG. Where differences had been detected between the IG and the CG at either post-intervention or 12 week follow-up, paired t-tests were then used to test for differences in scores within the IG at pre-intervention and 24 week follow-up.

Clinical significance

The clinical significance of any changes in outcomes was examined in the following ways:

1. Effect size is a measure of the size of difference between group mean scores. It can help show whether a statistically significant result is clinically meaningful or important (Field, 2009). Effect size within, as opposed to between, groups was measured. This approach was chosen because a small sample size can mean that spurious differences in pre-intervention scores between groups make effect size difficult to interpret. Effect size is calculated by dividing the difference between the means by the pooled standard deviation (Cohen's $d = (MT1 - MTx)/SD$). An effect size of 0.2 is small, 0.5 is medium and 0.8 is large (Coe, 2002).

⁸ Behaviour interventions only.

⁹ The time when the goals were set.

¹⁰ Except Programme C where goals were set towards the end of the intervention.

¹¹ Improvement/Deterioration is based on whether the goal scores have moved 1+ scores in a positive or negative direction.

2. Reliable change analysis tests whether a change in scores on a measure is true change or just a reflection of the consistency of the measure (i.e. the reliability of the measure to produce the same score from one administration to the next). To compare rates of reliable improvement in IG and WLC, the following analysis was conducted. Cases were classified as reliably improved if they achieved a score >1.96 on the reliable change index (RCI) (Jacobson and Truax, 1991). The reliable change index (RCI) for each case was calculated by dividing the difference between pre-intervention and post-intervention scores, pre-intervention and 12 week follow-up scores and pre-intervention and 24 week follow-up scores (intervention group only) by the standard error of measurement (SEmeas) [$RCI = (M_{t1} - M_{t2}) / S_{diff}$]. S_{diff} will be obtained by calculating the square root of double the standard error squared ($S_{diff} = \sqrt{2(SE)^2}$). Chi-square statistics were used to examine whether reliable change was significantly different between the IG and CG.
3. Finally, for the behaviour interventions, movement around the clinical cut-off points on the two ECBI scales (ECBI-Problem; ECBI-Intensity) was examined. Cases were classified as clinically improved if they moved from the clinical to the non-clinical range. McNemar's Chi-Square test was used to examine movement around the cut-off point by the IG and CG between pre-intervention and each of the follow-up data collection points.

Individually delivered sleep interventions (Programmes E and F)

Programme E comprised two treatment arms (home visit vs. telephone support). The samples in these two arms were compared against the same set of variables as listed above.

Samples sizes were small for Programmes E and F. Group mean scores for the goals data and the standardised child and parent outcome measures were calculated for each time point. Due to the very small samples tests of statistical significance were not applied. Tests of clinical significance were applied as appropriate.

Group delivered sleep interventions without a comparator group (Programmes G and H)

No comparator group was available for programmes G or H. The goals data was treated in the standard way (see above) and tests of clinical significance were applied as appropriate.

One-way repeated measures ANOVA was used to examine changes in group mean scores on the standardised outcome measures across the study time points. Where results were significant, paired *t*-tests were used to identify the source(s) of difference in scores on the outcome measure.

References

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Appendix F

The Standardised Outcome Measures

Appendix F

The Standardised Outcome Measures

The Eyberg Child Behaviour Inventory (ECBI) (Eyberg and Ross, 1978)

The ECBI is a 36-item parent rating scale designed to be used for children aged 2-16 years. Items consist of behaviours that often cause problems for parents. This measure is widely used in research as well as in clinical practice and was re-standardized for both children and adolescents in 1999 (Colvin, Eyberg and Adams, 1999).

It is scored on two scales, the "Intensity scale" (IS) and the "Problem scale" (PS). On the IS parents rate the frequency of each behaviour from "never happens" (1) to "always happens" (7). On the PS the parents also report whether they perceive the specific behaviour as a problem or not (yes – 1 or no - 0). The number of "yes-answers" is summed and constitutes "the problem index". The IS measures the severity of the child's behaviour whilst the PS reflects the parents' tolerance of the behaviour.

The established cut off scores are 127 for the impact score and 11 for the problem score (Eyberg and Ross, 1978). These have been validated in clinical studies for young children (Webster-Stratton, 1984). However, when Colvin *et al.* (1999) restandardised the ECBI – new cut offs of 132 (impact score) and 15 (problem score) were suggested.

The ECBI has been shown to have good psychometric properties with an internal consistency of .95 (IS) and .93 (PS) (Colvin *et al.*, 1999). Mother and father ratings have been compared (Colvin *et al.*, 1999) and were not found to differ. The discriminative validity of the ECBI has been demonstrated in studies showing significant differences between non-referred, conduct problem, neglected and other clinic-referred children (Funderburk, Eyberg, Rich and Behar, 2003). The ECBI has been shown to correctly classify 96% of clinic-referred and 87% of non-referred preschoolers (Rich and Eyberg, 2001).

Funderburk *et al.* (2003) examined the test-retest reliability of the ECBI and found the Intensity and Problem scales yield test-retest reliability coefficients of .80 and .85 across 12 weeks and .75 and .75 across ten months, respectively. Colvin *et al.* (1999) concluded the ECBI is an internally consistent and homogenous measure with strong internal consistency coefficients demonstrated in the total sampled and within age, gender and race subgroups.

The psychometric properties of this measure in samples of children with disabilities have been examined. In samples of parents of children with learning disabilities (Bagner and Eyberg, 2007) and Aspergers (Sofronoff *et al.*, 2004) acceptable levels of internal reliability were reported. These studies also found the ECBI to successfully detect change following a behavioural intervention (Bagner and Eyberg, 2007; Sofronoff *et al.*, 2004).

Eyberg Child Behaviour Inventory Items
(Eyberg and Ross, 1978) (This measure is subject to copyright.)

Below are phrases that describe children's behaviour. Please (1) circle the number describing how often the behaviour currently occurs with your child, (2) and circle either "yes" or "no" to indicate whether the behaviour is currently a problem for you.

	Never	Seldom	Sometimes		Often		Always	Is this behaviour a problem to you?	
	1	2	3	4	5	6	7	Yes	No
Dawdles in getting dressed									
Dawdles or lingers at mealtimes									
Has poor table manners									
Refuses to eat food presented									
Refuses to do chores when asked									
Slow in getting ready for bed									
Refuses to go to bed on time									
Does not obey house rules on own									
Refuses to obey until threatened with punishment									
Acts defiant when told to do something									
Argues with parents about rules									
Gets angry when doesn't get own way									
Has temper tantrums									
Sasses adults									
Whines									
Cries easily									

Appendix F The Standardised Outcome Measures

Yells or screams									
Hits parents									
Destroys toys and other objects									
Is careless with toys and other objects									
Steals									
Lies									
Teases or provokes other children									
Verbally fights with friends own age									
Verbally fights with sisters and brothers									
Physically fights with sisters and brothers									
Constantly seeks attention									
Interrupts									
Is easily distracted									
Has short attention span									
Fails to finish projects or tasks									
Has difficulty entertaining self alone									
Has difficulty concentrating on one thing									
Is overactive or restless									
Wets the bed									

The Child's Challenging Behaviour Scale (CCBS) (Bourke-Taylor *et al.*, 2009)

The Child's Challenging Behaviour Scale is a newly developed 11-item parent rating scale. It was designed to assess a mother's observation of home based behaviours of their disabled child that were difficult to manage. It is entirely derived from parents' accounts of the behaviours they find difficult to manage in the home.

The CCBS has one total score from its scale. Items are scored on a 5-point scale from strongly agree (1) to strongly disagree (5). Items three and six are reverse coded so that a higher score reflects behaviour that is more difficult to manage. Scores can range from 11-55.

The CCBS has shown excellent internal consistency ($\alpha=0.89$) and factor analysis supported a unidimensional scale. Construct validity has been supported with correlations with the PedsQL Psychological Health Summary Score ($\rho=-0.51$). Parents of children with autism of psychiatric conditions were found to score significantly differently than parents with children without these conditions.

The Child's Challenging Behaviour Scale (CCBS)

	Strongly agree	Agree	Unsure	Disagree	Strongly disagree
1. My child does not usually yell and scream when things do not go his/her way.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My child never has tantrums.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My child aggravates others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. My child is never aggressive and violent toward others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. My child does not mind when I leave them at home with another adult while I go out.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My child can be stubborn and uncooperative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I am able to manage my child's behaviour easily at home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I am able to manage the most challenging and difficult behaviours effectively on my own at home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. My child is happy and content at home most of the time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. My child follows the family routine easily.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. My child copes well with disruption to the family routine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The Child's Sleep Habits Questionnaire (CSHQ) (Owens *et al.*, 2000)

This is a 33-item parent-report questionnaire developed to assess the severity of sleep problems in children aged 4-10 years. Parents are asked to respond about the child's sleep over a 'typical' recent week. Sleep behaviours are rated on a three-point scale: 'usually' (behaviour occurred five to seven times); 'sometimes' (occurred two to four times); 'rarely' (occurred zero or once). All scores are combined to calculate a Total Sleep Disturbance Score. Items can also be grouped into eight domains for further analysis: bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night wakings, parasomnias, sleep disordered breathing, daytime sleepiness and scores for each of these calculated.

The Child's Sleep Habits Questionnaire has been validated with a community sample of 469 children and a paediatric clinic sample of 154 children diagnosed with sleep disorders. Internal consistency in both samples was acceptable; Cronbach's alphas 0.68 and 0.78 with variability in the subscales ranging from 0.36 (parasomnias) to 0.70 for the community and clinic sample respectively. All subscales apart from parasomnias and sleep disordered breathing were over 0.60. In the clinic sample, alpha was 0.78 for the total scale and ranged from 0.44 (night wakings) to 0.83 for the subscales. All subscales apart from parasomnias and night wakings were over 0.60.

Test-retest reliability over a two-week period ranged from $r=0.62$ to $r=0.79$ for the subscale scores. Discriminant validity was assessed by comparing scores for clinic and community samples. The clinic group had higher scores on all items; statistically significant for 30 of the 33 items at $p<0.001$. The three non-significant items were on the daytime sleepiness scale. There were also significant differences between the groups on all subscale scores ($p<0.001$) and on total scores ($p<0.0001$). Using a cut-off score of 41 of the Total Sleep Disturbance Score correctly identified 80% of the clinical group.¹²

Owens *et al.* (2000) conclude that the CSHQ appears to be a useful screening instrument to identify both behaviourally based and medically based sleep problems in school aged children. They suggest that validity in the clinical setting would be enhanced by using sleep diaries to describe sleep onset delay, and that the CSHQ could be useful in identifying sleep disturbances in children with chronic illnesses or mental health disorders.

The CSHQ has been used and validated on younger children (aged 2 plus) and children with disabilities. Goodlin Jones *et al.* (2008) used the CSHQ to screen for sleep problems in 194 toddlers and preschool children, 68 of whom had autism spectrum disorders and 57 with developmental delay. Scores were compared with actigraph data, parent diaries and reports of sleep problems from families. Total and subscale scores were significantly different for parents who did and did not report a sleep problem ($p<0.001$). For those that were identified by the CSHQ as having a sleep problem, there were no differences related to diagnostic group. For those that were not identified as having a sleep problem, the only significant difference between groups with different diagnoses was that children with developmental delay had higher scores on the sleep disordered breathing scale than those with ASD or typically developing children. The advantage of using the CSHQ for evaluations of interventions for young disabled children are that it has been validated with children between two and ten years, it has been validated with disabled children, and it includes sleep disorders due to sleep disordered breathing, which is more common in some disabled children. Its disadvantage could be its length, neither study have reported completion rates.

¹² Inconsistencies in the advice given regarding the numerical values to use when scoring some items resulted in the team choosing not to use the clinical cut-off point in this study.

Child's Sleep Habits Questionnaire

The following statements are about your child's sleep habits and possible difficulties with sleep. Think about the past week in your child's life when answering the questions. If last week was unusual for a specific reason (such as your child had an ear infection and did not sleep well or the TV set was broken), choose the most recent typical week. Answer **'Usually'** if something occurs **5 or more times** in a week; answer **'Sometimes'** if it occurs **2-4 times** in a week; answer **'Rarely'** if something occurs **never or 1 time** during a week. Also, please indicate whether or not the sleep habit is a problem by ticking [✓] 'Yes', 'No' or 'Not applicable (N/A)'.

Bedtime

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
Child goes to bed at the same time at night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child falls asleep within 20 minutes after going to bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child falls asleep alone in own bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child falls asleep in parent's or sibling's bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child falls asleep with rocking or rhythmic movements	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child needs special object to fall asleep (doll, special blanket etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child needs parent in the room to fall asleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child is ready to go to bed at bedtime	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child resists going to bed at bedtime	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child struggles at bedtime (cries, refuses to stay in bed etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child is afraid of sleeping in the dark	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child is afraid to sleep alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>

Sleep behaviour

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
Child sleeps too little	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child sleeps too much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child sleeps the right amount	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child sleeps about the same amount each day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child wets the bed at night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child talks during sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child is restless and moves a lot during sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child sleepwalks during the night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child moves to someone else's bed during the night (parent, brother, sister etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child reports body pains during sleep. If so, where? _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child grinds teeth during sleep (your dentist may have told you this)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child snores loudly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child seems to stop breathing during sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child snorts and/or gasps during sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child has trouble sleeping away from home (visiting relatives, vacation)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child complains about problems sleeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child awakens during night screaming, sweating, and inconsolable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>

Child awakens alarmed by a frightening dream	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
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Waking during the night

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
Child awakes once during the night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child awakes more than once during the night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child returns to sleep without help after waking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>

Morning waking

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
Child wakes up by him/herself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child wakes up with alarm clock	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child wakes up in negative mood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Adults or siblings wake up child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child has difficulty getting out of bed in the morning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child takes a long time to become alert in the morning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child wakes up very early in the morning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child has a good appetite in the morning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>

Daytime sleepiness

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
Child naps during the day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child suddenly falls asleep in the middle of active behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Child seems tired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>

During the past week, your child has appeared very sleepy or fallen asleep during the following (please tick [✓] all that apply).

	1 Not sleepy	2 Very sleepy	3 Falls asleep
Playing alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Watching TV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Riding in car	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Eating meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The Parenting Sense of Competence Scale (PSOC) (Gibaud-Wallston and Wandersman, 1978, Johnson and Mash, 1989)

The PSOC is a 16 item scale that has two subscales: the Satisfaction Subscale measures the extent to which parents are satisfied with their role as a parent, and the Efficacy Subscale measures the extent to which parents feel they are managing the role of being a parent. The Satisfaction subscale is an affective dimension reflecting the extent of parental frustration, anxiety and motivation, whilst the Efficacy subscale is an instrumental dimension reflecting competence, problem solving ability and capability in the parenting role (Plant and Sanders, 2007). Parents are asked to respond to a series of questions about parenting, indicating their level of agreement or disagreement on a 7-point Likert scale (1=strongly disagree, 7=agree).

The measure has been shown to be reliable, with internal consistency estimates in a normative sample of 0.77 (efficacy and satisfaction scales) and 0.75 (efficacy scale) and 0.70 (satisfaction scale) in a sample of high risk control group (McCarty and Doyle, 2001). This internal consistency has been repeated in a sample of parents of children with developmental disabilities; Plant and Sanders (2007) found satisfactory internal consistency levels of $\alpha=.74$ (Total), $\alpha=.80$ (satisfaction) and $\alpha=.70$ (efficacy).

Parenting Sense of Competency Scale (PSOC)
(Gibaud-Wallston and Wandersman, 1978; Johnson and Mash, 1989)

For each of the 16 statements below, please consider if it applies to you. Then for each statement please tick [✓] **one** box only from A to F to indicate how much you agree or disagree. Do not make any marks to the right of the double line.

	A Strongly agree	B Agree	C Slightly agree	D Slightly disagree	E Disagree	F Strongly disagree
1. The problems of taking care of a child are easy to solve once you know how your actions affect your child. I have acquired this understanding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Even though being a parent could be rewarding, I am frustrated now while my child is at his/her present age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I go to bed the same way I wake up in the morning, feeling I have not accomplished much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I do now know why it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. My mother/father was better prepared to be a good mother/father than I am	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I would make a fine model for a new mother/father to follow so that she/he could learn to be a good parent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Being a good parent is manageable, and any problems are easily solved	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Sometimes I feel like I'm not getting anything done as a parent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I meet my own personal expectations in my ability to care for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. If anyone can find the answer to what is troubling my child, I am the one	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix F The Standardised Outcome Measures

	A Strongly agree	B Agree	C Slightly agree	D Slightly disagree	E Disagree	F Strongly disagree
12. My talents and interests are in other areas, not in being a parent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Considering how long I've been a mother/father, I feel thoroughly familiar with this role	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. If being a mother/father of a child were only more interesting, I would try harder to do a good job as a parent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I honestly believe that I have all the skills necessary to be a good mother/father to my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Being a parent makes me tense and anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix G

Sample Costs Data Collection Sheet

Appendix G Sample Costs Data Collection Sheet

Name of intervention											
Duration of the intervention		Total number of sessions comprising the intervention						How long does each session last?			
Geographical location(s) of where delivered (postcode)											
Staff (including any administrative staff)											
Name	Job title	Employer (e.g. NHS, LEA, vol sector org. etc.)	Grade / banding	Role in delivering the intervention	Hours spent on setting up the group (incl. pre-group visits, phone calls to families etc.)	Total hours spent planning sessions	Total hours spent delivering intervention	Total hours spent de-briefing	Number of sessions attended		
Venue used/costs											
Additional things provided											
	Y/N										
Childcare/crèche			Description:								
Transport			Description:								
Handouts (more than photocopies)			Description:								
Presents/ gifts			Description:								
Refreshments			Description:								
Interpreters/translators			Description:								
Specialist equipment (e.g. video camera, DVD player, projector)			Description:								

Appendix H

Client Service Receipt Inventory (adapted version)

Appendix H: Client Service Receipt Inventory (adapted version)

Some parents say that having a child with an ASC or other disability affects their work and their health. The first questions in this section ask you about this, and then we finish off with some questions about the support and services your child has used.



1. Are you working at all at the moment?

- | | | |
|---|---|---|
| <input type="checkbox"/> Paid employment | <input type="checkbox"/> Volunteer work | <input type="checkbox"/> Primary home maker (go to q.5) |
| <input type="checkbox"/> Long-term sick (go to q.5) | <input type="checkbox"/> Unemployed / job seeking (go to q.5) | |
| <input type="checkbox"/> Student (go to q.5) | <input type="checkbox"/> Retired (go to q.5) | |

ONLY ANSWER THESE QUESTIONS IF YOU ARE CURRENTLY WORKING (IF NOT GO TO Q.5)

2. What is your job/ occupation? _____

3. How many hours a week do you usually work?

- | | |
|---|---|
| <input type="checkbox"/> 30 hours or more | <input type="checkbox"/> Less than 30 hours |
|---|---|

4. In the last 3 months have you had to take time off work because of your child's behaviour problems?

- | | |
|-----------------------------|--|
| <input type="checkbox"/> No | <input type="checkbox"/> Yes, approximately _____ days in the last three months. |
|-----------------------------|--|

NOW PLEASE GO TO QUESTION 6

ONLY ANSWER THIS QUESTION IF YOU ARE CURRENTLY NOT WORKING

5. In the past 3 months have there been any days when your child's problems have meant that you felt you couldn't take part in your usual activities?

- | | |
|-----------------------------|---|
| <input type="checkbox"/> No | <input type="checkbox"/> Yes, approximately _____ days? |
|-----------------------------|---|

6. Do you think that your child's behaviour problems have affected your health?

- | |
|---|
| <input type="checkbox"/> No (please go to q.8) |
| <input type="checkbox"/> Yes (please go to q.7) |

7. Have you sought help in the last three months from any service because your child's behaviour problems have affected your health?

- | |
|--|
| <input type="checkbox"/> No (please go to q.8) |
|--|



- ☐ Yes, please tell us (on the next page) where you have gone for help in the last three months because your child's behaviour problems have affected your health:

✓		<i>Approximately how many times in <u>the past three months</u> have you used this service?</i>
<input type="checkbox"/>	GP	
<input type="checkbox"/>	Practice nurse	
<input type="checkbox"/>	Hospital outpatient clinic	
<input type="checkbox"/>	Counsellor	
<input type="checkbox"/>	Alternative therapist	
<input type="checkbox"/>	Self help or Support group	
<input type="checkbox"/>	Website/ Telephone helpline	
<input type="checkbox"/>	Other	

This section is all about the support and services your child has received or used in the past three months.

8. In the past 3 months has your child had any prescriptions for medication?

- ☐ No ☐ Yes. How many? _____

9. In the past 3 months, how many times has your child....? (please tick if you have used this service and insert how many times you have used it)

- ☐ Visited accident and emergency: _____ times. ☐ Stayed overnight in hospital: _____ times

10. Does your child use a short break services?

- ☐ No ☐ Yes, please tell me about how many days a year? _____

11. Please tick which support and services your child has received/ used in the past three months and give detail about how often they have used them.

✓		If yes, about how many times in the past 3 months?
<input type="checkbox"/>	GP for help with child's behaviour	
<input type="checkbox"/>	GP for other reasons	
<input type="checkbox"/>	Health visitor / specialist health visitor about child's behaviour	
<input type="checkbox"/>	Health visitor / specialist health visitor for other reasons	
<input type="checkbox"/>	Community nurse about child's behaviour	
<input type="checkbox"/>	Community nurse for other reasons	
<input type="checkbox"/>	Hospital outpatient appointment/clinics for child's behaviour	
<input type="checkbox"/>	Hospital outpatient appointment/clinics for other reasons	
<input type="checkbox"/>	Practice nurse	
<input type="checkbox"/>	Alternative therapist	
<input type="checkbox"/>	Social worker	
<input type="checkbox"/>	Key worker	
<input type="checkbox"/>	Home help/home care worker	
<input type="checkbox"/>	Family support worker	
Please tick if you have had any appointments in the past 3 months with any of the following people which have taken place somewhere other than a hospital?		
<input type="checkbox"/>	Specialist doctor (not GP)	
<input type="checkbox"/>	Family therapist	
<input type="checkbox"/>	Child and adolescent mental health team	
<input type="checkbox"/>	Speech and language therapist	
<input type="checkbox"/>	Occupational therapist	

12. What type of school did you child go to last term?

- ☐ Too young to attend school/ nursery (please move to the next section on page 9)
- ☐ Nursery (not child-care) / pre-school
- ☐ Mainstream primary school
- ☐ Special unit in mainstream school
- ☐ Special school



- ☐ Secondary school
☐ Other (please describe) _____

13. During this last term how many days a week did your child usually go to nursery/school? _____

14. Did your child have any days off during this last term because of his/her behaviour problems?

- ☐ No ☐ Yes, please tell me about how many times? _____

15. Does your child have a statement of educational needs (SEN statement)?

- ☐ No ☐ Yes

16. Has your child ever been excluded from school?

- ☐ No ☐ Yes, please describe how your child has been excluded:

✓		<i>Approximately how many days or months?</i>
<input type="checkbox"/>	Permanently excluded	
<input type="checkbox"/>	Formally excluded	
<input type="checkbox"/>	Excluded informally	

Appendix I

Costs Data: The Plan of Analysis

Appendix I

Costs Data: The Plan of Analysis

An exploration of the use of services and supports was integrated into the study. Such data, alongside the outcomes evaluation, provide the basis for a cost-effectiveness analysis. We were cautious in our initial assessment of the extent to which we could complete cost-effectiveness analyses for each site, or indeed across the sleep and behaviour interventions, as we were unsure whether sufficient intervention and control samples could be recruited.

Economic analyses tend to require much larger samples than outcome analyses due to the common right-hand skew of the cost data where many sample members will have relative low levels of service use (low costs) and just a few will be high users of services (high costs) leading to a non-normal distribution. Following the design of the study in each site our aims were to collect sufficient data to allow the following tasks:

- to estimate the costs of the interventions
- to present a profile of how children and parents used services in each site, including the intervention
- to estimate the costs of these 'support packages' before and after receiving the intervention
- to set that cost information in the context of the outcomes generated
- and to undertake cost-effectiveness analysis where the data allowed.

The questionnaire to be completed by each parent in the study included an amended short form of the Client Service Receipt Inventory, a schedule on which the use of service and supports can be recorded (Beecham and Knapp, 2001). We asked parents to report whether the child's problems had affected their health and whether this had meant they had used any of the following services in the past three months; general practitioner (GP), general practice nurse, outpatient appointment, counsellor, alternative (complementary) therapy, self-help/support groups, and an open question to record use of other services. We also asked whether the child's sleep or behaviour problems had an impact on their work – how many days' work they had missed – or on their daily activities.

We asked about the type of school the child attended and whether they had missed days at school because of their sleep or behaviour problems. A further section of the questionnaire focused on the child's use health and social care services such as the general practitioner, community-based nurses, hospital care, mental health services, social workers, keyworkers, and respite care. We asked parents to separate use of some services into behaviour-related visits or visits for other reasons; GPs, health visitors, community nurses and out-patient appointments. Data on their use of the sleep or behaviour intervention were recorded separately. This information forms the basis of our calculation of the public sector costs of supporting both children and parents and while we summarise this information in the main part of the report, tables describing the utilisation rates for each service for both parents and children, groups by the intervention they used, can be found in Appendices Q, R and S.

To attach costs to these service use data, we identified 'unit costs' (per day, per contact, etc.) for each of the services and supports used. In the main, the unit costs were taken from a well-established annual compendium of nationally applicable unit costs (Curtis, 2010) although as unit costs for children's services are less well researched some, such as for the

interventions under study, were specifically estimated using a commensurate method (see, for example, Beecham, 2000). All costs are expressed at 2009-2010 prices.

Each unit cost was then multiplied by the use made of the relevant service by each parent or child to arrive at a 'support package cost' per child (Beecham, 1995). We distinguish costs for parental supports and for child supports, and for the latter present the costs data in 'service groups' according to broad categories of providers. We also describe the impact of the children's sleep or behaviour problems on parents' work and daily life. As the data were collected at the same time as the outcomes data, for most of the samples we have information at Time 1 (baseline, prior to intervention) and T3 which was collected some 12 weeks after the intervention was finished. For some sites we have information at Time 2 – just after the intervention had finished.

Our approach to estimating the cost of the intervention was similar; we were interested in the totality of resources a parent received rather more than simply the cost to the providing agency. Staff hours comprise the major part of the intervention costs (for organising the group, preparing and delivering session and debriefing) but costs also accrue for the venue, refreshments and the various materials used on the course. While the costs to the public sector remain the same regardless of how many parents attend the course, the costs for the amount (or 'dose') of the intervention that each parent receives varies with

- a) the number of participants at each session (for example, fewer attenders mean that the facilitating staff are 'shared' between fewer parents and those parents get a relatively more intensive (more costly) session; and
- b) the number of sessions each parent attends.

Our main 'unit cost' for the intervention therefore reflected the 'average cost per attender per session' and varied with the number of facilitators *and* attendees at that session. One of the behaviour interventions, for example showed a more than four-fold difference in this unit cost; between £19 and £89. The *intervention cost per parent* was obtained by adding together the 'unit cost' of each session they attended. Intervention costs accrued between the T1 and T2 interviews.

Once the data had been collected we found we had sufficient information to estimate support package costs, for parents and children receiving three of the interventions; Cygnet, Ascend, and Riding the Rapids. For each of these we present the data in the manner described above. The costs have been derived using SPSS and t-tests have been used to identify differences between groups in the mean cost. Given the small sample sizes and wide variation in costs, bootstrapped confidence intervals (1000 repetitions) have also been reported; where the confidence interval passes through zero, there is no significant difference between the means being tested.

For other interventions, where data could not be collected for a large enough sample or where there were insufficient data from a comparison group, we have presented 'costed case studies'. These describe the circumstances of some of the parents in the studies drawing on the clinical data, the qualitative interviews as well the service use profiles and their associated costs.

References

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Appendix J

Exemplar Interview Schedule and Topic Guides: Practitioners

J1 Practitioner interview schedule

OPENING: thanks; time needed, remind re confidentiality, consent process

QUESTIONS FOR THOSE IN CHARGE OF DELIVERING THE SERVICE (1/SITE)

1. History behind deciding to offer an intervention
2. When trying to set it up, were there any barriers that had to be overcome?
3. Factors which helped/supported the setting up process
4. Those using Cygnet/non-York ASCEND (or skip to Q5): Rationale for choosing to deliver Cygnet
 - Probe*
 - the content of the intervention
 - group mode
 - cost issues? (including cost of purchasing manualised intervention)
 - was there any special training provided for facilitators/trainers?
 - Any others considered before choosing Cygnet
5. Where interviewee involved in developing the intervention: rationale for what they developed
 - Probe*
 - the content of the intervention
 - group mode
 - cost issues? (including cost of purchasing manualised intervention)
 - was there any special training provided for facilitators/trainers?
 - any 'special' things they do (*fill in here:* _____)
 - has the intervention been changed/modified since started using it and why
6. Referral
 - how do families get referred to / get to join the intervention
 - views on barriers to referral / parents finding out about the intervention
7. Take-up
 - General views on take up rate
 - Barriers to take-up
 - Probe:* time of day/childcare, the mode of the intervention (e.g. group), 'readiness' and any others
 - Views on how to improve take-up
8. Missing sessions/'drop out' rates
 - Practical barriers parents face to getting along to/completing the intervention
 - Views re. other reasons why parents 'drop out'
 - What do they do when parent misses a session
 - What do they do if a parent stops coming altogether
9. Views on involvement or not of fathers and/or other family members
 - 'Policy' re this and reasons for that position
10. Are other organisations/services working with the child informed the parent is receiving the intervention? If yes, Why? Are any efforts made to ensure consistency in the approach to managing the child's behaviour.

QUESTIONS FOR ALL INTERVIEWEES

11. Main desired outcome(s) for parents and children through receiving the intervention
12. How successful is the intervention in achieving these?
13. Views on aspects of the intervention which makes it effective
 - Content
 - Delivery mode
 - Practitioner skills and knowledge
 - 'Homework'
 - Views on ways in which intervention could be improved to improve effectiveness (e.g. Content, way it is delivered, other...)
14. Views on other factors perceived to affect effectiveness
 - Parent factors (e.g. parental readiness, educational attainment, self-confidence)
 - Family factors (e.g. participation of /support from other family members, chaotic families, families with more pressing issues)
 - Disability factors (e.g. nature of disability, severity, health crises)
 - Other
15. Experiences of delivering the intervention
 - What aspects of the intervention work well/are easy to deliver and why
 - Any aspects more difficult to deliver and why
 - [For sleep interventions] is there a tension between dealing with sleep issues rather than other challenging issues such as behavioural problems? If yes, how do you manage this?
16. Where relevant, delivering to ethnic minority groups: any particular issues feel need to accommodate/address
 - Delivering the intervention via a translator: how satisfactory; any views on impact on group dynamics etc.
17. Views on what gets in the way of positive outcomes being maintained once the intervention is finished
 - What the services does to support on-going implementation of new knowledge/skills and maintaining positive outcomes
 - Views on how this could be improved/what would like to do regarding this.
 - Barriers to making these improvements
18. Views on impact of the intervention on longer term outcomes – do they know whether the intervention has lasting benefits?
 - Any concerns/thoughts re this?
 - What would like to do to address this issue?
 - Barriers to doing this.
19. **Wind up questions:** Views on the general state of support (across the country) available to parents of disabled children regarding managing their child's sleep and/or behaviour.

- What are the 'costs'/risks (for child, parent and family) of not properly supporting parents with disabled children to manage their sleep/behaviour.
- From a personal point of view, what was it like for you delivering the intervention?

CLOSE

Opportunity for questions for researcher

Remind re timetable for publication of findings

Remind re confidentiality

Thanks

J2 Exemplar Topic Guide for Focus Groups with Practitioners (Behaviour)

FOCUS GROUP: [name of intervention]

Venue: [venue]

Date: [date]

Session 1: Introductory Session

Time: 1.30pm

TOPICS TO COVER:

- 1. Welcome and thanks for coming to talk about your experiences of running a parent group.**
- 2. Introduce research team**
- 3. Programme of afternoon**
 - 1.30pm Introduction
 - 1.40pm DYNAMICS OF DELIVERING A GROUP INTERVENTION
 - 2.10pm MAINTENANCE OF IMPROVEMENTS
 - 2.25pm Closing remarks
- 4. A word about ...**
 - Confidentiality
 - Phones/mobiles
 - Check ok to record session

***** SWITCH ON RECORDER *****

5. Round group introductions

Go round group and ask each professional to introduce themselves - tell us their name; their job title and their experience of running/facilitating parent groups.

Session 2: Dynamics of Delivering a Group Intervention

Time: 1.40pm

FUNCTION: to explore the benefits and shortcomings of delivering a group (as opposed to a one-to-one) intervention

WARM UP ACTIVITY

What things do you think are really good about the parent-training programme?

TOPICS TO COVER:

1. What works well delivering the intervention through a group format?

- How do parents use each other to get added value? (e.g. provide mutual support, sense of not 'being alone', learn from each other, etc.)
- What do you do to foster that added 'group' value? (e.g. type of activities, purposefully select parents, size of group)

2. What doesn't work so well?

- Are there particular situations/types of group when does the group dynamic fail / break down or just don't work as well? (e.g. when one parent dominates or another doesn't get involved; group size; when children differ e.g. disability, age, time since diagnosis)

3. Does the group dynamic differ between a mothers only group and a mixed group of mothers and fathers, or mothers and other family members?

- What are the benefits / disadvantages of a mothers only group?
- What are the benefits / disadvantages of a mixed group?

4. How well do parents who do not speak English as a first language engage in the group? (what is done to make sure that these parents feel part of the group?)

- Do groups where more than one language is spoken differ to English only groups? Explore how they are different (benefits/disadvantages).
- What has been your experience of including interpreters in the group?
 - Lessons learnt.

5. How do you tailor the sessions so that they are relevant to the different disabilities represented?

- How easy is it to provide disability-specific strategies that relate to how the child sees the world, e.g. helping parents to understand mindblindness in children with autism (or behaviours associated with cerebral palsy) when you are working with a mixed disability group.

Session 3: Maintenance of Improvements

Time: 2.10pm

FUNCTION: to explore longer term positive effects of intervention and ways to support continuing positive outcomes.

TOPICS TO COVER:

1. Do you think the parent-training programme has a long term positive effect for parents?

Probe reasons for opinions/difference in opinion within the group.

- Do you have any evidence/examples of positive outcomes being maintained over time?
- ?? what gets in the way of maintaining improvements??

2. What does the intervention do to support longer term positive outcomes? (e.g. organise a reunion meeting, signpost to other sources of support, provide telephone support, facilitate parents to keep in touch)

3. What else could RtR do? (e.g. see above)

Concluding Session: Closing Remarks

Time: 2.25pm

TOPICS TO COVER:

- Summarise discussion and ask staff for any additional comments.
- Thank participants and remind re confidentiality
- Explain what happens next (summary of findings/dissemination)
- Any questions
- Close

MATERIALS

- Labels for name badges
- Consent forms
- Information leaflets
- Flip chart paper
- Blu tac
- Marker pens
- Pens
- Digital recorder (plus back up) and spare batteries
- Topic guides
- Cakes!

J3 Exemplar Topic Guide for Focus Groups with Practitioners (Sleep)

FOCUS GROUP: [name of intervention]

Venue: [venue]

Date: [date]

Session 1: Introductory Session

Time: 2.00pm

TOPICS TO COVER:

1. Welcome.

2. Introduce research team

3. Programme of afternoon

- 2.00pm Introduction
- 2.10pm DYNAMICS OF DELIVERING THE SLEEP INTERVENTION
- 2.35pm MAINTENANCE OF IMPROVEMENTS
- 2.55pm Closing remarks

4. A word about....

- Confidentiality
- Phones/mobiles
- Check ok to record session

***** SWITCH ON RECORDER *****

5. Round group introductions

Go round group and ask each professional to introduce themselves - tell us their name; their job title and their experience of delivering the intervention.

Session 2: Dynamics of Delivering a Sleep Intervention

Time: 2.10pm

FUNCTION: to explore the benefits and shortcomings of delivering this sleep intervention

ACTIVITIES

What are the main things that parents are hoping to achieve when they come along to the intervention?

Ask sleep counsellors to call out their responses – researcher to write up on flip chart.

How successful do you think the intervention is in helping families achieve these outcomes?

Ask sleep counsellors to come and rate on a ladder how successful the service has been for the families they have worked with:

1 – Not successful for families

10 – Very successful for families

What makes the intervention effective and what gets in the way?

Hand out coloured cards and ask sleep counsellors to list up to three things about the intervention that helped the families they have worked with to achieve these outcomes, and three things that can get in the way.

Collect the cards and put the different responses up on two spider charts.

1. What makes the sleep support intervention effective?
2. What can limit the effectiveness of the intervention?

Use these charts to spark a discussion about what helps the intervention to be successful and what can stop it from working.

The following aspects may be used as probes:

CONTENT/DELIVERY

- Content of the intervention (assessment, sleep diaries, home visit, progress meetings)
- Meeting parents 1-1. Providing flexibility. Missed appointments.
- Are sessions always face to face?
- The importance of the Children's Centre – familiar place for the families? Close geographically/ easy to access?

THE FAMILY SITUATION

- How easy is it to focus on the sleep work or do other issues (child's ill health, parent's health, family issues ...) get in the way?
- Is it usually just one parent, or both that you tend to work with? How important are the rest of the family when implementing the intervention?
- What do families need to do to prepare for the intervention and make it work? Capability and readiness.

SLEEP COUNSELLOR – FAMILY RELATIONSHIP

- Confidence in delivering the intervention. Check how the sleep counsellors usually work (alone/in pairs) and why they work in this way
- Do you usually know the families they are working with? What might be helpful or unhelpful about this (e.g. parents feel comfortable, sleep work can get mixed up with other issues the sleep counsellors are working on).
- Time – do you feel you have enough time to provide this support. How many families will you typically be working with on their sleep at one time?

Session 3: Maintenance of Improvements

Time: 2.35pm

FUNCTION: to explore longer term positive effects of intervention and ways to support continuing positive outcomes.

TOPICS TO COVER:

4. Do you think the intervention has a long term positive effect for parents?

Probe reasons for opinions/difference in opinion within the group.

- Do you have any evidence/examples of positive outcomes being maintained over time?
- ?? what gets in the way of maintaining improvements??

5. What does the intervention do to support longer term positive outcomes? (eg organise a follow up meeting, signpost to other sources of support, provide telephone support, keep in touch with parents as they are using other services in the Children's Centre)

6. What else could the intervention do? (e.g. see above)

Concluding Session: Closing Remarks

Time: 2.55pm

TOPICS TO COVER:

- Summarise discussion and ask staff for any additional comments.
- Thank participants and remind re confidentiality
- Explain what happens next (summary of findings/dissemination)
- Any questions
- Close

MATERIALS

- Labels for name badges
- Consent forms
- Information leaflets
- Flip chart paper
- Ladder
- Coloured paper
- Blu tac
- Marker pens
- Pens
- Digital recorder (plus back up) and spare batteries
- Topic guides
- Chocolates!

Appendix K

Description of Qualitative Research with Practitioners

Appendix K

Description of Qualitative Research with Practitioners

This appendix describes the methods used during the qualitative phase of the project with practitioners, which consisted of 23 individual interviews and two focus group discussions. The individual interviews took place between October 2010 and April 2011; the focus groups were held in September and November 2010.

Procedure

Individual interviews

A purposive sampling strategy was used which aimed to recruit the programme authors and other key practitioners involved in delivering the programmes in each of the intervention sites. All the selected practitioners were sent an email by one of the members of the research team, inviting them to take part in a telephone interview. A leaflet with further information about the interviews was attached to the email. If the practitioner was willing to take part, a mutually convenient date and time of the interview was arranged. A list of interview topics was then sent to the practitioner.

Three researchers conducted the phone interviews, which typically lasted between 60 and 90 minutes. The interview schedule is contained in Appendix J.

Focus groups

In two cases, it was deemed more practical and resource-efficient to conduct group interviews with practitioners. These focus groups involved discussions with eight co-facilitators from one behaviour-management intervention (D) and seven sleep counsellors from one sleep management intervention (F). All participants were sent an information leaflet about the focus group which included a description of the topics to be discussed. The focus groups took place in meeting rooms in the local CAMHS (D) and Children's Centre (F) and lasted around 60 minutes. Two researchers facilitated discussions which began with participants agreeing the ground rules of the meeting. The topic guide for these group interviews can be found in Appendix J.

Sample

The final interview sample comprised 24 practitioners (behaviour interventions) and 25 practitioners (sleep interventions). A breakdown of this sample by intervention is provided in Table K.1.

Table K.1 Interview sample in each intervention and/or site

		Intervention site number (where applicable)	Interview participants n
BEHAVIOUR	Intervention A	1	2
		2	2
		3	2
	Intervention B	1	2
		2	1
	Intervention C	1	2
		2	3 ¹
	Intervention D	n/a	2
	Focus group		8
	Sub total		24
SLEEP	Intervention E	n/a	2
	Intervention F	n/a	1
	Focus group		7
	Intervention G	n/a	3
	Intervention H	n/a	2
	Sub total		15
	All interventions		39

¹ One interview took place with two practitioners

Ethical considerations

Ethical approval for the study was obtained from the South Humber NHS Research Ethics Committee, and research governance approval was obtained from local R&D Committees in intervention sites. Verbal consent was obtained from all practitioners at the time of interview and written consent obtained post interview. Consent included permission from each participant to digitally record the interviews for transcription.

Analysis

All the interviews were digitally recorded and then transcribed for thematic analysis.

Use of quotations

Quotations from interviews were used to illustrate the topics and themes identified. Each of the practitioners who took part in an interview was assigned a unique identity number, which is displayed after each quote used throughout this report. If the practitioner was participating in a focus group discussion, this is indicated after the identity number by 'FG'.

Appendix L

Description of Qualitative Research with Parents

Appendix L

Description of Qualitative Research with Parents

This appendix describes the methods used during the qualitative phase of the project with parents, which consisted of focus group discussions and/or individual interviews. The focus groups took place between March and October 2010, and the individual interviews between July 2010 and March 2011.

Procedure

Focus groups were initially undertaken to inform the development of the schedules for the individual interviews with parents. However, the data generated through discussion and interaction within the group became an important source of primary data in itself.

Focus groups

Parents who had participated in the group-based training programmes (excluding the one-day workshops) were invited to take part in focus group discussions about their experiences of the programme. All those who had attended a parenting group in the last 18 months were forwarded a letter of invitation from the research team by the programme's lead facilitator. (Most of these parents had already completed questionnaires for the study.) Enclosed with the letter was an information leaflet providing further details about the group, and a response form for parents to indicate their willingness to take part and return to the research team.

In total, there were six focus groups with parents: five groups from three of the behaviour interventions and one group from the sleep interventions (see Table AL.1). The research team were unable to recruit a sufficiently large enough group of parents from the remaining group-based parent-training programme (B), despite the inducement of a £20 high street shopping voucher for those who took part. Attempts to set up a meeting on two different occasions failed, and the research team took the decision to carry out more in-depth individual interviews with the few parents that did positively respond.

Each achieved group had between four and eight participants. The time that elapsed between the end of the intervention and the focus group taking place ranged between 12 and 82 weeks for the behaviour interventions (mean=33), and was 28 weeks for the one sleep intervention focus group.

Discussions lasted around 75 minutes, preceded or followed by lunch provided by the research team. The interviews were conducted by two researchers in meeting rooms in local CAMHS, a children's centre, school and hotel. Where requested, an interpreter was used to provide language support.

At the start of the discussion, the researchers suggested a list of basic ground rules that participants agreed to adhere to, such as respecting each other's views and giving people time to have their say, and parents were invited to add to the list if they wished.

Individual interviews

A purposive sampling strategy was used which aimed to recruit first, a minimum of eight parents from each intervention, and second, parents from each intervention whose sleep or behaviour goals had deteriorated or remained unchanged. Across the entire sample, the research team also tried to represent a number of other factors, namely:

- Fathers

- Parents from BME groups who required an interpreter or had some difficulties with English comprehension/communication
- Working parents
- Mothers who attended with their partner
- Parents with variable levels of qualifications upon leaving school
- A range of different types of disabilities where the intervention was not delivered to autism-specific groups.

Invitation letters were sent out to parents in batches until the desired sample described above was achieved or exhausted. An explanatory information leaflet was enclosed with the letter of invitation, which was sent directly by the research team. Parents were then contacted by a member of the team to answer any queries or concerns and, if they were willing to participate, to arrange a suitable time and date for the interview.

In total, 65 individual interviews with parents were completed: 37 in relation to behaviour interventions and 28 in relation to sleep (see Table L.1). Parents were recruited who had completed questionnaires for the quantitative stage of the research, and parents who expressed an interest in the focus group that was cancelled due to insufficient numbers. The mean number of weeks that had elapsed between the end of the intervention and the interview was 25 for the behaviour interventions and 18 for the sleep interventions.

Three researchers conducted the interviews, which typically lasted between 30 and 60 minutes. The majority of interviews were conducted over the telephone, but interviews with parents from minority ethnic groups who had difficulties with English comprehension were carried out face-to-face (n=5). Of these, four parents were supported by an interpreter in the interviews.

Sample

The final study sample comprised 65 parents (behaviour interventions) and 38 parents (sleep interventions). Of these, 38 took part in focus groups (31 behaviour interventions and 7 sleep interventions) and 65 in individual interviews (37 behaviour interventions and 28 sleep interventions). The overall achieved sample is shown in Table L.1.

Table L.1 Parent sample achieved

		Individual interview participants	Focus group participants	Total participants
		n	n	n
BEHAVIOUR	Intervention A	11	14	25
	Intervention B	6	-	6
	Intervention C	10	5	15
	Intervention D	10	12	22
	Sub total	37	31	68
SLEEP	Intervention E	8	-	8
	Intervention F	4	-	4
	Intervention G	8	7	15
	Intervention H	8	-	8
	Sub total	28	7	35
	All interventions	65	38	103

Table L.2 shows the breakdown of the overall sample by goal ratings at time 2 (immediately post intervention), time 3 (12 weeks post intervention) or time 4 (24 weeks post intervention).

Table L.2 Goal ratings of all interview participants

		Improved	Not much change	Deteriorated	Data missing	Total participants
BEHAVIOUR	Intervention A	9	5	0	11	25
	Intervention B	2	2	0	3	7
	Intervention C	8	1	1	5	15
	Intervention D	12	4	2	3	21
	Sub total	31	12	3	22	68
SLEEP	Intervention E	6	1	0	1	8
	Intervention F	0	2	0	2	4
	Intervention G	8	3	0	4	15
	Intervention H	3	4	0	1	8
	Sub total	17	10	0	8	35
	All interventions	48	22	3	30	103

Demographic and other characteristics of the interviewees, and the children they represented, are shown in Table L.3.

Table L.3 Demographic and other characteristics of all interview participants

		Behaviour interventions (n=68)	Sleep interventions (n=35)
Parenting status (n=68)	Mothers	55	30
	Fathers	13	5
Language (n=68)	English as first language	55	34
	English as extra language	13	1
Employment outside home (n=58 ¹)	Working	26	12
	Non working	32	23
Mothers attendance with/ without partner (n=68)	With partner	17	9
	Without partner	51	26
Child's disability (n=68)	Autism only	39	11
	Autism plus another disability	16	10
	Other disability only	13	14
Qualifications (n=64 ²)	No post-16 qualifications	30	13
	Post-16 qualifications	34	22

¹ Missing data=10.

² Missing data=4.

Topic guides and interview schedules

As reported above, the focus groups were initially undertaken to inform the development of the schedules for the individual interviews. Both the topic guides and the interview schedules were produced in consultation with the research advisory group.

Focus group interviews

The topic guide for these group interviews can be found in Appendix M. Parents discussed issues in the group as a whole. However, in order to jog parents' memories about the content of the programme and to facilitate group discussions, parents were given a set of cards outlining the topics covered in each session.

Individual interviews

The one-to-one interviews aimed to explore individual experiences in more depth, particularly around maintaining parenting skills and generalising these skills to other behavioural contexts. See Appendix M for the interview schedule.

Ethical considerations

Ethical approval for the study was obtained from an NHS Research Ethics Committee, and research governance approval was obtained from local R&D Committees in intervention sites. Consent was obtained from all parents who took part in the study. In the case of the focus groups, this was gained at the start of the meeting and included permission from each participant to digitally record the interviews for transcription. For the individual interviews, if there was sufficient time between the interview being arranged and conducted, written consent was obtained from the parent prior to the interview. If not, this consent was provided verbally and recorded at the time of interview, and/or provided in writing retrospectively. In all circumstances, consent included parental agreement to use direct quotations in project outputs providing anonymity was assured. Where interviews were digitally recorded, consent included agreement for conversations to be recorded and transcribed.

Analysis

All the focus group interviews were digitally recorded and then transcribed for thematic analysis. However, on one occasion the recording failed so the researchers wrote up detailed field notes the following day. Of the individual interviews with parents, some conversations were digitally recorded and then transcribed, others were digitally recorded and notes written up from the recordings, and others were written-up from detailed notes taken during the interview, depending on the preference of the individual researcher.

The data generated from the group and individual interviews were analysed using the framework approach for ordering and synthesising qualitative data (Ritchie *et al.*, 2003). Three researchers through familiarisation with a set of interview and group transcripts/notes identified the key topics and themes emerging from the data. From this, a series of thematic charts were drawn up using *Excel* software to produce a matrix in which each column denoted a separate sub topic or theme and each row an individual respondent. One researcher then extracted data from the transcripts/notes and entered this onto the matrix enabling the detailed exploration of the charted data. In order to ensure a consistent approach to charting, a second researcher double-charted 25 per cent of the interviews.

Use of quotations

Quotations from interviews were used to illustrate the topics and themes identified. Each of the 103 parents that took part in an interview was assigned a unique identity number, which is displayed after each quote used throughout this report. If the parent was participating in a focus group discussion, this is indicated after the identity number by 'FG'.

Appendix M

Topic Guides and Interview Schedule for Interviews with Parents

M1 Exemplar Topic Guide for Focus Groups with Parents

FOCUS GROUP: [NAME OF INTERVENTION]

Venue:

Date:

ARRIVAL (*ALL*)

Time

11.15am – 11.30am

Function

Welcoming parents

Offering refreshments, housekeeping

Name badges

Dealing with expenses

Obtaining signed consent

Handing out/collecting demo questionnaires

Collecting contact details if not already received

Materials

Labels for name badges

Clip Boards

Expenses forms/SAEs

Consent forms

Information leaflets

Demo questionnaires

Contact forms

Felt tips and pens

Signs (for entrance and door of rooms)

Session 1: Introductory Session

Time

11.30am – 11.40am

Function

Welcome, plan of meeting, purpose of meeting, setting of ground rules and introductions.

ACTIVITIES

1. Welcome and thanks for coming to talk about your experiences of [NAME OF INTERVENTION]

2. Introduce research team

3. Programme of morning

- 11.30am Introduction
- 11.40am Practicalities of attending [NAME OF INTERVENTION] and deciding to join up
- 11.55pm Content of [NAME OF INTERVENTION] Programme
- 12.25pm Putting it into practice
- 12.40pm Closing remarks
- 12.45pm Lunch

4. Ground rules

Pin up A3 printed sheet of ground rules and invite additions

- No right or wrong answers
- OK to disagree but respect each other's views
- We will listen to each other
- We will give people time to have their say
- We will treat what is said as confidential
- It's OK to pop out for a break if we need to
- If possible switch mobiles to silent/vibrate

*****CHECK OK TO RECORD SESSION AT THIS STAGE AND SWITCH ON RECORDER*****

5. Round group introductions

Go round group and ask each parent to introduce themselves - tell us their name and a little bit about the child for whom they were seeking support (e.g. age/diagnosis), and about who else is in the family.

Materials

A3 Programme of meeting
A3 printed sheet of ground rules
DVR and spare batteries

Session 2: Practicalities of Attending [Name Of Intervention] and Deciding to Join Up

Time 11.40am – 11.55pm

Function

Warm up exercise to get everyone talking. Parents to call out facilitators / barriers to joining group and attending weekly meetings. Write up on flip chart.

ACTIVITY

1. Practical issues (7 mins)

- *Ask parents:* When you were thinking about joining [NAME OF INTERVENTION], were there any practical issues that made it easy or hard to come along to [NAME OF INTERVENTION]?

Probes:

- timing of meetings (e.g. time of day, length of meetings)
- time commitment
- getting to meetings (e.g. venue easy/difficult to get to, availability/lack of parking)
- childcare (e.g. availability of/lack of)
- flexibility of employer (allowing/refusing time-off to attend meetings)
- availability/lack of information about intervention

2. Acceptability of the group (8 mins)

- Was there anything in particular that appealed to you about [NAME OF INTERVENTION]?

Probes:

- being in a group (e.g. meeting/learning from other parents)
- being able to bring a partner, friend or relative
- group leader/facilitator (e.g. personal qualities, expertise)
- came at a good time/readiness to do something about it

- Was there anything in particular about joining [NAME OF INTERVENTION] that you were worried or anxious about?

Probes:

- understanding what was being said (e.g. jargon or fancy words, language barriers)
- speaking up in front of others (e.g. embarrassment, upsetting sharing personal stories)
- not a good time /not sure ready to do something about it
- any concerns about homework

Materials

4 x flip chart sheets [headed up 'what made it easy'; 'what made it hard'; 'what made it appealing'; 'what caused concern']

Flip chart pens

Blu-tac

Clock

Session 3: Content of [Name of Intervention]

Time:

11.55 – 12.25pm

Function:

To explore which [NAME OF INTERVENTION] sessions/topics were most and least helpful, and why. Parents to tick sheet to identify which sessions they found most helpful.

ACTIVITIES

1. Display A3 sheets which break down the [NAME OF INTERVENTION] course into parts/topics:
2. Ask parents, to place a tick on the sheet with the part they found most helpful.
3. Once all parents have done this, comment on any similarities/differences, then ask parents to explain why a session/topic was helpful or useful OR not very helpful or not relevant to them. Use this to lead into a group discussion.

Probes:

- [if individual sessions/topics not mentioned at all] ask why not?
 - Were there any issues with which you would have liked more support? How could the course have helped with this?
 - Unexpected benefits
 - Learning from other parents'
 - Readiness to engage (i.e. the 'right time' to tackle an issue)
4. Before moving on to the next session, make sure parents have talked about
 - i. Group facilitator
 - What contribution did the facilitator make to the success of the session(s)?
 - Did they explain things clearly?
 - ii. Homework
 - Did they manage to do the homework?
 - Was the homework helpful?

Materials

Set of session cards for each parent

Blu-tac

Laminated A3 sheets [headed up 'most helpful session' / 'least helpful session']

Session 4: Life After the Group

Time: 12.25am – 12.40am

Function: To explore how parents have been able to put into practice at home what they have learnt from [NAME OF INTERVENTION] about understanding and managing their child's behaviour/sleep.

ACTIVITIES

1. Ask parents for examples of things they have learnt through [NAME OF INTERVENTION] that have helped them deal with their child's behaviour. (NB: if parents have already talked about techniques/strategies they have learnt, refer to these first before asking for further examples).
Probes:
 - Positive reinforcement
 - Visual timetables
 - Social stories
2. After the sessions each week, what was it like trying things out at home with their child? Was it easy or difficult? What helped, what got in the way?
Probes:

➤ Discouraged because doesn't seem to be working	➤ School doing things differently
➤ Not sure doing the right thing	➤ Holidays
➤ Others in the family did not support what trying to do	➤ Illness
	➤ Family crisis
3. After the group had finished, what was it like keeping going with applying or trying out the things they had learnt without the support or the group? Was it easy or difficult to keep at it and maintain any improvements? What helped, what got in the way?
Probes:

➤ Discouraged because doesn't seem to be working	➤ School doing things differently
➤ Not sure doing the right thing	➤ Holidays
➤ Others in the family did not support what trying to do	➤ Illness
	➤ Family crisis
4. Have parents been able to apply similar techniques/approaches that have helped with a particular behaviour, to other aspects of their child's behaviour?
Probes:
 - Examples
 - Successful/ not successful?
 - Ideas as to why / why not?

Materials: none

Session 5: Summary and Closing Remarks

Time

12.40pm – 12.45pm

Function

- To provide a brief oral summary of what was covered in the session and to check if there is anything anyone would like to add.
- To praise group, explain what happens next, remind re confidentiality.

ACTIVITIES

- Summarise discussion and ask parents for any additional comments.
- Thank parents and remind re confidentiality
- Explain what happens next (summary of findings/dissemination)
- Any questions
- Lunch

M2 Interview Schedule for Individual Interviews with Parents (Group-Based Interventions)

Interviews with parents who have received a group-based intervention

Interview schedule

Introduction

Thanks

Purpose of interview

Verbal consent

Remind re confidentiality

Warm-up questions

What was the main thing you got out of going along to [name of intervention] ?

Can you tell me one new thing you've learnt which has been very helpful re managing child's sleep/behaviour, and how you have used that new knowledge?

Achieving goals

Talk through the way ratings on parent-set goals changed. Ask parents what helped/what got in the way of making progress.

- Probe: 'homework'

Since the group finished: maintaining and generalising skills

How did parent feel when the intervention came to an end? (For example, confidence re carrying on using what learnt; missing the group/social support)

Were you offered any follow-up support? Explore.

In the weeks since, what's it been like? Have improvements (sleep/behaviour or just own confidence) been maintained?

- Factors which have supported maintenance (check re support of family members)
- Factors which have hindered maintenance (check re support of family members)
- How confident things will continue to improve/remain as better?

In the weeks since, has parent found they have applied what learnt to other problems/difficulties you have parenting the child?

- Describe
- Factors which have supported generalisation of skills (check re role of family members)
- Factors which have hindered generalisation of skills (check re role of family members)
- Generalising to other children within the family?

Additional outcomes

Have there been other benefits to along to the group for the parent and/or family?

Did parent experience anything negative, unpleasant or difficult through going along?

The experience of the group format

Views on how well the group format worked for them.

- What was good about this type of support being delivered in a group format?
- Any disadvantages/things they found difficult about this?
- Would they have preferred individual work?

What contribution did the different facilitators/trainers make?

- Probe: different professional backgrounds; easy to understand; knowledgeable; approachable

Intervention specific issues

Confident Parenting: How useful were the videos/pampering sessions? What made them so helpful?

Riding the Rapids: How useful was it to think of a specific goal and check your progress towards it each week? How important/valuable was it thinking about your own well-being and setting aside 'me time' each week? Do you think that helped with managing your child's behaviour?

ASCEND: How useful were the sessions with individual therapists exploring specific problems and developing strategies...? The course covered both finding out about ASC and managing behaviour – how important was it to have both...? Which was most helpful...?

Cygnets: The course covered both finding out about ASC and managing behaviour – how important was it to have both...? Which was most helpful...?

Sleep training course: How useful was it to complete a sleep diary/to identify reinforcers/to set up a bedtime schedule/to reflect on your child's sleeping environment ...?

Going along with someone else

Did they go along with someone?

- Who?
- Why?
- Does parent think it made a difference – and in what ways?

If not gone with someone – would that have been a good idea – ie for others responsible for child to also receive intervention?

Comparing this intervention with any others previously received

Has parent used/attended other interventions/support/ resources previously used re managing child's sleep/behaviour?

- Quick description (incl. mainstream and 'special')
- How compares to intervention under investigation

Future support needs

Would parent like to do this intervention again some time in the future? When? Why?

Would you prefer to do the same thing or do something different? (eg look at new needs/age of child)

Improving the intervention

Does parent have any suggestions for improving the intervention?

- content
- when and how delivered

For parents with poor English communication/comprehension

As someone who doesn't speak English as their first language, how did you find coming along to the group?

- understanding of facilitator/other parents
- ability to join in discussions/ask questions/take part in group as well as others
- usefulness of handouts (probe: were they translated)

Only for parents who used a translator

Do you think the facilitator was good at remembering you were using a translator?

Close

Thanks. Any questions for researcher?

Remind re timetable for publication of findings – we will send a summary in late spring summer next year.

Remind re confidentiality.

Thanks again.

M3 Interview Schedule for Individual Interviews with Parents (One-to-One Interventions/Workshops)



Interviews with parents who have received a one-to-one interventions/attended a workshop

Topic Guide

Introduction

Thanks

Purpose of interview

Verbal consent

Remind re confidentiality

Warm-up questions

What was the main thing you got out of going along to [name of intervention] ?

Achieving goals

What did you hope to achieve from intervention (refer to parent-set goals if available)?

Explore sleep problems and any improvements achieved (what helped/hindered) .

Possible probes:

- greater understanding of sleep
- keeping a sleep diary
- improving bedroom environment
- establishing good bedtime routine
- advising on night awakenings
- ruling out physical cause/advising on medication
- any other benefits

Initial home visit

What was it like?

How helpful was this?

Why/why not helpful?

Mode of delivery

Explore how intervention delivered

At a workshop

- Were topics covered in sufficient depth? → Did the workshop feel rushed?
- Did the workshop cover the issues important to you? → Were you left with unanswered questions?
- Was the workshop easy / difficult to get to → were there issues with getting time off work, childcare costs, travel, etc.
- Did you attend with anyone else – was this / would this have been helpful?
- Would you have preferred one-to-one support? If YES, explore reasons why.
- If a mixed group of parents and professionals, what was this like?

At home/children's centre/CDC or over the phone).

- advantages/disadvantages of this type of support
- preference for this or other type of support
- Were sessions too short/too long?
- Would you have liked more/less frequent support?

How did you get along with the workshop trainer/sleep counsellors/specialist health visitor?

- easy to understand, knowledgeable, approachable?

Since the group finished: maintaining and generalising skills

How did parent feel when the intervention came to an end? (For example, confidence re carrying on using what learnt; anxious now 'on your own', etc)

Were you offered any follow-up support? (describe)

- If not, would this be helpful?

Were you signposted to other sources of support (describe)

- If not, would this be helpful?

In the weeks since, what's it been like? If there have been improvements have these improvements been maintained?

- Factors which have supported maintenance (check re support of family members)
- Factors which have hindered maintenance (check re support of family members)
- How confident things will continue to improve/remain as better?

In the weeks since, has parent found they have applied what learnt to other problems/difficulties you have parenting the child? (briefly describe)

If applicable

Have you been able to apply any new skills to help with your other children?

Past and future support

Have you received any support in the past to help with your child's sleep problems?

- If yes, how does it compare with support from this intervention?

Would you like support from this intervention in the future?

- If yes, would you like this support to be similar or different?

Improving the intervention

Does parent have any suggestions for improving the intervention?

- content
- when and how delivered

Close

Thanks. Any questions for researcher?

Remind re timetable for publication of findings – we will send a summary in late spring summer next year.

Remind re confidentiality.

Thanks again.

Appendix N

Parent and Child Demographics and Parents Scores Pre-Intervention for the Behaviour Interventions

Appendix N

Parent and Child Demographics and Parents Scores Pre-Intervention for the Behaviour Interventions

Table N.1 Intervention A

		Intervention Group		Waiting List Control		
Child Characteristics		n=36		n=21		
		Mean (SD)		Mean (SD)		
Age of child in years		8 (3.53)		9.95 (3.74)		
		n (%)		n (%)		
Male		33 (91.7)		18 (85.7)		
ASC with LD		21 (58.3%)		8 (38.1%)		
In segregated specialist education ^a		14 (38.5)		3 (14.3)		
Parent Characteristics for all parents		n=41		n=21		
Mother		35 (85.4)		19 (90.5)		
Two parent household (%)		31 (79.5) ^d		18 (85.7)		
Higher Education (%)		24 (66.7) ^d		10 (47.6)		
White British (%)		27 (69.2) ^d		21 (100)		
English First Language		34 (87.2) ^d		21 (100)		
Working parent		19 (46.3)		15 (71.4)		
Pre-intervention outcome scores						
Scale scores	<i>N</i>	<i>M</i>	<i>SD</i>	<i>N</i>	<i>M</i>	<i>SD</i>
ECBI Intensity Score	30	140.57	33.22	17	132.53	35.27
ECBI Problem Score	31	18.19	9.17	20	15.25	6.97
CCBS Score	32	34.84	7.07	20	34.15	8.02
PSOC Efficacy Score	37	27.51	5.21	21	28.14	6.37
PSOC Satisfaction Score	38	33.92	6.37	21	36.76	8.41
Clinical Cut off Rates	<i>N</i>	Above cut-off (n, %)		<i>N</i>	Above cut-off (n, %)	
ECBI Intensity Score	30	17 (56.7%)		17	9 (52.9%)	
ECBI Problem Score	31	22 (71.0%)		20	11 (55.0%)	

^a 'Segregated specialist education' includes specialist units in a mainstream school or special school.

^b 'Higher Education' denotes education beyond GCSE level.

^c This may be in a paid or voluntary capacity.

^d Data missing for some parents.

Table N.2 Intervention B

		Intervention Group		No Treatment Control		
Child characteristics		n=20		n=20		
		Mean (SD)		Mean (SD)		
Age of child in years		6.85 (1.694)		7.45 (2.35)		
		n (%)		n (%)		
Male		13 (65%)		13 (65%)		
Has a diagnosis of, or presenting with symptoms of an LD		16 (80%)		14 (70%)		
In segregated specialist education ^a		16 (80%)		19 (95%)		
Parent characteristics		n=20		n=20		
Mother		17 (85%)		18 (90%)		
Two parent household		14 (70%)		15 (75%)		
Higher Education ^b		7 (35%)		17 (85%)		
White British		17 (85%)		17 (85%)		
English First Language		20 (100%)		20 (100%)		
Working outside the home ^c		4 (20%)		12(60%)		
Pre-intervention outcome scores						
Scale scores	N	M	SD	N	M	SD
ECBI-Intensity	19	148.37	32.21	18	117.39	25.01
ECBI-Problem	19	20.00	8.49	20	13.75	7.26
CCBS	15	36.73	8.01	19	30.95	7.05
PSOC-Efficacy	20	28.30	6.20	19	29.32	5.92
PSOC-Satisfaction	20	30.65	6.09	19	35.00	8.69
Clinical Cut off Rates	N	Above cut-off (n, %)		N	Above cut-off (n, %)	
ECBI- Intensity	19	15 (78.9%)		18	6 (33.3%)	
ECBI- Problem	19	13 (68.4%)		20	8(40%)	

^a 'Segregated specialist education' includes specialist units in a mainstream school or special school.

^b 'Higher Education' denotes education beyond GCSE level.

^c This may be in a paid or voluntary capacity.

Table N.3 Intervention C

	Intervention Group			Waiting List Control		
Child characteristics	n=29			n=31		
	Mean (SD)			Mean (SD)		
Age of child in years	10.19 (3.73)			9.90 (3.06)		
	n (%)			n (%)		
Male	26 (89.7)			25 (80.7)		
Received diagnosis within past 6 months	17 (54) ^d			8 (27.6) ^d		
In segregated specialist education ^a	8 (24.1) ^d			6 (19.4) ^d		
Parent characteristics	n=35			n=33		
Mother	26 (74.3)			30 (90.9)		
Two parent household	30 (85.7)			22 (66.7)		
Higher Education ^b	23 (65.7)			24 (72.7)		
White British	32 (91.4)			28 (87.5)		
English First Language	34 (97.1)			31 (93.9)		
Working outside the home ^c	24 (68.6)			18 (54.5)		
Pre-intervention outcome scores						
	N	M	SD	N	M	SD
ECBI-Intensity	27	139.97	34.45	27	136.52	31.72
ECBI-Problem	23	16.78	9.17	23	13.93	6.97
CCBS	25	35.04	6.85	25	34.63	7.17
PSOC-Efficacy	34	27.21	4.75	33	26.33	6.55
PSOC-Satisfaction	35	33.76	6.43	33	33.45	7.12
Clinical Cut off Rates	N	Above cut-off (n, %)		N	Above cut-off (n, %)	
ECBI-Intensity	27	16 (59.3%)		27	16 (59.3%)	
ECBI-Problem	23	13 (56.5%)		27	13 (48.1%)	

^a 'Segregated specialist education' includes specialist units in a mainstream school or special school.

^b 'Higher Education' denotes education beyond GCSE level.

^c This may be in a paid or voluntary capacity.

^d Data missing for some parents.

Table N.4 Intervention D

	Intervention Group			Waiting List Control		
Child characteristics	n=47			n=29		
	Mean (SD)			Mean (SD)		
Age of child in years	7.07 (2.117) ^d			6.07 (2.68) ^d		
	n (%)			n (%)		
Male	38 (80.9%)			21 (72.4%)		
Has a diagnosis of, or presenting with symptoms of an ASC	29 (67.4%) ^d			17 (60.7%) ^d		
In segregated specialist education ^a	28 (63.6%) ^d			13 (52.0%) ^d		
Parent characteristics	n=48			n=28		
Mother	42 (87.5%)			25 (89.3%)		
Two parent household	35 (79.5%) ^d			13 (48.1%) ^d		
Higher Education ^b	16 (35.6%) ^d			9 (33.3%) ^d		
Ethnicity (White British)	25 (52.1%)			14 (51.9%) ^d		
English Preferred Language	37 (80.4%) ^d			21 (77.8%) ^d		
Working outside the home ^c	12 (27.9%) ^d			3 (13.6%) ^d		
Pre-intervention outcome scores						
	<i>N</i>	<i>M</i>	<i>SD</i>	<i>N</i>	<i>M</i>	<i>SD</i>
ECBI-Intensity	40	138.97	32.24	27	145.56	36.70
ECBI-Problem	34	17.82	7.17	25	20.40	7.25
CCBS	37	35.86	6.34	28	34.18	7.58
PSOC-Efficacy	46	29.54	4.97	27	30.33	6.45
PSOC-Satisfaction	46	32.26	7.80	27	32.74	8.23
Clinical Cut off Rates	<i>N</i>	Above cut-off (n, %)		<i>N</i>	Above cut-off (n, %)	
ECBI- Intensity	40	26 (65%)		27	16 (59.3%)	
ECBI- Problem	34	20 (58.8%)		25	20 (80%)	

^a 'Segregated specialist education' includes specialist units in a mainstream school or special school.

^b 'Higher Education' denotes education beyond GCSE level.

^c This may be in a paid or voluntary capacity.

^d Data missing for some parents.

Appendix O

Parent and Child Demographics and Parents Scores Pre-intervention for the Sleep Interventions

Appendix O

Parent and Child Demographics and Parents Scores Pre-intervention for the Sleep Interventions

Table O.1 Intervention E

	Type of support provided					
	Home visits			Telephone support		
Child characteristics	n=6			n=7		
	M	SD		M	SD	
Age of child in years	2.67	.816		2.86	1.069	
	n (%)			n (%)		
Male child	6 (100%)			5 (71.4%)		
Description of child's additional needs	ASC (with or without other impairments) 3 (50%), LD 1 (16.7%), PD/SD 1 (16.7%), no diagnosis 1 (16.7%) ¹³			ASC (with or without other impairments) 5 (71.4%), LD 1 (14.3%), PD/SD 1 (14.3%)		
Parent Characteristics	n=6			n=7		
Mother	6 (100%)			7 (100%)		
Two parent household	5 (83.3%)			6 (85.7%)		
Higher Education ^a	2 (33.3%)			3 (42.9%)		
White British	6 (100%)			7 (100%)		
Working parent ^b	1 (20%) ^c			0 (0%)		
Pre-intervention outcome scores						
	<i>N</i>	<i>M</i>	<i>SD</i>	<i>N</i>	<i>M</i>	<i>SD</i>
CSHQ Total Sleep Disturbance Score	4	59.50	11.82	6	53.33	4.27
CSHQ-Bedtime Resistance	4	13.00	3.83	6	9.00	1.90
CSHQ-Sleep Anxiety	4	8.50	4.12	6	6.17	1.17
CSHQ-Night Wakings	4	6.75	2.06	7	5.57	2.30
PSOC-Satisfaction	5	36.80	10.71	7	31.57	9.43
PSOC-Efficacy	5	30.80	4.82	7	27.86	8.38

^a 'Higher Education' denotes education beyond GCSE level.

^b This may be in a paid or voluntary capacity.

^c Data missing for some parents.

¹³ ASC – Autistic Spectrum Condition, LD – Learning Disability, PD/SD – Physical or Sensory Disability.

Table O.2 Intervention F

Child characteristics	n=12		
	M (SD)		
Age of child in years	2.88 (1.25)		
	N (%)		
Male child	6 (50%)		
Description of child's additional needs	ASC/pres 3 (25%), LD(2 with PD) 3 (25%) no diagnosis – additional needs 6 (50%)		
Parent characteristics	n=12		
Mother	9 (75%)		
Two parent household	7 (58.3%)		
Higher Education ^a	3 (25%)		
White British	7 (58.3%)		
Working parent ^b	3 (27.3) ^c		
English preferred lang	11 (91.6%)		
Pre-intervention outcome scores			
	<i>N</i>	<i>M</i>	<i>SD</i>
CSHQ Total Sleep Disturbance Score	11	59.55	7.59
CSHQ-Bedtime Resistance	10	11.40	3.84
CSHQ-Sleep Anxiety	11	7.18	2.36
CSHQ-Night Wakings	12	5.92	1.24
PSOC-Efficacy	11	31.18	4.21
PSOC-Satisfaction	10	32.20	5.73

^a 'Higher Education' denotes education beyond GCSE level.

^b This may be in a paid or voluntary capacity

^c Data missing for some parents

Table O.3 Intervention G

Child characteristics	n=22		
	M (SD)		
Age of child in years	8.91 (3.25)		
Male child N (%)	11 (50%)		
Description of child's additional needs	ASC (with or without LD) N=14 (63.6%),LD N=6 (27.3%), PD/SD N=1 (4.5%), No diagnosis N=1 (4.5%)		
Parent characteristics	n=23		
Mother	20 (87%)		
Two parent household ^a	22 (95.7%)		
Higher Education	8 (34.8%)		
White British	22 (95.7%)		
Working parent ^b	9 (39.1%)		
Pre-intervention outcome scores			
	N	M	SD
CSHQ Total Sleep Disturbance Score	21	57.86	9.76
CSHQ-Bedtime Resistance	20	10.65	3.07
CSHQ-Sleep Anxiety	20	7.95	2.52
CSHQ-Night Wakings	20	5.85	1.90
PSOC-Efficacy	23	26.48	5.13
PSOC-Satisfaction	22	35.18	7.13

^a 'Higher Education' denotes education beyond GCSE level.

^b This may be in a paid or voluntary capacity.

Table O.4 Intervention H

Child characteristics	n=25		
	M (SD)		
Age of child in years	7.00, 3.304		
	n(%)		
Male child	16 (64%)		
Description of child's additional needs	ASC (9, 36%), LD (4,16%), PD/SD (4,16%) LD & PD/SD (3, 12%), ASC other (5, 20%)		
Parent characteristics	n=26		
Mother	24 (92.3%)		
Two parent household	21 (80.8%)		
Higher Education	12 (46.2%)		
White British	25 (96.2%)		
Pre-intervention outcome scores			
	N	M	SD
CSHQ Total Sleep Disturbance Score	24	56.58	9.50
CSHQ-Bedtime Resistance	24	10.04	3.51
CSHQ-Sleep Anxiety	24	7.38	2.48
CSHQ-Night Wakings	22	6.09	1.66
PSOC-Efficacy	25	31.04	4.95
PSOC-Satisfaction	25	34.52	7.45

^a 'Higher Education' denotes education beyond GCSE level.

^b This may be in a paid or voluntary capacity.

Appendix P

Intervention Details

P1 ASCEND (Autism Spectrum Conditions - Enhancing Nurture and Development)

Name of intervention	ASCEND (Autism Spectrum Conditions - Enhancing Nurture and Development)
Authors of intervention	Barry Wright and Chris Williams
Details of intervention manual	<p>Wright, B. & Williams, C. 2007. Intervention and Support for Parents and Carers of Children on the Autism Spectrum: A Resource for Trainers, London, UK, Jessica Kingsley Publishers.</p> <p>The course can be run from the information in the manual alone by suitably qualified professionals. However, the authors are happy to be contacted about running training courses for professionals interested in starting their own ASCEND programmes if they prefer to gain more detail about the course in practice.</p>
Contact person for further information	<p>Dr Chris Williams Consultant Child Clinical Psychologist CAMHS Lime Trees 31, Shipton Rd York YO305RF Tel 01904 726610</p>
Associated Publications	<ul style="list-style-type: none"> Williams, C. & Wright, B. 2004. How to live with Autism and Asperger Syndrome: Practical strategies for Parents and Professionals, London, UK, Jessica Kingsley Publishers. Pillay, M., Alderson Day, B., Wright, B., Williams, C. & Urwin, B. 2011. Autism Spectrum Conditions - Enhancing Nurture and Development (ASCEND): An evaluation of intervention support groups for parents. Clinical Child Psychology and Psychiatry, 16, 5-20.

P2 Confident Parenting

Name of intervention	Confident Parenting
Authors of intervention	Annette Hames and Chris Rollings
Details of intervention manual	Hames, A., Rollings, C. & Janes, E. 2009. Confident Parenting. A guide for group facilitators, HEADS.
Contact person for further information	HEADS Office Hadrian School Bertram Crescent Newcastle upon Tyne NE15 6PY Telephone: 0191 273 4440 General email: admin@hadrian.newcastle.sch.uk HEADS Website: http://www.headstraining.co.uk
Associated Publications	Hames, A. & Rollings, C. 2009. A group for the parents and carers of children with severe learning difficulties and challenging behaviour. Educational and Child Psychology, 26, 47-54.

P3 Cygnet Parenting Support Programme

Name of intervention	Cygnet Parenting Support Programme
Authors of intervention	Various
Details of intervention manual	Cygnet Programme. 2010. Trainer's notes with handouts and evaluation sheets. Barnardo's.
Contact person for further information	<p>Andy Morris Cygnet Training Coordinator Cygnet Parenting Support Service Queens Road Bradford BD8 7BS</p> <p>Tel: 01274 481183 Email: andy.morris@barnardos.org.uk</p>
Associated Publications	<ul style="list-style-type: none"> • Raghavan, R. 2008. Cygnet Autistic Spectrum Training Programme for Parents: Evaluation Report. Northumbria University. • Barnardo's 2006 - 2010. Barnardo's Cygnet Service (2006-2010) Evaluation Reports. Barnardo's, Queen's Road, Bradford. • Robson, K. 2010. Birmingham CAMHS Cygnet Evaluation. Birmingham CAMHS.

P4 Riding the Rapids

Name of intervention	Riding the Rapids
Authors of intervention	Jo Bromley, Christine Mellor and Sam Todd
Details of intervention manual	On request from contact person below
Contact person for further information	<p>Jo Bromley Consultant Clinical Psychologist Service Lead for Clinical Psychology Service for Children with Disabilities Carol Kendrick Centre Stratus House Southmoor Road Wythenshawe Manchester M23 9XD.</p> <p>Tel: 0161 902 3400. Email: jo.bromley@cmft.nhs.uk</p>
Associated Publications	<p>Todd, S., Bromley, J., Ioannou, K., Harrison, J., Mellor, C., Taylor, E. & Crabtree, E. 2010. Using Group-Based Parent Training Interventions with Parents of Children with Disabilities: A Description of Process, Content and Outcomes in Clinical Practice. <i>Child and Adolescent Mental Health</i>, 15, 171-175.</p>

P5 Specialist Health Visitor Sleep Support Service

Name of intervention	Specialist Health Visitor Sleep Support Service
Authors of intervention	Dr Megan Thomas, Marion Lingard, Margaret Carter
Details of intervention manual	Individually delivered intervention following a set protocol. Further details from contact person below.
Contact person for further information	<p>Dr Megan Thomas Consultant Community Paediatrician Blackpool, Fylde and Wyre Hospitals NHS Foundation Trust Blenheim House Child Development and Family Support Centre 145-147 Newton Drive Blackpool Lancashire FY3 8LZ</p> <p>Tel: 01253 651615 (reception) Tel: 01253 651633 (Sarah Ward Secretary) Tel: 01253 651634 (Dr Megan Thomas)</p>

P6 NEYS (Neighbourhood Early Years Service) Sleep Service

Name of intervention	NEYS (Neighbourhood Early Years Service) Sleep Service
Authors of intervention	Adapted from “Sleep Scotland” Programme
Details of intervention manual	On request from contact person below
Contact person for further information	<p>Karen Mpetha Operational Manager/ Nurse Specialist Learning Disability Team Alder Hey Children's NHS foundation Trust 1st Floor Mulberry House Liverpool L12 2AP</p> <p>Ext: 3568 Direct Tel: 0151 2933568 Fax: 0151 2525076 Email: karen.mpetha@alderhey.nhs.uk web: www.alderhey.com</p>
Associated Publications	<ul style="list-style-type: none"> Brady, A., Mpetha, K., Humphreys, S. & Carney, A.-M. 2011. Developing a sleep service for children with learning disabilities or autistic spectrum disorders aged 0-5: Setting up the service and lessons from practice. Clinical Psychology Forum. Number 222, June 2011.

P7 Managing Your Child's Behaviour to Promote Better Sleep

Name of intervention	Managing Your Child's Behaviour to Promote Better Sleep
Authors of intervention	Julie Curtis and Patti Boon
Details of intervention manual	On request from contact person below.
Contact person for further information	<p>Julie Curtis, CALD Team Co-ordinator, or Samantha Ives, Secretary to CALD Team</p> <p>The Modular Building Northgate Hospital Morpeth NE61 3BP</p> <p>Tel: 01670 394032 Email: Samantha.Ives@nhs.net</p>

P8 Sleep Solutions 'Time2Sleep' Workshops

Name of intervention	Sleep Solutions 'Time2Sleep' Workshops
Authors of intervention	Authors - Vicki Dawson Sleep Consultant and Jackie Logue Scope Early Years Co-ordinator Products and Tools Lead Contributors – Jane Ansell, Director of Sleep Scotland
Details of intervention manual	Workshops can be tailored to the needs, knowledge and experience of the participants dependant on learning outcomes required. The workshop aims to cover many common sleep issues that children may face and introduces simple cognitive behavioural therapy techniques. The workshop is divided into 11 sessions and includes a 'Delegate Resource Pack' of useful materials to take away.
Contact person for further information	Karen Hunt Sleep Solutions National Service Development Manager Scope Suite 18 The Rural Enterprise Centre Vincent Carey Road, Rotherwas Industrial Estate Hereford HR2 6FE Tel: 01432 355308 Website: www.sleepsolutions.org.uk , or www.scope.org.uk/sleep - main sleep website providing information about the service, one-to-one intervention, training, tips and strategies to try etc.
Associated Publications	Department For Education. 2010. Information for Parents Booklet - Sleep: ES82 [Online]. Available: https://www.education.gov.uk/publications/standard/EarlySupport/Page1/ES82

Appendix Q

Programme A: Further Service Use and Costs Data

Appendix Q

Programme A: Further Service Use and Costs Data

Table Q.1 Parental service use in 3 months prior to data collection time points

Service/support	Pre-intervention time point: number using		12 week follow-up time point: number using	
	Intervention n=39	Comparator n=20	Intervention n=28	Comparator n=18
GP	7	3	6	4
GP nurse	1	0	1	0
Outpatient appointment	2	0	1	0
Counsellor	3	2	1	1
Alternative therapy	1	0	2	1
Self-help/support group	3	1	4	3
Other	1	1	2	1
Total costs of main carer's service use: £ mean (£ range)	£31.20 (£0 - £440)	£39.10 (£0 - £264)	£65.20 (£0 - £955)	£36.20 (£0 - £444)

Table Q.2 Child's service use and costs in 3 months prior to data collection time points

Service/support	Time 1; n (%) using		Time 3; n (%) using	
	Intervention n=41	Comparator n=21	Intervention n=28	Comparator n=18
Hospital services				
Inpatient stay	2 (5%)	0	0	0
Outpatient appt. for other reasons	13 (32%)	2 (10%)	8 (29%)	4 (22%)
A&E	6 (15%)	2 (10%)	2 (7%)	1 (5%)
Community health				
Community nurse for behaviour	0	1 (4%)	1 (4%)	3 (14%)
Community nurse other reasons	3 (7%)	2 (10%)	1 (4%)	0
Specialist doctor	10 (24%)	2 (10%)	6 (21%)	1 (5%)
Speech & language therapist	15 (37%)	6 (29%)	10 (36%)	3 (14%)
Occupational therapist	9 (22%)	3 (14%)	7 (25%)	3 (14%)
Mental health services				
Outpatient appt. for behaviour	2 (5%)	3 (14%)	5 (18%)	0
Family therapist	0	0	0	1 (5%)
CAMHS	20 (49%)	10 (48%)	9 (32%)	5 (28%)
Primary care				
GP for behaviour	2 (5%)	2 (10%)	2 (7%)	1 (5%)
GP for other reasons	16 (39%)	3 (14%)	12 (43%)	5 (28%)
GP nurse	3 (7%)	0	0	(5%)
Health visitor for behaviour	1 (2%)	1 (4%)	2 (7%)	1 (5%)
Health visitor for other reasons	1 (2%)	0	0	1 (5%)
Repeat prescriptions	20 (49%)	5 (24%)	14 (50%)	6 (21%)
Social care				
Short breaks	4 (10%)	2 (10%)	5 (18%)	3 (14%)
Social worker	8 (20%)	5 (24%)	9 (32%)	1 (5%)
Key worker	4 (10%)	3 (14%)	2 (7%)	2 (11%)
Home help/carer	2 (5%)	0	1 (4%)	0
Family support worker	4 (10%)	1 (4%)	0	0
Alternative therapist	9 (22%)	2 (10%)	7 (25%)	2 (11%)

Appendix R

Programme C: Further Service Use and Costs Data

Appendix R

Programme C: Further Service Use and Costs Data

Table R.1 Parental service use, 3 months prior to interview

Service/support	Intervention; n using		Control; n using	
	T1 n=33	T3 n=28	T1 n=28	T3 n=20
GP	4	4	2	4
GP nurse	1	0	0	0
Outpatient appointment	0	0	1	0
Counsellor	1	1	2	1
Alternative therapy	0	0	1	0
Self-help/support group	1	1	5	1
Other	1	1	0	2
Total costs of parental service use: £mean (£range)	£9 (£0-£105)	£31 (£0-£328)	£10 (£0-£140)	£68 (£0-£664)

Table R.2 Child's service use and costs, 3 months prior to interview

Service/support	Pre-intervention time point; n (%)		12 week follow-up time point; n (%)	
	Intervention n=35	Control n=33	Intervention n=29	Control n=22
Hospital services				
Inpatient stay	0 ()	1 ()	0 ()	0 ()
Outpatient appt. for other reasons	7 ()	8 ()	4 ()	10 ()
A&E	4 ()	3 ()	1 ()	0 ()
Community health				
Community nurse for behaviour	1 ()	0 ()	0 ()	0 ()
Community nurse other reasons	0 ()	0 ()	0 ()	1 ()
Specialist doctor	8 ()	6 ()	9 ()	3 ()
Speech & language therapist	10 ()	8 ()	12 ()	7 ()
Occupational therapist	3 ()	9 ()	6 ()	5 ()
Mental health services				
Outpatient appt. for behaviour	3 ()	9 ()	5 ()	8 ()
Family therapist	0 ()	1 ()	0 ()	1 ()
CAMHS	10 ()	15 ()	8 ()	10 ()
Primary care				
GP for behaviour	5 ()	1 ()	1 ()	1 ()
GP for other reasons	10 ()	11 ()	6 ()	9 ()
GP nurse	1 ()	1 ()	0 ()	0 ()
Health visitor for behaviour	1 ()	3 ()	1 ()	2 ()
Health visitor for other reasons	0 ()	1 ()	0 ()	1 ()
Repeat prescriptions	15 ()	18 ()	5 ()	11 ()
Social care				
Short breaks	3 ()	3 ()	2 ()	2 ()
Social worker	4 ()	4 ()	5 ()	2 ()
Key worker	2 ()	5 ()	2 ()	5 ()
Home help/carers	1 ()	1 ()	2 ()	1 ()
Family support worker	1 ()	2 ()	1 ()	1 ()
Alternative therapist	2 ()	1 ()	3 ()	0 ()

Appendix S

Programme D: Further Service Use and Costs Data

Appendix S

Programme D: Further Service Use and Costs Data

Table S.1 Parental service use, 3 months prior to data collection time point

Service/support	Pre-intervention time point; n using		Post-intervention time point; n using		12 week follow-up; n using
	IG n=59	CG n=20	IG n=43	CG n=22	IG n=44
GP	7	3	5	4	7
GP nurse	1	0	1	1	1
Outpatient appointment	4	0	1	2	0
Counsellor	0	0	0	0	0
Alternative therapy	1	0	0	1	1
Self-help/support group	3	1	2	1	3
Other	1	0	3	2	5
Total costs of main carer's service use: £ mean (£ range)	£42.30 (£0 - £672)	£8.50 (£0 - £64)	£24.90 (£0 - £408)	£79.70 (£0 - £672)	£23.70 (£0 - £251)

Table S.2 Child's service use, 3 months prior to data collection time point

Service/support	Pre-intervention time point n (%)		Post-intervention time point n (%)		12 week follow-up n (%)
	IG n=59	CG n=20	IG n=45	CG n=22	IG n=44
Hospital services					
Inpatient stay	7 (12%)	3 (15%)	6 (13%)	2 (9%)	5 (11%)
Outpatient appt. for other reasons	24 (41%)	8 (40%)	17 (38%)	12 (55%)	12 (27%)
A&E	17 (29%)	2 (10%)	9 (20%)	7 (32%)	7 (16%)
Community health					
Community nurse for behaviour	4 (7%)	1 (5%)	5 (11%)	3 (14%)	3 (7%)
Community nurse other reasons	1 (2%)	2 (10%)	1 (3%)	0	3 (7%)
Specialist doctor	15 (25%)	8 (40%)	13 (29%)	5 (23%)	12 (27%)
Speech & language therapist	22 (37%)	10 (50%)	15 (33%)	7 (32%)	6 (14%)
Occupational therapist	6 (10%)	2 (10%)	11 (24%)	0	7 (16%)
Mental health services					
Outpatient appt. for behaviour	2 (3%)	4 (20%)	3 (7%)	2 (9%)	4 (9%)
Family therapist	0	0	0	0	2 (5%)
CAMHS	11 (19%)	6 (30%)	8 (18%)	6 (27%)	7 (16%)
Primary care					
GP for behaviour	1 (2%)	1 (5%)	2 (4%)	1 (5%)	3 (7%)
GP for other reasons	25 (42%)	10 (50%)	26 (58%)	8 (36%)	19 (43%)
GP nurse	2 (3%)	1 (5%)	2 (4%)	2 (9%)	1 (2%)
Health visitor for behaviour	3 (5%)	4 (20%)	5 (11%)	3 (14%)	1 (2%)
Health visitor for other reasons	2 (3%)	3 (15%)	3 (7%)	0	0
Repeat prescriptions	30 (51%)	10 (50%)	31 (69%)	13 (59%)	29 (66%)
Social care					
Short breaks	7 (12%)	2 (10%)	8 (18%)	3 (14%)	6 (14%)
Social worker	10 (17%)	2 (10%)	6 (15%)	4 (18%)	5 (11%)
Key worker	5 (8%)	3 (15%)	4 (9%)	2 (9%)	3 (7%)
Home help/carers	1 (2%)	1 (5%)	0	0	0
Family support worker	3 (5%)	2 (10%)	4 (9%)	1 (5%)	4 (9%)
Alternative therapist	4 (7%)	1 (5%)	3 (7%)	2 (9%)	6 (14%)