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A preliminary investigation into the effectiveness of a group delivered sleep management intervention for parents of children with intellectual disabilities

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Abbreviated title: A sleep management group for parents of children with intellectual disabilities

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Abstract

Sleep problems are more prevalent and severe among children with intellectual disabilities and autism compared to typically developing children. Training parents in behavioural approaches to manage sleep problems is advocated. However, delivering such interventions via groups is novel. This paper reports the findings from a preliminary evaluation of a group-delivered intervention routinely delivered by a Child and Adolescent Mental Health Service Learning Disability team in England. Parents (n=23) of children with intellectual disabilities were recruited to the study. The Children's Sleep Habits Questionnaire, Parents' Sense of Competence Scale and parent-set goals captured outcomes at pre-intervention, post-intervention, three- and six-month follow-up. Intervention delivery costs were collected. Take-up was high (86%) and no parent dropped out. Statistically significant improvements in night-wakings, parent-set goals, and parents' sense of efficacy were observed. The estimated mean cost of delivering each intervention was £1570. Findings suggest the intervention is a low-cost, acceptable service warranting further evaluation.

Keywords

autistic spectrum conditions, intellectual disabilities, parent-training programme, sleep problems, children

Introduction

Sleep problems are particularly common among children with intellectual disabilities and/or autistic spectrum conditions (ASC) (MacCrosain and Byrne, 2009; Quine and Wade, 1991; Krakowiak et al., 2008; Allerton et al., 2011) and are unlikely to disappear without intervention (Lancioni et al., 1999). Once physiological/anatomical reasons for sleep disturbance have been ruled out, behavioural interventions, which seek to change parents' responses to sleep-related behaviour problems, are advocated (Wiggs, 2009; Galland and Mitchell, 2010). Behavioural interventions can involve one or many behavioural techniques, for example, extinction, where the child is left to 'cry it out' for a timed interval before the parent briefly reassures the child, with this sequence repeating until the child falls asleep; or sleep restriction, where night-time sleep duration and/or daytime naps are limited. Research on the effectiveness of these interventions with respect to sleep problems in children with intellectual disabilities is promising, though limited, (Vriend et al., 2011; McDaid and Sloper, 2009). Current evidence and clinical guidance advocates behavioural approaches to addressing sleep problems in children with intellectual disabilities and/or ASCs as 'the first line of approach' (Bruni and Novelli, 2010; NICE/SCIE, 2013b).

Sleep problems are associated with poor outcomes for both the parent (for example, heightened levels of parental stress and irritability; Quine, 1991; Wiggs, 2007; Tietze et al., 2014; Wiggs and Stores, 1998) and child (for example, poorer educational progress and daytime behaviour problems; Simola et al., 2014). Parents consistently prioritise the need for support with their child's sleep problems (Beresford, 1995; Allard et al., 2014). However, compared to pharmacological

approaches, and despite evidence of their effectiveness, behavioural interventions can be perceived by practitioners to be too resource intensive (Montgomery et al., 2004). This is primarily because, to date, such interventions are typically delivered on a one-to-one basis. Whilst groups are the predominant mode by which (behavioural) parenting support interventions (for parents of typically developing children and, more recently, children with disabilities) are delivered (e.g. Triple P, Stepping Stones Triple P, Riding the Rapids; Sanders et al., 2000; Sanders et al., 2004; Stuttard et al., 2014), the use of groups to deliver sleep management interventions is relatively unusual. Single/half-day sleep workshops for parents, including those of children with disabilities, are now being offered by some specialist sleep services and third sector organisations in the United Kingdom (UK, e.g. SCOPE, 2015), though are yet to be systematically evaluated (Beresford et al., 2012). Delivering a more sustained and individualised sleep intervention via a group remains relatively untested and is less usual in practice. Yet it is potentially more cost-efficient and also offers parents the added benefit of peer support (Steiner et al., 2012). We identified just one (US) evaluation of a group-delivered sleep intervention to parents of children with disabilities. Here the authors concluded the intervention appeared promising (Reed et al., 2009).

This paper reports a preliminary evaluation of a group delivered sleep management intervention for parents of children with intellectual disabilities and/or ASCs which is routinely delivered by learning disability nurses based in a Child and Adolescent Mental Health Service (CAMHS) Learning Disability team in England. Please

note, in a UK context the term 'learning disability' should be considered interchangeable with 'intellectual disability', its international equivalent (Bristol University, 2015).

Method

The study was conducted by an independent research team from the University of York (BB, LS, SC) and London School of Economics (JB). A before-and-after study design, incorporating a six-month follow-up period, was used. Outcomes under investigation were children's sleep problems and parents' sense of competence. We also recorded group attendance and intervention drop out as indicators of acceptability of the programme. The study took place between November 2009 and June 2010, during which time the intervention was delivered four times across the locality. The costs to the service of delivering the intervention were also collected. NHS Research Ethics approval was obtained (REC approval number 09/H1305/46).

The intervention: Managing Your Child's Behaviour to Promote Better Sleep (MCBPBS)

MCBPBS is a manualised intervention which aims to enable parents/carers to understand and manage their child's behaviour in order to encourage a more consistent and settled sleep/waking pattern. The programme was developed by learning disability nurses who had already formulated and integrated into routine practice a group-delivered day-time behaviour management intervention (Curtis and Boon, unpublished). This informed the structure and approach of *MCBPBS*, developed in response to an observed need among parents on their caseload.

MCBPBS comprises four three-hour sessions, delivered over a five-week period (two weeks elapse between sessions three and four). The intervention is founded on a non-aversive and problem-solving approach to addressing behaviours which a parent is finding difficult to manage (for example, being uncooperative, aggressive to peers, tantrums) alongside training on sleep. Principles of experiential learning (Kolb, 1984) inform the training approach with both didactic teaching and group-based problem-solving, and home-based observation and practice used. Parents are also introduced to use simple tools (e.g. visual schedules using story boards) to support implementing bedtime/sleep routines (Figure 1). In addition to behavioural strategies, parents are encouraged to review the child's bedroom to determine whether there are any environmental factors that are inhibiting or interrupting their child's sleep (Figure 1, session 2). During Session One parents identify their child's sleep problems. In subsequent sessions they apply and operationalise their learning to these sleep problem(s). 'Homework' is set after each session. A detailed manual sets out the intervention and also contains all the materials required to deliver the intervention (Curtis and Boon, Forthcoming).

Figure 1. Overview of *Managing Your Child's Behaviour to Promote Better Sleep (MCBPBS)*

Session 1:

- *Group Discussion*: child's sleep and current management, perceived impact of sleep habits on child and family
- *Individual exercise:* Identification of target behaviour(s)
- *Teaching:* behavioural approaches to behaviour management
- *Group Discussion:* identifying positive and negative reinforcers

- *Teaching:* communication
- *Group Discussion:* children's communication
- *Homework:* observe child's communication, sleep behaviours and management

Session 2:

- Recap *Group Discussion*: homework tasks
- *Teaching:* sleep routines; structuring bedtime; using reinforcers to manage behaviour
- *Group Discussion*: planning bedtime routines*:* bedroom environment
- *Homework:* implement bedtime routine; observation of bedroom environment

Session 3:

- Recap *Group Discussion*: homework feedback
- *Teaching:* Principles of behavioural analysis then applied to children's sleep problems
- *Homework:* complete Albany Sleep Scale and sleep diary

Session 4:

- Recap
- *Group Discussion:* review homework
- *Teaching:* specific strategies to manage sleep problem behaviours; the use of medication.
- Question and answer session
- Evaluation

Two community learning disability nurses, trained in the programme, typically deliver each session. Occasionally one of the facilitators was a clinical psychologist. Parents are referred to the intervention by members of the Learning Disability team, school, health, and/or social care practitioners. Children aged 3-18 years can be referred, although children are typically aged 8-12 years. Referrals are placed on a waiting list. Once there are a sufficient number of families (n=4) on the waiting list living in the same geographical area, arrangements are made to run the programme. No more than eight children are represented in each group. During the study period, between 4 and 9 parents attended each programme. Community venues are used and the sessions are held during the day-time. Whilst both parents are encouraged to attend, the composition of groups is predominantly mothers.

Study administration

Study participants were parents attending one of four routine deliveries of *MCBPBS*. Recruitment materials were posted to parents in advance of Session One. A member of the research team attended this session to introduce the study, respond to questions and take informed (written) consent. Pre-intervention (T0) and post-intervention (T1) questionnaires were administered during the first and final sessions respectively. Any parents not attending the final session received the questionnaire by post. The research team also posted three- (T2) and six (T3)-month follow-up questionnaires directly to participants. The research questionnaires included the standardised outcome measures described below and collected demographic and disability-related information. An incentive (£10 voucher, funded by the research budget), postal, phone and/or text reminders supported retention to the study.

Outcome measures

The *Children's Sleep Habits Questionnaire* (CSHQ, Owens et al., 2000) is a 33-item parent-completed scale measuring sleep disturbance in children. Whilst originally developed for children aged 4-10, it has been validated for use in younger children (Goodlin-Jones et al., 2008) and seen as acceptable for use with older children with developmental delay and/or autism (MacCrosain and Byrne, 2009; Carter et al., 2009;

Rzepecka et al., 2011). Items describe sleep problems/sleep disturbance; the response format is a three-point scale. Scores increase with the level/amount of sleep disturbance. In addition to a total score (CSHQ-Total); the CSHQ has eight subscales, three of which were used in this study: Bedtime Resistance (CSHQ-BR, 6 items), Sleep Anxiety (CSHQ-SA, 4 items) and Night Wakings (CSHQ-NW, 3 items). Psychometric testing with clinic and community samples has shown adequate internal consistency (α=0.68) and test-retest reliability (0.62-0.79). Its ability to differentiate children with sleep disorders, including those with autism and developmental delay, has been demonstrated (Owens et al., 2000).

Parent-identified child sleep goals: during Session One parents identified up to three goals they wanted to achieve through attending the programme. Examples included: 'To go to sleep within one hour of going to bed', 'To help [daughter] sleep through the night at least three-four nights a week'. A ten-point scale (1: very far from my goal; 10: I have achieved my goal) captured progress towards each goal.

The *Parenting Sense of Competence Scale* (PSOC; Gibaud-Wallston and Wandersman, 1978; Johnston and Mash, 1989) is a 16-item, parent-completed measure comprising two subscales. PSOC-Satisfaction (9 items) measures parents' satisfaction with their role as a parent. PSOC-Efficacy (7 items) measures the extent to which parents feel they are managing the parenting role. A 6-point scale captures respondents' agreement with each item. The efficacy scale is reverse coded so that higher scores consistently indicate greater parenting confidence. The PSOC has been

shown to have internal consistency when used with parents of children with intellectual disabilities (Plant and Sanders, 2007).

Implementation fidelity

A 'session checklist' comprising a list of the topics, activities and materials specified in the intervention manual was completed by the lead facilitator following each session. Deviations from the manual were recorded. Implementation fidelity, in terms of the content of the sessions, was 100%. Whilst several professionals were trained to deliver the intervention, for each delivery the facilitators remained the same for all sessions.

Recruitment and response rates

Twenty-three of the 25 parents receiving the intervention during the study period were recruited. Retention to the research was reasonable: T1: n=16/23; T2: n=15/23, T3: n=18/23. Non-respondents at each time point were typically the same individuals. The mean scores at T0 of T1 responders and non-responders were compared. Responders scored higher on the PSOC-Efficacy scale at baseline ($p<.05$). No other significant differences were found.

Study participants

Nineteen mothers and four fathers, representing 22 children aged 5-15 years (M=8.64, SD=3.17) were recruited. This included three couples, and a father attending alone. Two parents had two children with disabilities and completed the study instruments for each child. All but one parent reported their child's sleep problems had lasted for over 12 months.

Children (13 boys, 9 girls) were typically living in two-parent families (21/22). Parents predominantly identified themselves as White British (21/22) and all spoke English. Parents' academic qualifications ranged from: none (2/23), school leaving qualifications (6/23), further or higher education (15/23). All children had an intellectual disability (IQ < 70). Twelve were also diagnosed with autism. Fifteen children attended a specialist educational provision.

Sample size and power

A priori sample size calculations were carried out using 'G-Power' (version 3.1, Faul et al., 2007). To detect a large effect size in CSHQ scores T0-T3 with a power of 80%, a sample size of 19 was required. Whilst this was reached with the overall sample – loss at follow-up and missing data means that the study was underpowered to detect such changes.

The costs of delivering the intervention

The following information was collected to estimate costs of delivery:

- staff involved in delivering each session (professional qualification, grade); session duration; staff travelling time; number of parents in attendance
- further staff costs: preparation and debriefing time; administration
- other resource costs (materials/resources, refreshments, venue costs)

Results

Data were analysed using SPSS 18.0. Where both parents had been recruited to the study, mothers' CSHQ scores and goal attainment ratings were used. The protocol for managing missing data was that up to 10% of items missing would be replaced by the scale /subscale mean. If greater than 10% of items were missing, the participant's data for that scale was excluded. The CSHQ-Total (α= .828) and PSOC-Satisfaction (α=.800) had satisfactory internal reliability. The CSHQ subscales (BR: α=.580, SA: α=.561, NW, α=.595) and PSOC-Efficacy (α=.507) had poorer internal reliability, something to be expected with sub-scales comprising few items (e.g. Owens et al., 2000).

Intervention take-up and adherence

During the study period 29 families were offered the intervention of whom 25 subsequently attended. Among the study sample (n=23), no parent dropped out. Eleven parents attended all four sessions, three attended only two sessions.

Exploring intervention effectiveness

Group mean scores, 95% confidence intervals and effect sizes were used to describe outcomes. Outcomes at T0 and T3 for the CSHQ and PSOC were compared using paired t-tests. Repeated measures ANOVAs were not employed for the CSHQ and PSOC due to missing data. Achievement of parent identified goals was analysed using a one-way repeated measures ANOVA with parent ID entered as a between subjects factor. Bonferroni adjustments were not applied, in accordance with guidance (Perneger, 1998). Effect sizes were used to determine clinical significance.

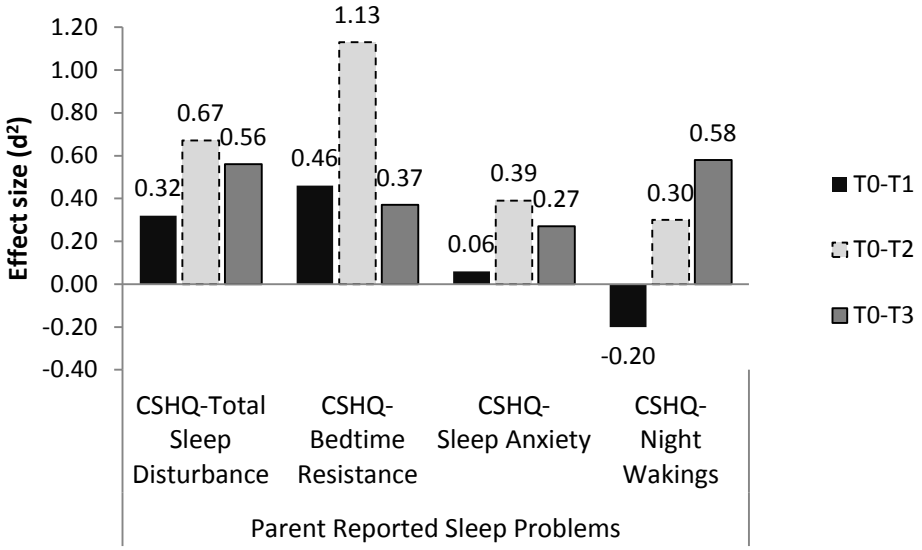
Child sleep outcomes

Compared to T0, mean scores for CSHQ-Total and the subscales used in this study were lower (i.e. improved) at T1, T2 and-T3 (Table 1). At T3, this difference was approaching significance for CSHQ-Total ($p=.06$) and was significant ($p<.05$) for CSHQ-NW. The largest effect sizes were typically at T2, with the exception of the CSHQ-NW where, after a negative effect size post-intervention, the largest effect size was observed at T3. Although all scores were improved at T3 compared to T0, there was a large reduction in the size of improvement for CSHQ-BR at T3 (see Figure 2).

Table 1. Sleep Outcomes T0-T3

	T0			T1			T2			T3			T0-T3
	N	M	95% CI	N	M	95% CI	N	M	95% CI	N	M	95% CI	**T-test/ Repeated measures ANOVA**
CSHQ-Total	21	57.86	53.41-62.30	14	51.79	46.64-56.93	14	50.29	45.21-55.36	16	52.75	47.12-58.38	T(14) 2.054, p=.059
CSHQ-BR	20	10.65	9.22-12.08	14	9.21	7.32-11.11	13	7.69	6.82-8.56	16	9.06	7.37-10.75	T(13) 1.407, p=.183
CSHQ-SA	20	7.95	6.77-9.13	13	7.08	5.51-8.65	13	6.46	5.37-7.55	15	6.73	5.66-7.81	T(12) 1.1.09, p=.289
CSHQ-NW	20	5.85	4.96-6.74	14	5.79	4.82-6.75	14	5.29	4.46-6.12	15	5.13	4.15-6.11	T(13) 2.590, p<.05
Parent-set goals	29	2.10	1.67-2.53	22	5.0	4.19-5.81	21	4.90	3.82-5.99	26	5.35	4.20-6.49	F(3)=31.920, p<.001

Figure 2. Effect sizes for the CSHQ



Thirty-nine goals were set by parents. These predominantly concerned bedtime routine/settling (n=28) and night-time self-settling (n=9). The ANOVA was highly significant ($p<.001$, Table 1). Pairwise comparisons showed significant change from T0 to each follow-up time point ($p<.001$).

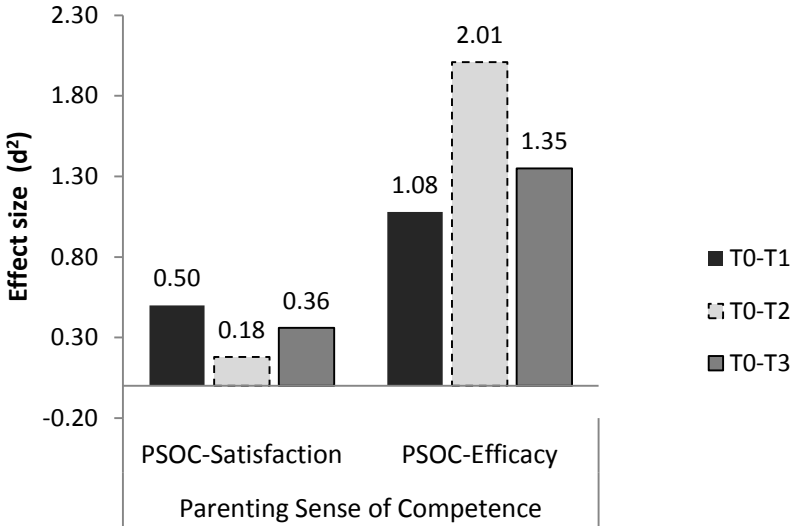
Changes in parental competence

PSOC-Satisfaction and PSOC-Efficacy group mean scores had improved from T0 at each subsequent time-point. The improvement on PSOC-Efficacy was significant ($p<.001$,Table 2). Effect sizes for PSOC-Efficacy were large and maintained at T3. The size of improvement in PSOC-Satisfaction scores was smaller and more variable (Figure 3).

Table 2. Parents' sense of competence T0-T3

	T0			T1			T2			T3			T-Test T0-T3
	N	M	95% CI	N	M	95% CI	N	M	95% CI	N	M	95% CI	
PSOC-Satisfaction	22	35.18	32.02-38.34	15	39.13	36.24-42.03	15	37.67	33.95-41.39	18	38.78	35.42-42.14	T(16)= -1.596, p=.130
PSOC-Efficacy	23	26.48	24.26-28.69	15	28.47	25.81-31.12	15	28.67	26.62-30.71	18	29.39	27.00-31.78	T(17)= -4.912, p<.001

Figure 3. Effect sizes for PSOC-Satisfaction and PSOC-Efficacy subscales



Cost of delivery

The mean cost of delivering the intervention was £1570 (range: £1480-£1640, 2009-2010 prices). Staff time accounted for the greatest proportion of the cost. Childcare was not provided and parents were not reimbursed their travel costs.

Discussion

Group-delivery of sleep support interventions is relatively novel and untested. This study provides preliminary evidence of the acceptability and effectiveness of a group-delivered sleep-management intervention for parents of children with intellectual disabilities and ASCs. At the time of the study the CAMHS Learning Disability team had been routinely delivering this intervention for three years. During this time no one had re-attended the programme. During the study period, no parents dropped out of the intervention. Intervention drop-out was generally low with reasons for drop-out typically because of commitments with other children, or ill-health. As these children remain on the CAMHS LD team's caseload, their progress would be monitored in the longer term; however, there is no data available for the research team as to whether the team did further work with a family with respect to the child's sleep.

Evidence regarding the acceptability of the intervention, and hence mode of delivery, are promising. Take up was high. All parents completed the intervention, although only half attended all sessions. This is perhaps inevitable given the multiple and sometimes unpredictable demands on these parents' lives. Most parents reported that their child's sleep difficulties had been present for at least a year suggesting that these sleep behaviours may have become entrenched and, therefore, resistant to change (Kuhn and Elliott, 2003).

Compared to pre-intervention scores, improvements in mean scores on the child sleep outcome measures were observed. Resolving bedtime resistance was the goal parents most frequently identified at the start of the programme, followed by reducing/eliminating night waking. Monitoring parent-set goals revealed strong progress at T1-T3 in resolving these target behaviours. These findings indicate the intervention was supporting parents to tackle the sleep areas they found most problematic. However, CSHQ ratings indicated that improvements in bedtime resistance were not always maintained, suggesting further, follow-up support may be useful for at least some parents.

Improvements in the child's sleep often occurred gradually, for some parents their child's sleep problems became more challenging before improvements were reported. This was particularly the case for night wakings, where a negative effect size was observed post-intervention, followed by statistically significant improvement at three-month follow-up. An initial resistance to changes in parenting practices (e.g. a new bedtime routine, withdrawal of attention during the night) is not atypical. Indeed, practitioners agree that the success of a behavioural intervention partially depends on parents having the emotional and physical resources to endure a short-term worsening of the problem (Beresford et al., 2012). As information on specific sleep management strategies and resources was only delivered in the later session, implementation may not occur until late into, or indeed after, the intervention has been delivered with measurable changes in outcomes taking time to occur (see Quine and Wade, 1991).

The most marked changes were initially observed for parenting sense of competence. This gives credence to the possibility that a 'sleeper effect' was being observed, with the intervention initially supporting changes in parents' beliefs, attitudes and confidence which then support sustained changes in parenting practices and the consequent resolution, or amelioration, of sleep problems. Large effect sizes, indicating improvement, were observed post-intervention and maintained during follow-up for parental efficacy. Changes in the measure of parental satisfaction, whilst positive, were more variable among the sample. However, the purpose of the intervention is to equip parents with the knowledge and skills to better manage their child's sleep and improvements in perceived parenting efficacy would therefore be hoped for. Parenting satisfaction may be more closely associated with secondary outcomes such as improvements in parents' own sleep, the child's daytime behaviour, or associated improvements in parent-child relationships. The mechanisms by which group programmes may encourage greater parental confidence is explored in more detail elsewhere (Beresford et al., 2012).

The costs of delivering an intervention are an important consideration. Staff time was the greatest cost element, varying according to the grades of staff involved. However, group delivered interventions are typically more cost-effective than individually delivered support (National Institute for Clinical Excellence, NICE, 2006) and are currently advocated for behavioural problems more generally (NICE/SCIE,

2013a). The data presented here are basic and are for illustrative purposes only and any future research will need to incorporate an economic element.

This was an exploratory study of a group delivered sleep intervention for parents of children with intellectual disabilities and ASC. The achieved sample, whilst not diverse in terms of socio-demographic variables, was representative of parents referred to this programme. However, we should note that practitioners may be selective in whom they refer, with families perceived as more 'complex' (for example, families with multiple difficulties or high support needs) possibly offered one-to-one support. Almost all parents attending the programme over the study period participated in the research and the follow-up response rates were good.

The lack of a comparator group is a key limitation and means it is not possible to attribute observed improvements to the intervention. Further, the sample size was small and thus, non-significant findings may be a consequence of lack of statistical power. Using the practitioners who delivered the intervention to administer the research materials at T0 and T1 may have encouraged bias in parents' responses. However, this appears unlikely given that the greatest improvements were typically at T2 and T3 when outcome measures were posted to parents directly by the research team. Whilst take-up to the intervention was high and representative of the population served, there was an under-representation of single parents, parents who have fewer academic qualifications, and minority ethnic groups. Whilst the PSOC-

Efficacy scale had low internal reliability in this sample, this subscale is typically robust (e.g. Ohan et al., 2000).

Conclusion

No evidence was obtained suggesting this intervention is harmful. Indeed, the evidence supports the continued delivery of this programme and for more robust evaluations using randomised trial designs. Other CAMHS Learning Disability teams are currently being trained in delivering the programme offering the potential of a larger sampling pool from which to evaluate this promising intervention. Further research could usefully investigate the effectiveness of alternative modes of delivery, facilitator composition and data capturing wider outcomes for the child.

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