

***Riding the Rapids: Living with autism or disability – an evaluation of a parenting support intervention for parents of disabled children***

Lucy Stuttard<sup>1</sup>, Bryony Beresford<sup>1</sup>, Sue Clarke<sup>1</sup>, Jennifer Beecham<sup>2</sup>, Samantha Todd<sup>3</sup> and Jo Bromley<sup>3</sup>

<sup>1</sup> Social Policy Research Unit, University of York, York, UK

<sup>2</sup> Personal Social Services Research Unit, University of Kent, Canterbury, UK

<sup>3</sup> Central Manchester University Hospitals NHS Trust, Manchester, UK

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**Corresponding Author:**

Lucy Stuttard. Social Policy Research Unit, University of York, York, YO10 5DD, UK.

Email: [lucy.stuttard@york.ac.uk](mailto:lucy.stuttard@york.ac.uk)

**Telephone: +44 01904 321965**

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## **Abstract**

Evidence on the effectiveness of interventions to support parents of disabled children to manage their child's behaviour problems is limited. The aim of this study was to evaluate a group-delivered intervention (*Riding the Rapids*) which was specifically developed for parents of a child with a disability or autistic spectrum condition. This programme has been routinely delivered by a community-based mental health team across an urban, multi-ethnic locality for a number of years. A non-randomised controlled study design comprising an intervention group (n=48) and comparator (no intervention) group (n=28) was used to evaluate the effects of the intervention on child behaviour (Eyberg Child Behaviour Inventory; parent-set goals) and parenting efficacy and satisfaction (Parents Sense of Competence Scale) at post-intervention and six-month follow-up. Data on costs to the service provider of delivering the intervention were also collected. Receipt of the intervention was associated with significant reductions in parent-reported behaviour problems and significant improvements in parenting efficacy and satisfaction. At six-month follow-up, progress towards achieving parent-set child behaviour goals and parenting satisfaction had been maintained. Post-hoc analysis suggests parents who do not have English as a first language may not benefit as much as other parents from this intervention. Findings suggest this is a promising intervention for parents of a child with a disability that is likely to be less resource intensive to service providers than individually-delivered interventions. Limitations and implications for future research are discussed.

## **Keywords**

Autism, disability, behaviour problems, parent-training programme, early intervention, prevention.

## **1. Introduction**

### **1.1 Background**

Disabled children are up to four times more likely to demonstrate behaviour problems than their non-disabled peers (Baker, Blacher, Crnic, & Edelbrock, 2002; Baker et al., 2003; Emerson, 2003a; Volmar & Dykens, 2002). Such behaviours can be difficult to manage, anti-social, distressing, and/or interfere with family routines and activities. Problems often persist into later childhood and adolescence (Emerson, 2003a) and increase in severity. Behaviour problems can threaten children's safety and well-being, potentially hindering their participation in school, community, and social activities. Severe behaviour problems are one of the main reasons disabled children are placed in residential schools (Abbott, Morris, & Ward, 2000). They can also prevent access to services such as short breaks (Kahng & Deleon, 2008). The presence of behaviour problems is also associated with high levels of maternal stress and mental health difficulties (Emerson, 2003b; Glidden & Schoolcraft, 2003; Hastings, 2002, 2003). Sibling relationships can also suffer long-term negative consequences (Rossiter & Sharpe, 2001). Parents consistently report high levels of unmet need for skills to manage their child's behaviour (Beresford, 1995; Bromley, Hare, Davison, & Emerson, 2004).

The relationship between behaviour problems and the risk of poor outcomes for the family is moderated by several factors, including perceived levels of support (Blacher, Neece, & Paczkowski, 2005; Neece & Baker, 2008; Plant & Sanders, 2007). Current evidence suggests that access to early/preventive interventions which help parents better manage the behaviours they find difficult may be important.

Parent-training interventions based on behavioural theory and informed by the Family Partnership Model, with its ethos of working collaboratively with parents to manage

problems and develop self-efficacy (Davis & Day, 2010), have been shown to be highly effective with parents of non-disabled children (Barlow, 2000; Lindsay et al., 2011). Group delivered interventions are also likely to be more cost-effective than individually delivered support (National Institute for Clinical Excellence, NICE, 2006). In light of this evidence, group-delivered parent-training programmes have been incorporated into family support strategies by many Western countries (Lindsay et al., 2008). However, these strategies have not necessarily embraced the needs of parents of disabled children. It is not clear from existing research whether generic parenting programmes are appropriate or effective for parents of children with disabilities or autism (Beresford, 2009). Some well-established generic interventions have created disability-specific programmes, e.g. Stepping Stones Triple P, (Sanders, Mazzucchelli, & Studman, 2004). Practitioners also report modifying and adapting their content to respond to the particular needs of these parents (Lindsay et al., 2008; McIntyre, 2008) or developing disability/autism-specific parenting programmes ‘from scratch’. There have been some studies which have evaluated disability/autism-specific parenting programmes. However, these have not typically been conducted in routine service/clinical contexts. Thus, whilst there is some evidence for their efficacy, evidence about their effectiveness, and acceptability to parents, is much more limited (Beresford, 2009; McConachie & Diggle, 2007).

## **1.2 The Riding the Rapids Programme**

*Riding the Rapids: Living with Autism or Disability* was developed by UK clinical psychologists (based in a community-based Child and Adolescent Mental Health (CAMHS) Learning Disability (LD) team) and a specialist speech and language therapist. It was created in response to the dearth of manualised group-based parenting interventions specifically developed for parents of children with learning disabilities (LD) and/or autistic spectrum conditions (ASC) and the absence of evidence supporting the use of generic parenting

support programmes with parents of children with moderate or severe LD or ASC (National Institute of Clinical Excellence, 2006). The programme was developed and piloted in 2007 and has since been routinely delivered by the team across a large urban locality. An evaluation of the intervention whilst it was still under development yielded positive findings (Todd et al., 2010).

*Riding the Rapids* is for parents of pre- and primary-school aged children (typically aged 3-11 years old) with ASC and/or moderate/severe intellectual and/or complex disabilities. It comprises ten, weekly, two-hour sessions. An informal, voluntary follow-up session is held three months later. Two facilitators deliver the programme with the lead facilitator required to be a clinical psychologist. The aim of the programme is to enable parents/carers to understand, and have the skills and confidence to manage, their child's behaviour in the context of additional needs. The theoretical approach underpinning the elements and format of the programme are described in detail elsewhere (Todd et al., 2010). In essence, the intervention is grounded in behavioural theory and positive behaviour management. Thus applied behaviour analysis and behavioural approaches to behaviour management are core elements of the programme. Principles of experiential learning (Kolb, 1984) inform the training approach with didactic teaching used alongside group-based problem-solving, role play, modelling and home-based observation and practice used to support parents' learning.

Table 1 provides an overview of the intervention. In the first session parents identify a specific behavioural goal (or target behaviour) and learning throughout the intervention is applied to that goal with the expectation that skills/learning will generalise. The STAR (Settings Triggers Actions Results) approach (Zarkowska & Clements, 1994) is employed to develop parents' understanding of their target behaviour, and problem-solving exercises are used to support parents to implement a comprehensive approach to managing the target behaviour. Parents are also trained in the use of communication tools, positive reinforcement

and play. Finally, attention is paid to parental well-being. Throughout the intervention, small treats (magazines, toiletries) are given to parents to encourage to them to care for themselves. Simple cognitive-behavioural strategies for use as stress management techniques are also introduced.

Table 1. *Programme Content* (Todd, Bromley, & Mellor, 2014)

Session	Expected outcomes
1: <i>Setting Your Course</i>	Parents/carers will have introduced themselves and started to form as a group. Specific behavioural goals will have been set.
2: <i>Building Your Boat</i> – Understanding Behaviour I	Parents will have an understanding of the factors which influence children’s behaviour. They will have an understanding of STAR analysis and which settings and triggers are involved in their target behaviour.
3: <i>Making it Watertight</i> – Understanding Behaviour II	Parents will gain knowledge of behavioural theory and functions of behaviour, including the target behaviour.
4: <i>Good work Captain!</i> Encouraging Positive Behaviour	Parents will identify which skills/behaviours their child needs to learn in order to move away from the challenging behaviour, and will devise positive reinforcement schedules to support this.
5: <i>Navigating Your Route</i> – Communication	Parents will gain an understanding of the role of communication approaches in changing behaviour, including visual schedules and supports.
6: <i>Enjoying the Ride</i> Encouraging Positive Behaviour	Parents will practise play skills suited to their child’s needs, incorporating child-centred play approaches.
7: <i>Wear your life Jacket!</i> – Managing Stress	Parents will learn stress reduction techniques based on a cognitive-behavioural model.
8: <i>Mind the Rocks!</i> – Managing Unwanted Behaviour	Parents will consider which responses are appropriate for the target behaviour, using their knowledge of the function of the behaviour.
9: <i>Full Steam Ahead!</i> – Pulling it all together	Parents will develop a coherent plan to address the target behaviour, or a new behaviour if their goal has been reached.
10: <i>Land Ahoy!</i> – Party, planning for the future	Parents will complete outcome measures, reflect on the course, celebrate success and plan a review session.

Parents can self-refer to receive the intervention, or are referred by education and/or mental health practitioners. All referrals are recorded on the programme’s referral database by the service delivering the intervention. Individuals on this database receive an invitation to attend the programme when it is due to be delivered at their child’s school and/or venue

near to where they live in the coming weeks. Forthcoming deliveries of the programme are also widely advertised shortly before they commence (e.g. a special school sends a letter to parents) and some parents join the programme via this route. Overall, the programme is delivered in around six different locations (e.g. school, community hall) each year, with each location typically hosting the programme once very twelve months.

This paper reports findings from an evaluation of the effectiveness of *Riding the Rapids* during routine delivery of the programme in an urban locality with a mixed ethnic and socio-demographic population.

## **2. Method**

### **2.1 Study Design**

A pragmatic, non-randomised controlled study design was used to evaluate the effect of *Riding the Rapids* on child behaviour and parents' sense of competence as parents. The study was conducted within the context of routine deliveries of the intervention. Eight successive deliveries of the programme, spanning a 15 month period, were included in the study (September 2009 - November 2010). This represents the typical rate of delivery of the intervention. Parents on the programme's Referral Database between December 2009 and February 2010 and who had been allocated, due to geographical proximity, to be invited to three forthcoming deliveries of the programme were recruited to form a comparator group (CG). Data allowing estimates of the costs to the service of delivering the intervention were collected. The facilitators who delivered the intervention during the study period were the same individuals who deliver the programme routinely as part of the locality's Child and Adolescent Mental Health (CAMH) Learning Disability Service's provision to families with children with learning disabilities and/or autism.

UK National Health Service (NHS) Research Ethics Committee (REC) approved the study (REC Reference Number 09/H1305/46). The research was managed, and all data analysis conducted, by an independent academic research team (LS, BB, SC, JB) located elsewhere in the UK.

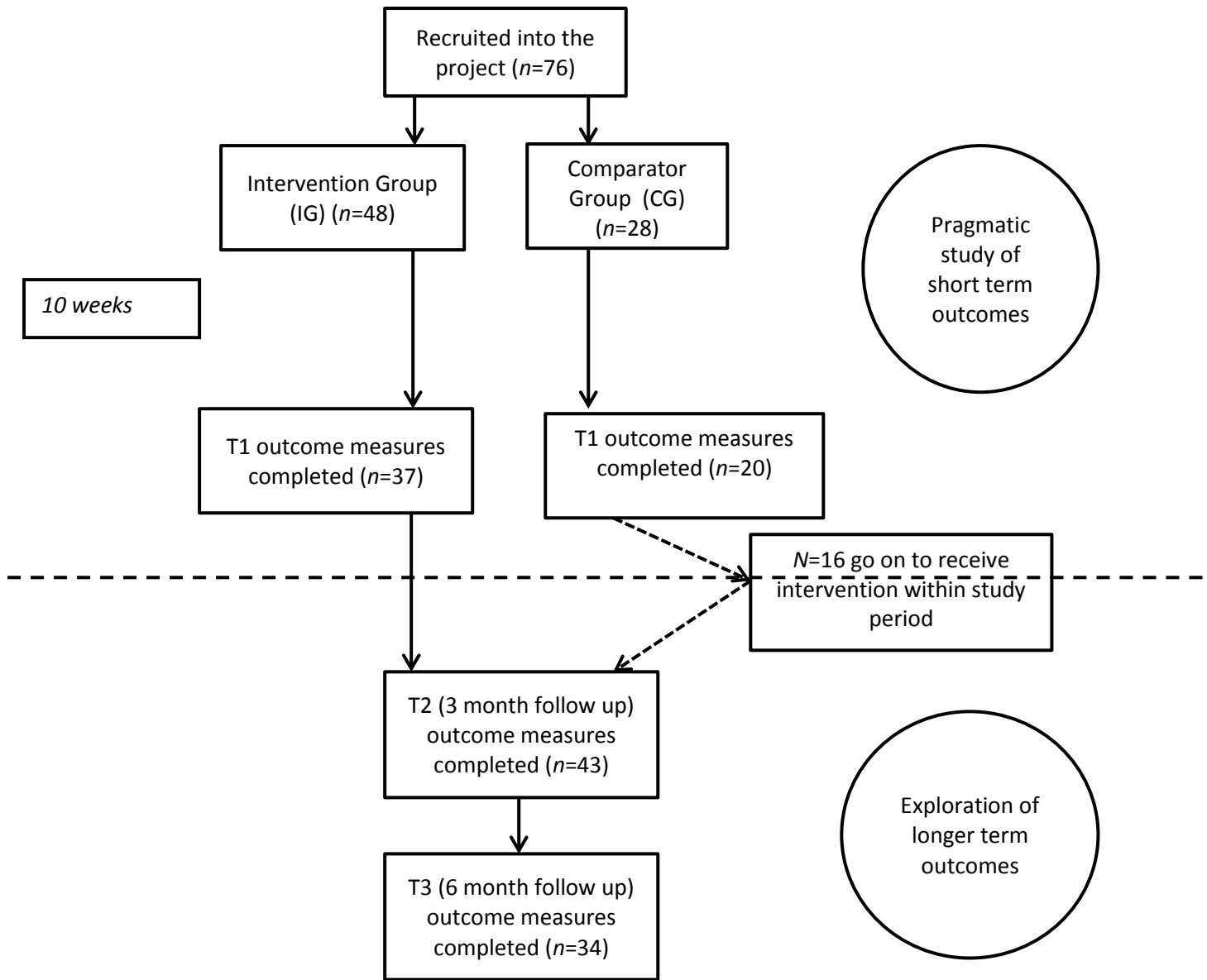
## **2.2 Procedure**

All parents received an information leaflet about the research prior to joining the study and written consent was obtained from all participants. Recruitment to the Intervention Group (IG) occurred at an informal session routinely held for parents a week before the intervention commences. The recruitment rate to the study was 80%. The Comparator Group (CG) received a recruitment pack in the post. Whilst the number of recruitment packs distributed to the CG sampling pool was not recorded, it is possible to assume, on the basis of usual practice by the service delivering the intervention, that around 40 recruitment packs were distributed given that they were sent to all parents/carers who had been offered a place to attend one of three up-coming deliveries of the intervention. From this we can estimate that take-up to the comparator group was approximately 70%.

Outcomes were measured at pre-intervention (T0) and post-intervention (T1). For the IG only, outcomes were also captured at three- (T2) and six- months (T3) post-intervention. During the study period, sixteen CG parents (57%) joined a programme. Data from these parents was included in the analysis of longer term outcomes for IG parents, see Figure 1.

Figure 1.  
*Recruitment and Data Collection Pathway*





For the IG, T0 and T1, outcome measures were administered during the first and final sessions respectively by group facilitators. Completed questionnaires were then passed straight to the research team. All other data were collected directly by the research team. Follow-up questionnaires and CG questionnaires were administered by post. A letter, phone and text reminders were used to boost response rates. An incentive (£10 shopping voucher) was used at each round of data collection.

Parents with English literacy difficulties were offered assistance, either via a telephone interview, or a home visit by a researcher and an interpreter. Whilst this approach introduces the possibility that social desirability may have affected the responses provided, the alternative was to exclude parents not literate in English from the study because, aside from an Urdu version of the child behaviour outcome measure (Eyberg Child Behaviour Inventory), validated versions of the outcome measures were not available in the languages required. On balance, it was deemed more important to include than exclude these parents from the study given the dearth of studies in which parents from minority ethnic groups are represented.

Follow up questionnaires were sent to all parents regardless of whether they had completed the intervention, with the only exception being if a parent withdrew from the study due to exceptional personal circumstances (for example, bereavement).

### **2.3 Outcome Measures**

Standardised measures of child behaviour and parents' sense of competence and progress towards a parent-identified child behaviour goal were used.

The *Eyberg Child Behaviour Inventory* (ECBI; Eyberg & Pincus, 1999; Eyberg & Ross, 1978) is a 36-item parent-completed measure for use with respect to children aged 2-16 years. Each item describes a behaviour that often causes problems for parents. There are two

response modes for each item. The first captures the frequency of each behaviour (named by the scale authors as the Intensity Scale (IS)) and uses a rating scale of *1=never* to *7=always*. The second response mode concerns parents' perceptions of each behaviour as a problem or not (Problem Scale (PS) using a simple 'yes' (=1) or 'no' (=0) response. Clinical cut-offs for the two scales (131 (IS); 15 (PS)) are suggested by the scale authors. The measure has been shown to have good psychometric properties with an internal consistency of .95 (IS) and .93 (PS) (Eyberg & Pincus, 1999); with test-retest reliability coefficients of .80 (IS) and .85 (PS) at 12 weeks and .75 (both scales) at ten months (Funderburk, Eyberg, Rich, & Behar, 2003). Colvin (1999) concluded that 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 discriminative validity of the ECBI has been demonstrated in studies showing significant differences between non-referred, conduct problem, neglected and other clinic-referred children, correctly classifying 96% of children referred by their clinic (Funderburk et al., 2003). Furthermore the measure has been used to show change following an intervention (Schuhmann, Foote, Eyberg, Boggs, & Algina, 1998; Webster-Stratton & Hammond, 1997).

There also evidence of the measure's utility on samples of children who have learning disabilities or those who are on the autistic spectrum. Sofronoff, Leslie, and Brown (2004) found moderate reliability in a sample of 51 parents of children (aged 6-12 years) who have recently been diagnosed with Asperger syndrome. Psychometric examination of the ECBI with children with learning disabilities referred for treatment of behaviour problems supported the use of these scales for measuring outcome in this population (Cone & Casper - Beliveau, 1997).

The *Parenting Sense of Competence Scale* (PSOC; Gibaud-Wallston & Wandersman, 1978; Johnston & Mash, 1989) consists of 16-items forming two subscales. A parenting satisfaction subscale (PSOC-Satisfaction) measures parents' satisfaction with their role as a

parent. The parenting efficacy subscale (PSOC-Efficacy) measures the extent to which parents feel they are managing their parenting role. A 6-point scale indicates agreement with each statement (*1=strongly disagree to 6=strongly agree*). The scale has strong internal consistency with alpha co-efficients on the Satisfaction and Efficacy subscales of .75 and .76 respectively (Johnston & Mash, 1989). 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  $\alpha = .80$  (satisfaction) and  $\alpha = .70$  (efficacy).

*Parent-identified child behaviour goal:* during the first session parents identified a specific child-behaviour goal (e.g. "to scream and shout less when something does not go his way", "child to sleep in his own bed"). Progress in achieving the goal was recorded using a ten-point scale (*1=very far from my goal; 10=I have achieved my goal*)

## **2.4 Implementation Fidelity**

Complex interventions may be designed to be adapted to the settings in which they are being delivered (Medical Research Council, 2008). This was the case with the *Riding the Rapids* programme with facilitators responding to the specific needs of the children represented in a particular group. Some degree of variation in implementation fidelity was therefore expected. In order to monitor fidelity, checklists detailing the topics specified for a session in the intervention manual were completed by facilitators at the end of every session. Facilitators also recorded any deviations, including reasons, from the manual.

## **2.5 Sample**

*A priori* sample size calculations were carried out using 'G-Power' (version 3.1) (Faul, Erdfelder, Lang, & Buchner, 2007). To detect a large effect size in the IG as measured by the

primary outcome measure (ECBI) with a power of 80%, a sample size of just over 50 was required with a minimum sample size of 25 in both arms.

Seventy-six parents took part in the study (67 of whom were mothers). The children were aged 3-12 years ( $M=6.68$ ,  $SD=2.38$ ). Forty-eight parents were recruited to the Intervention Group (IG) and 28 to the Comparator Group (CG). A third of the sample ( $n=23$ ) were lone parents. Parents' academic qualifications ranged from: none ( $n=12$ ), school leaving qualifications ( $n=35$ ), and further/higher education qualifications ( $n=25$ ). Just under half identified themselves as belonging to a minority ethnic group ( $n=37$ ), of whom two fifths ( $n=15$ ) reported English was not their preferred language.

The majority of children were boys (78%). Parent-reported diagnoses included: autistic spectrum conditions ( $n=42$ ), intellectual disabilities ( $n=27$ ), physical disabilities ( $n=20$ ), sensory disabilities ( $n=7$ ). Children often had multiple impairments. Over half of the children ( $n=41$ ) were in specialist education provision.

The IG and CG were compared on socio-demographic characteristics and scores on outcome measures at T0. Whilst a fifth of children in the IG lived with a lone parent ( $n=9$ ), this increased to half ( $n=14$ ) for the CG ( $X^2=7.532$ ,  $p<.01$ ). No other differences were found between the IG and SG.

### **2.5.1 Retention to the research.**

Compared to T0, response rates at T1 were 77% ( $n=37$ , IG) and 71% ( $n=20$ , CG). Longer term follow-up response rates (IG group only) were: 67 % (T2) and 53% (T3). T1 responders and non-responders were compared against their T0 outcome scores. T1 non-responders reported significantly poorer ratings of parental satisfaction at T0 ( $t=1.993$ ,  $p<.05$ ). There were no other significant differences.

## **2.6 Service Delivery Costs Data**

In order to estimate the costs to the service of delivering the intervention, the following information was collected from the provider service: numbers, professional qualifications and grades of staff involved in preparing for and delivering the intervention; time and other resource costs associated with delivering the intervention (for example, materials/resources, refreshments, venue costs). Facilitators also recorded parents' attendance at sessions.

### **3. Results**

#### **3.1 Data Management and Analytical Approach**

Data was analysed using PASW 18. An established protocol for managing missing data on the ECBI was followed (see Eyberg & Pincus, 1999). As there is no published protocol for management of missing data for the PSOC, the following rubric was adopted: i) response to one item missing: substitute with subscale mean; ii) responses to two or more items were missing: data not used. Internal consistency alpha reliability coefficients of the outcome measures were calculated on T0 data for the whole sample. All scales had good reliability ( $\alpha > 0.7$ ).

##### **3.1.1 Short-term intervention effects.**

Analysis of covariance (ANCOVA) was used to compare changes in group mean scores for the measures of parent-reported child behaviour (ECBI) and parents' sense of competence (PSOC) for the IG and CG between T0 and T1. Assumptions of the test were met unless otherwise specified. T0 scores and family composition (lone vs. two-parent) were entered as covariates to control for baseline scores. Where both parents had attended, only the mother's ECBI responses were used. Bonferroni adjustments were not applied, in accordance with guidance (Perneger, 1998).

##### **3.1.2 Change in intervention group scores at follow up.**

Data on longer-term intervention outcomes, including progress towards achieving parent-set goals, were explored using one-way repeated measures ANOVA. Where results were significant, pairwise comparisons identified the source(s) of difference in scores.

### **3.1.3 Clinical significance.**

The Reliable Change Index (RCI) examined clinical significance at an individual level. *The Reliable Change Index* (RCI; Hawley, 1995; Jacobson & Truax, 1991) determines the significance of a change in an individual's score on a measure after accounting for the reliability of the measure. Reliable change is defined as having been achieved when the RCI is calculated is  $> 1.96$ . RCI is calculated on a case by case basis using the following formula:  $RCI = \frac{Score\ 1 - Score\ X}{Sdiff}$ . Sdiff is obtained by calculating the square root of double the standard error squared ( $Sdiff = \sqrt{2 (SE)^2}$ ). In this study RCIs were calculated for ECBI and PSOC scores between pre-intervention scores and scores at each post-intervention time point.

### **3.2 Intervention Fidelity**

Reported levels of intervention fidelity were very high ( $>90\%$ ) for all but two groups. Here modifications to the approach set out in the manual were made in response to the specific make-up of the group. However, core elements of the intervention had been retained. For example, for a group where none of the children represented had an ASC diagnosis, the programme was adapted to better reflect the disabilities represented (fidelity=69%). Similarly, a group delivered to parents of children under 5-years was modified to increase input on play and communication (fidelity=89%).

### **3.3 Indicators of the Acceptability of the Intervention**

Sixty-six parents (85%) completed the intervention. Reasons for dropout were obtained for 6/11 parents and were: bereavement, relocation, ill-health and work commitments. None of the identified cases suggested unacceptability of the intervention as a reason for drop-out. Attendance was also good with an average attendance of eight out of ten sessions. Again, this provides evidence in support of the acceptability of the intervention.

### 3.4 Short-term Intervention Effects

At T1, the mean score of the IG and CG differed significantly on all outcome measures (Table 2). For the IG, the mean score improved across all measures between T0 and T1. T0 scores were significantly associated with T1 scores; however, family composition (lone vs. two-parent family) added nothing to the explanatory model.

**Table 2.**

*Short-term Intervention Effects Measured by ECBI and PSOC*

	Group	N	T0				T1			F, p	% Reliably Improved T0-T1	% Reliably Deteriorated T0-T1
			M	SD	95% CI	M	SD	95% CI				
ECBI-IS	IG	29	134.72	33.84	121.85-147.60	125.72	33.33	113.04-138.40	9.077, p=.004	9 (31%)	2 (7%)	
	CG	17	145.12	37.31	125.94-164.30	151.94	36.20	133.38-170.50		1 (6%)	3 (18%)	
ECBI-PS	IG	23	17.61	7.35	14.43-20.79	13.04	9.43	10.33-15.75	16.216, p<.001	11 (48%)	1 (4%)	
	CG	17	18.71	7.20	15.00-22.41	20.65	6.27	15.80-25.60		1 (12%)	5 (29%)	
PSOC-Sat	IG	34	33.53	7.78	30.81-36.25	37.62	6.05	35.50-39.73	23.802, p<.001	15 (44%)	3 (9%)	
	CG	20	34.05	8.53	29.94-38.16	30.63	7.55	26.99-34.27		2 (10%)	8(40%)	
PSOC-Eff	IG	34	29.06	5.49	27.14-30.98	32.26	4.40	30.73-33.80	4.492, p=.039	16 (47%)	1 (3%)	
	CG	20	30.26	6.69	27.04-33.49	30.53	6.05	27.61-33.44		3 (15%)	5 (25%)	

Differential N across the scales due to incomplete data returned and discarded as directed by missing data protocols

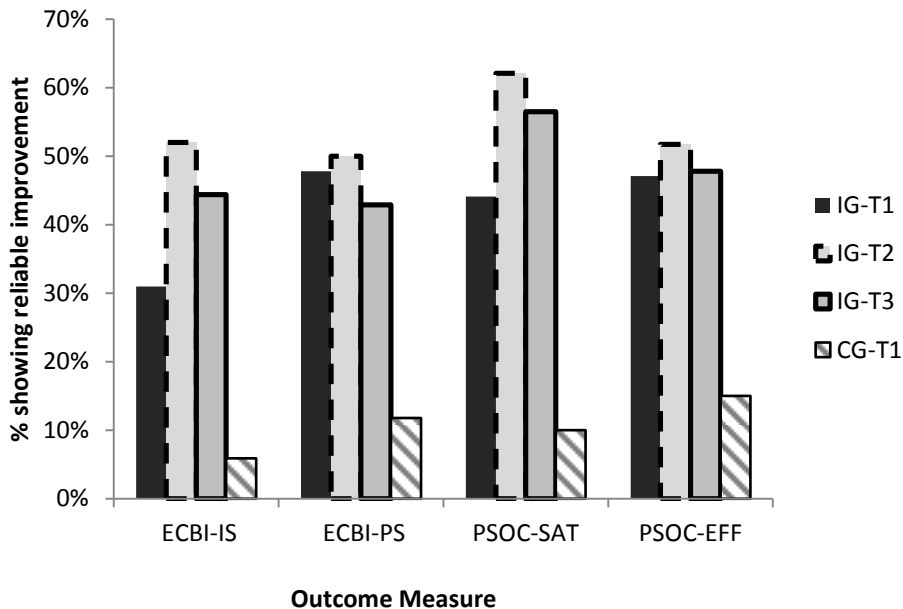


### 3.4.1 Clinical significance.

At an individual level, the proportion of parents whose scores had reliably improved at post-intervention was greater among the IG than the CG across all the outcome measures (Table 2/Figure 2). The difference between these proportions was significant for the ECBI-PS (IG:  $n=11$ , 48%, CG:  $n=1$ , 6%, Fisher's Exact Test  $p=.016$ ), PSOC-Satisfaction (IG:  $n=15$ , 44%, CG:  $n=2$ , 10%, Fisher's Exact Test  $p=.005$ ); and PSOC-Efficacy (IG:  $n=16$ , 47%, CG:  $n=3$ , 15%, Fisher's Exact Test  $p=.009$ ). In terms of deterioration in scores, few IG parents' scores had reliably deteriorated at T1 (between 3-9% across all measures), in comparison between 18-40% of parents in the CG had reliably deteriorated between T0-T1.

Figure 2.

*Proportions of Parents Demonstrating Reliable Improvement from T0 at T1-T3*



### 3.5 Outcomes for the Intervention Group at Three- and Six-Month Follow-up

There were significant improvements between group mean scores at pre-intervention (T0) and three- and six-month follow-up on PSOC-Satisfaction ( $p<.001$ , Table 3). No significant

differences were found in group mean scores between post-intervention (T1) and three- and six-month follow-up, or between three- and six-month follow up group mean scores.

Significant within group changes for the ECBI-PS scale ( $p=.002$ ) were also found. However, pairwise comparisons (with a Sidak adjustment for multiple comparisons) showed change to only be significant change between T0-T1 ( $p=.003$ ). All other comparisons were non-significant.

**Table 3.**  
*Long-term Intervention Effects Measured by ECBI and PSOC*

	T0			T1		T2		T3		F, p	Reliable Change	RCI T0-T2 N (%)	
	N	M	95% CI	M	95% CI	M	95% CI	M	95% CI			RCI T0-T3 N (%)	
ECBI-IS	22	145.41	129.16-161.66	133.37	120.23-146.50	134.55	117.39-151.70	137.27	122.10-152.45	2.742, $p=.051$	Improvement Deterioration	13 (52) 5 (20)	8 (44) 4 (22)
ECBI-PS	17	18.88	14.97-22.80	12.12	8.86-15.37	14.00	10.23-17.77	14.12	9.58-18.65	5.970, $p=.002$	Improvement Deterioration	10 (50) 4 (20)	6 (43) 3 (21)
PSOC-Sat	28	32.14	29.32-34.97	36.64	34.48-38.80	36.32	33.41-39.23	37.79	34.94-40.63	8.308, $p<.001$	Improvement Deterioration	18(62) 5 (17)	13 (57) 5 (22)
PSOC-Eff	28	29.43	27.34-31.51	30.93	29.29-32.57	30.43	28.15-32.71	31.25	28.56-33.94	1.401, $p=.254$	Improvement Deterioration	15 (52) 2 (7)	11 (48) 4 (17)

\*A Greenhouse-Geisser adjustment was used as the ANOVA violated the assumption of sphericity.  
Differential N across the scales due to incomplete data returned and discarded as directed by missing data protocols

### 3.5.1 Reliable improvement in the longer term.

At T2, there were further increases in the proportion of parents where the change in scores was classified as reliably improved on the ECBI-IS ( $n=13$ , 52%) and PSOC-SAT ( $n=18$ , 62%; Table 3/Figure 2). Proportions were maintained for ECBI-PS and PSOC-Efficacy. By T3, the proportion of parents reporting reliable improvement had reduced from T2. However, with the exception of the ECBI-PS a greater proportion were still demonstrating reliable improvement at T3 than T1. At six-month follow-up, the proportion of parents reporting reliable deterioration (from pre-intervention) had increased to approximately one fifth across all measures (17% PSOC-Eff – 22% ECBI-IS /PSOC-Sat).

### **3.6 Achievement of Parent-identified Goals**

Mean ratings on progress towards achieving a specific child behaviour goal significantly improved ( $F=20.931, p<.001^1$ ) at each data collection point compared to the baseline rating (T0: M=2.72, SD=2.42; T1: M=6.45, SD=2.91; T2: M=6.85, SD=2.64, T3: M=6.79, SD=2.57). Pairwise comparisons (with a Sidak adjustment for multiple comparisons) showed significant changes occurred between: T0-T1, T0-T2, and T0-T3 (all  $p<.001$ ). There were no other significant changes in goal ratings between measurement time-points.

### **3.7 The Impact of English Language Fluency on Intervention Effectiveness**

The facilitators' strategy for managing language ability in a group was to provide interpreters if requested by a parent. Experience of delivering the intervention had resulted in the facilitators limiting this to two interpreters per group. However, the facilitators did find interpreting support may be refused. In addition, on occasions other members of the group did informally interpret for members of the group (see Beresford, Stuttard, Clarke, Maddison, & Beecham, 2011).

One in six parents ( $n=8$ ) recruited to the intervention group reported English was not their preferred language. Given the scarcity of evidence on the impact of accessing parenting support via a second, or non-preferred language, we took the opportunity to conduct an exploratory post-hoc analysis of its impact on intervention outcomes at T1. Chi-square tests (or Fisher's Exact Test when  $X^2$  assumptions were not met) were used to compare reliable change in ECBI and PSOC scores in terms of their language preference, see Table 4.

The association between whether English was a parent's first language and outcomes was approaching significance in terms of one of the outcome measures: ECBI-IS ( $p=.078$ ). Over

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<sup>1</sup> A Greenhouse-Geisser adjustment was used as the ANOVA violated the assumption of sphericity.

a third of IG parents ( $n=11$ ) who described English as their preferred language (we refer to these parents as English speaking) had reliably improved scores on the ECBI-IS at post-intervention (Table 4). In contrast, none of the parents who preferred another language showed reliable improvement on this outcome measure. No other associations were found.

Table 4.

*Post-hoc Exploration of the Relationship Between Outcomes and Favoured Language*

	Number reliably improved at T2 n/total sample		Fisher's Exact Test
	English Speaking	Non-English Speaking	
ECBI-IS	11/31	0/8	$p=.078$
ECBI-PS	14/23	2/8	$p=.113$
PSOC-Sat	15/36	5/8	$p=.436$
PSOC-Eff	16/36	3/8	$p=1.000$

### 3.8 Costs to Providers of Delivering the Intervention

The mean cost of delivering a *Riding the Rapids* programme was £3,225. Costs ranged from £2,582-£4,200 per intervention delivery depending on the number, profession and grade of the facilitators. Staff time (included setting up the group, planning, travelling, delivering the intervention and debriefing) accounted for the greatest proportion of the cost. The remaining intervention delivery costs to the service included refreshments and ‘treats’ for parents. The service delivering the intervention did not incur any costs related to venue hire nor did it reimburse families for transport costs. In addition, the schools in which the intervention was delivered offered a childcare facility free of charge. The cost for interpreters was met from a different funding stream and information about these costs was not available.

In terms of the cost of programme delivery per parent, this depended on the number of attendees at each session. In this study between eight and 13 parents started each programme, although attendance at some sessions was as low as three parents.

## 4. Discussion

This paper reports an independent evaluation of the effectiveness of a group-delivered parenting intervention developed specifically for parents of children with LD and/or ASC. The intervention is one of the core services provided by a CAMHS LD team in the UK and is routinely delivered across a large urban locality. Implementation fidelity was typically high. Lower levels of fidelity were observed as a result of the facilitators responding to the specific needs of families and their presenting difficulties. In delivering complex interventions, the expertise of a facilitator to not only deliver a programme as designed, but to also have the skills to adapt a programme to best meet the needs of those served, should be recognised (Kendall & Beidas, 2007).

Attendance rates for the programme were good and drop-out was lower than has been found for generic parent support interventions (Lindsay et al., 2008). Where reasons for drop-out were given they were not with regard to the acceptability of the intervention or appropriateness of the course material. It is important to note that the intervention appears to have been successful in reaching parents across the socio-demographic spectrum. For example, nearly half of the study sample were from ethnic minority groups and only a minority of parents had achieved further or higher education qualifications. These figures fit with what is known from census data about the demographics of the population in the locality where *Riding the Rapids* was being delivered (<http://www.ons.gov.uk/ons/guide-method/census/2011/index.html>). These groups have not typically been (adequately) represented in the majority of previously published studies which have looked at the efficacy or effectiveness of group-delivered parenting support interventions for parents of disabled children. This study therefore makes a useful contribution to testing the effectiveness of such interventions with minority groups, a point we return to later.

At T1, parents who had received the intervention reported fewer problems with their child's behaviour (ECBI-PS; ECBI-IS) and an improved sense of parenting competence (PSOC-Satisfaction; PSOC-Efficacy) compared to those who had not received the

intervention. A statistically significant proportion of the IG parents had also reliably improved in terms of their scores on the ECBI-PS and the PSOC subscales. We should note however, that whilst the mean IG scores improved at T1 from T0, mean CG scores deteriorated, particularly in terms of parental satisfaction, where 40% of the CG had reliably deteriorated at T1. This will have inflated the difference between the IG and CG. The cause of the deterioration within the CG is unknown. Unlike studies where treatments are deliberately withheld from participants in the waiting list control group, parents in our CG were recruited whilst waiting to attend the group they would have always attended regardless of the study taking place. Therefore, the deterioration of scores is unlikely to be a consequence of parents' frustration at being 'held back' from receiving the intervention. However, completion of the outcome measures at T0 may have sensitised parents to their child's behaviour and parenting strategies and this may have affected on parents' responses at T1. Another explanation for this observed deterioration is that once the parents knew they were going to receive support they desisted from trying to address their child's behaviour on their own, preferring to wait for the intervention to begin (see Cunningham, Kypri, & McCambridge, 2013). However, our longer-term analysis of change within the intervention group suggests that improvements noted at T1 are more than a result of the contrast against the deteriorated scores in the CG. We explore these in more detail below.

The follow-up data for parents receiving the intervention allowed us to examine outcomes over the longer-term. Statistically significant improvements in parent set goals were noted at each follow-up point, with the greatest improvements being made between during the intervention period (T0-T1) with these improvements maintained over the longer term. In terms of child behaviour more generally (as measured by the ECBI), mean scores remained improved from T0 at each follow-up point for the ECBI; however, they only reached statistical significance at T1 for the ECBI-PS, suggesting that some parents may not have observed maintained improvements. Parents also reported improvements in their

parenting competence, specifically there were statistically significant improvements in parenting satisfaction (PSOC-SAT) which were maintained at six months (T3). This provides reassurance that earlier significant results at T1 were not simply a result of the (possibly spurious) deterioration in CG scores. However, improvements in within group mean scores for parenting efficacy did not reach statistical significance.

This data has given us insight into the possible processes by which outcomes were achieved. Consistently positive findings at post-intervention and three- and six-month follow-up regarding progress towards achieving parent-set goals certainly indicate that the intervention was successful at helping parents to develop strategies to manage specific problem behaviours. However, unless the skills learnt to manage a specific behaviour are generalised the benefit of an intervention is likely to be short-lived. At T1, a greater number of parents had reliably improved scores on the ECBI-PS than ECBI-IS. By T2, however, this difference was marginal. Indeed, approximately half of scores on both ECBI scales were classified as reliably improved. A possible explanation is parents' perceptions of their child's behaviour (ECBI-PS) changed during the intervention period whilst changes in parenting (required to achieve behavioural change) took longer to assimilate, implement and take effect. Changes in perceptions of the child's behaviour may also need to occur before parents adopt new approaches to behaviour management / parenting. This finding lends support to the argument for the need for disability-specific parenting support interventions because they can incorporate input to help parents to understand how their child's impairments may (or may not) influence or affect behaviour.

The RCI statistics on ECBI scores indicate that further improvements appear to take place post-intervention for some parents. However, this is not visible from simply looking at the mean scores. This is because following the intervention, whilst some parents continued to report further improvements in the ECBI subscales, approximately one fifth of parents reported a reliable deterioration. These findings suggest that not all parents appear equally

able to maintain the improvements they may have initially observed during the intervention period. For a minority of parents in the IG, their RCI scores on outcome measures reliably deteriorated. This may indicate variability in parents' ability to generalise skills and learning acquired during the programme, and/or the programme's effectiveness in supporting generalisation of learning. A consequence may be that some parents are unable to adapt behaviour strategies to new problem behaviours as they emerge. It was not possible with the current dataset to fully explore whether certain parent- or child/disability-centred factors are associated with an increased likelihood of improved outcomes achieved during the intervention being maintained and/or lost. Finally, it is also important to note that, given the deterioration in mean CG scores from T0 to T1, it may be that for some parents the intervention prevents deterioration, as opposed to fostering improvement.

The differences in the strength of change in parenting competence (measured by the PSOC) are also worthy of comment. The pattern of reliable improvement for parental satisfaction appears to mirror that of the ECBI-IS: this may indicate increased parenting satisfaction as parents become to better understand and manage their child's behaviour. Whilst at an individual level, many parents demonstrated reliable improvement on the PSOC-Efficacy scale, improvement was not so visible with regard to a change in mean scores. This is perhaps surprising given this scale captures parents' sense of efficacy, a construct in which we might expect to see an improvement at post-intervention. Interestingly, evidence from other studies on the impact of parenting support interventions on parents' sense of efficacy differs. For example, Sofronoff and Farbotko's (2002) evaluation of an autism-specific intervention found a positive impact on PSOC-Efficacy scores at post-intervention. In contrast, a study evaluating the effectiveness of a disability-specific intervention with parents of children with ASC found parenting efficacy decreased between pre- and post-intervention but this was then followed with a significant increase in scores, compared to pre-intervention, at six-month follow-up (Whittingham, 2009). It was noted that parents' trepidation about



their ability to sustain changes and learning once the intervention has finished may be one explanation for the observed deterioration in parenting efficacy at post-intervention. Given the variability in parents' ability to maintain improvements in child behaviour noted above, it may be that parents in this study also felt this same trepidation.

This study produced preliminary evidence that the effectiveness of the programme may be moderated by fluency in English. It is important to note at the outset that parents attending the programme were offered interpreting support and the interpreters used were familiar with the intervention. However, there was some evidence to suggest that parents for whom English was not a first or preferred language may be less likely to experience the same improvements in their child's behaviour compared to parents who were fluent in English. Importantly, this impact was not detected on the measure of parents' sense of competence, suggesting that these parents do get some benefits from receiving the intervention. There are a number of possible explanations for the impact of parents' language on intervention effectiveness. It may be due to interpreting difficulties (for example, lack of comparable words in the native language), or because parents are electing not to have an interpreter even though their English is not sufficient to fully understand input and discussions. Language may also pose a barrier to gaining peer support from other parents. However, the sample sizes used to explore this were small, and without normative data and validated translations of the measures this finding must therefore be treated as preliminary and with caution.

Whilst it was not possible to conduct a cost-effectiveness analysis with the data available, this study has provided evidence to suggest that improvements to child behaviour and parents' sense of competence can be made at a relatively modest cost to the delivering service. In terms of the cost of delivering the intervention, staff time was the greatest cost to the provider. The intervention authors stipulate that the lead facilitator has to be a qualified clinical psychologist with experience of working with children with ASC and LD. However, there is flexibility with regards to the co-facilitator. Indeed, learning disability nurses, special

needs teachers, speech and language therapists and parents of disabled children have been trained to co-facilitate delivery of *Riding the Rapids*. The intervention authors (JB, ST) believe parent co-facilitators can provide credibility to the strategies and solutions being presented.

The service delivering the intervention was fortunate in not needing to meet the costs of providing childcare or interpreters. These resources had enabled parents with younger children and/or those who did not speak English as their first language to access the intervention. Any service thinking of delivering this programme would have to consider these costs and the additional upfront costs of staff training and materials.

The study has a number of strengths. The intervention and comparator groups were well matched. The study sample was socio-demographically diverse and representative of typical referrals to the intervention. Standardised outcome measures were used, though we note issues around limited psychometric testing of these measures on parents whose first language is not English. There are, however, limitations. First, it was not possible to randomise parents into the Intervention and Comparator (i.e. non-intervention) Groups. This was because the intervention is part of routine practice and is delivered in various locations across a large urban area, with each location hosting the intervention every twelve months. For practical (and transport cost) reasons, parents attend the programme when it is being delivered near to where they live. Randomisation would have therefore meant some parents having to wait well over a year to receive the intervention: something the clinicians were unwilling to allow. Whilst randomisation is the gold standard research design, there is a growing recognition that this is not always feasible and should not preclude evaluations using less robust designs being carried out (Medical Research Council, 2008). However, it is important to note that a lack of randomisation means caution is required in interpreting the findings. This is because it is possible that undetected, or unknown, differences between the intervention and comparator groups affected the observed outcomes. Using the practitioners

who delivered the intervention to administer the research materials at T0 and T1 may have encouraged bias in response ratings; however, we are reassured that, for the most part, positive change was maintained at follow-up. In addition, some parents were lost at follow-up; we were not able to compare the IG and CG beyond T1; and the CG sample was smaller than ideal. Further robust evaluations of the intervention are recommended. Larger sample sizes would also allow identification of the characteristics of parents (and their children) who fare less well under such interventions.

The study findings also raise a number of questions or issues which warrant further research. The outcomes for parents from minority groups, including those whose preferred language is not English, emerged as a possible issue. Studies which investigate the effectiveness of such interventions for minority groups and the role of language, literacy, cultural factors and the use of interpreters on effectiveness would be beneficial. Evidence from generic parenting interventions suggests that they are effective across different cultural groups (Gardner, 2012) though others have noted the importance of addressing and responding to cultural diversity in the content of the intervention (Coard, 2004). Work looking at outcomes for parents whose first language is not the same as that in which the intervention is being delivered appears to be very limited. Importantly, and in addition, for children with learning disabilities and ASC there is the additional issue of addressing perceptions and beliefs about disability across different cultural groups (Danescu, 1997; Welterlin & LaRue, 2007). As noted earlier, to do this work the inadequacies of the outcome measures (for example, availability in minority languages) will need to be addressed. The longer-term impact of such programmes, and the extent to which they prevent use of more specialist services or intensive intervention approaches, is another key issue for future research especially as a key outcome for early intervention may be the prevention of deteriorating behaviour rather than improvements. Finally, clinicians based in services which support families with disabled children typically argue that disability-specific parenting

interventions are required. More research which tests the relative effectiveness of generic vs. disability parenting support interventions is needed.

#### **4.1 Conclusion**

There is a lack of robust evaluations of group-delivered behaviour management interventions for parents of children with disabilities within the communities in which they are typically delivered. Based on the evidence presented, *Riding the Rapids* programme appears to be an effective intervention for at least some parents with children with ASC or LD. Low drop-out and high attendance rates suggest it is an acceptable to parents who take-up this offer of support. The programme appeared to be particularly successful at helping parents to tackle specific challenging behaviours and improving parenting satisfaction. There appeared to be variability in parents' ability to maintain improvements in their child's behaviour once the intervention is over. These parents may have struggled to adapt and generalise the behaviour strategies they have learnt to new problem behaviours as they emerge. These findings support the argument that parenting support should not be delivered using a 'one-size fits all' approach. For some parents, in particular those whose children have more complex needs or whose parents are facing increased adversity, individual support may be most appropriate (National Institute of Clinical Excellence, 2006). Some parents may also need additional longer-term support to maintain these benefits and generalise their newly learnt skills: an issue noted in other studies (Beresford, 2009).

**Conflict of Interest Statement:** ST and JB are among the co-authors of the intervention.

Whilst supporting recruitment and some administration of research instruments to the intervention group during the programme. They were not involved in any data analysis. They

did not fund or commission this work. Their contribution to the paper is solely the detailed description of the intervention provided in the introduction.

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