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# **An evaluation of the *Cygnets* parenting support programme for parents of children with autism spectrum conditions**

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## **Running title**

Evaluation of the *Cygnets* parenting support programme

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## **Conflict of Interest statement**

AM was involved in developing *Cygnets*. His contribution to the paper has been solely the detailed description of the intervention and its development and critical revisions. AM was not involved in any of the data collection, analysis or interpretation.

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## Abstract

Parents of children on the autistic spectrum often struggle to understand the condition and, related to this, manage their child's behaviour. *Cygnets* is a parenting intervention which aims to help parents address these difficulties, consequently improving parenting confidence. It is widely used in the United Kingdom (UK). Despite this, there have been few evaluations. This paper reports a small-scale pragmatic evaluation of *Cygnets* as it was routinely delivered in two English cities. A non-randomised controlled study of outcomes for parents (and their children) was conducted. Data regarding intervention fidelity and delivery costs were also collected. Parents either attending, or waiting to attend, *Cygnets* were recruited (intervention group: IG, n=35; comparator group: CG, n=32). Parents completed standardised measures of child behaviour and parenting sense of competence pre- and post-intervention, and at three-month follow-up (matched time points for CG). Longer-term outcomes were measured for the IG. IG parents also set specific child behaviour goals. Typically, the programme was delivered as specified by the manual. Attending *Cygnets* was associated with significant improvements in parenting satisfaction and the specific child behaviour goals. Findings regarding other outcomes were equivocal and further evaluation is required. We conclude that *Cygnets* is a promising intervention for parents of children with autism in terms of, at least, some outcomes.

## Key words

Autistic spectrum, parent training, child behaviour, non-randomised controlled trial

## Highlights

- *Cygnets* is a psycho-educational intervention for parents of children with autism spectrum conditions.
- We compared outcomes for parents attending *Cygnets* to a waiting list comparator group.
- Parenting satisfaction was significantly improved for parents attending *Cygnets*.
- These parents also reported improved child behaviour.
- Improvements were maintained six-months post-intervention.

## **1. Introduction**

### *1.1. Background*

Children on the autistic spectrum are more likely to present with a range of challenging behaviours compared to typically developing children and children with disabilities (Brereton et al., 2006; Green et al., 2000; Guttmann-Steinmetz et al., 2009). A number of factors are believed to contribute to this, including; impairments in social functioning, anxiety, and/or misunderstandings of the social context (Baron-Cohen, 2008). Challenging behaviour can significantly impact on child and family well-being in the short and longer term (Hastings & Brown, 2002; Simonoff et al., 2008; Tomanik et al., 2004; Willey, 2003). Parents often describe themselves as feeling 'de-skilled' which compromises parenting confidence (Beresford et al., 2012; Kuhn & Carter, 2006; Sofronoff & Farbotko, 2002).

A lack of early/preventive interventions may result in behaviour problems becoming increasingly severe, difficult to manage and intractable, the costs of which are felt by the individual, family and society (Willey, 2003). Given the increasing reported prevalence of autism (Baird et al., 2006), improving outcomes for people of all ages with autism is now firmly on the United Kingdom's (UK) government's agenda (Department of Health, 2014). In support of this, the National Institute of Clinical Excellence (NICE) published guidance regarding the diagnosis and management of children with autism (NICE/SCIE, 2013). Psycho-educational parent training interventions, which seek to improve parents' understanding of the diagnosis and the implications in terms of parenting, are recommended post-diagnosis and subsequently.

In order to respond to demand for specialist support far outstripping resource availability, some services in the UK have begun to deliver interventions to groups of parents, which can be more cost-effective (NICE, 2006) and also offers the opportunity for peer support.

## *1.2. Evidence for group delivered psycho-educational programmes for parents of children on the autistic spectrum*

Manualised autism-specific interventions used in the UK include:

- The National Autistic Society's *EarlyBird* and *EarlyBird Plus* programmes
- Barnardo's *Cygnets* programme
- Wright and Williams (2007) *ASCEND* programme

*EarlyBird* (for parents of pre-school children) and *EarlyBird Plus* (for parents of children aged four-eight years old) (<http://www.autism.org.uk/earlybird>, Shields, 2001; Stevens & Shields, 2013) are three-month long programmes that work with up to six families at a time, combining weekly group training sessions with individual home visits. Parental feedback is typically positive, but the programmes have not been fully evaluated. A study conducted in New Zealand, using a custom-designed outcome measure reported improvements for parents completing *EarlyBird* (Anderson et al., 2006). More recently, Stevens and Shields (2013) conducted a survey of parents and professionals attending either *EarlyBird* programme in the UK. Both parents and professionals reported improvements in their knowledge of autism immediately post-intervention. Neither evaluation compared outcomes for parents who did not receive intervention.

*Cygnets* ([http://www.barnardos.org.uk/cygnets/yk\\_cygnets-parents\\_carers\\_support\\_programme.htm](http://www.barnardos.org.uk/cygnets/yk_cygnets-parents_carers_support_programme.htm)) is a six-session programme for parents of children aged 5-17 with a diagnosis of autism. The programme's authors routinely collect parent feedback (see Morris, 2011). Raghavan (2008) conducted the first independent evaluation, reporting increased parenting efficacy for parents who had attended *Cygnets*, using Sofronoff and Farbotko's (2002) not yet validated parental-efficacy measure. Robson (2010) conducted a before-and-after evaluation of outcomes of 38 parents attending *Cygnets*

delivered by a Child and Adolescent Mental Health Service. Statistically significant post-intervention improvements were reported for parenting confidence. More detail about the *Cygnets* programme is given in 1.3.

The *Autism Spectrum Conditions-Enhancing Nurture and Development (ASCEND)* is an 11 session programme developed to support families of all school aged children who have received a diagnosis of autism (Wright & Williams, 2007). An early service evaluation, using a before-and-after study design reported improvements in parent reported child behaviour and parental knowledge of autistic spectrum conditions immediately post-intervention (Pillay et al., 2011).

Whilst the emerging evidence base is positive, these evaluations have lacked scientific rigour: employing before-and-after techniques, non-validated outcome measures, often with an absence of comparator groups or exploration of longer term outcomes. The need for more robust evidence has been identified (NICE/SCIE, 2013).

### 1.3. The *Cygnets* parenting support programme

Barnardo's<sup>1</sup> *Cygnets* parenting support programme, which we will subsequently refer to as *Cygnets*, was developed in partnership with service users and practitioners during the late 1990s ([http://www.barnardos.org.uk/cygnets/yk\\_cygnets-parents\\_carers\\_support\\_programme.htm](http://www.barnardos.org.uk/cygnets/yk_cygnets-parents_carers_support_programme.htm)). The programme is currently available for parents of children on the autistic spectrum aged 5-18 years.

*Cygnets* aims to:

- increase parents' understanding of autistic spectrum conditions,

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<sup>1</sup> Barnardo's is one of the UK's leading children's voluntary sector organisations. It provides child and family support services, either independently or commissioned by local authorities. The charity continues to oversee the production and distribution of the *Cygnets* manual and also provides training on the programme.

- help parents develop their knowledge of how a child with autism experiences the world and what drives their behaviour,
- guide parents through practical strategies they can use with their children to manage and support their communication, play and behaviour,
- direct parents to relevant autism specific resources,
- give parents the opportunity to meet with other parents who have had similar experiences and to gain support and learn from each other.

*Cygnets* comprises six, weekly sessions, each lasting up to three hours. There is also an informal, voluntary follow-up session held six weeks later<sup>2</sup>. The sessions sequentially work from education about autism towards behaviour management (see Box 1). Up to six families are invited to attend each programme; every family is allocated two places for parents/carers, thus allowing for a maximum group size of twelve. Children do not attend. Localities vary in whether parents can self-refer or not and the extent to which referral to *Cygnets* is an integral part of the diagnostic process. Parents can see whether *Cygnets* is available in their area by visiting the *Cygnets* website [www.barnardos.org.uk/cygnets](http://www.barnardos.org.uk/cygnets).

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<sup>2</sup> At the time of this study, the follow-up session was held three-months after session 6. Following feedback and low take-up of this session, a decision was made to bring it forward.

### Box 1: *Cygnets* Programme Content

<b>Session 1: What are Autistic Spectrum Conditions (ASCs)?</b> <ul style="list-style-type: none"><li>• Introductions to the group</li><li>• Aims</li><li>• Content</li><li>• Introduction to ASCs</li><li>• What is it like to be autistic?</li><li>• Experience of diagnosis</li></ul>
<b>Session 2: Communication</b> <ul style="list-style-type: none"><li>• Why and how do we communicate?</li><li>• Communication in ASCs</li><li>• Strategies to aid communication<ul style="list-style-type: none"><li>- Visual supports</li><li>- Social Stories</li><li>- Comic strips</li></ul></li></ul>
<b>Session 3: Sensory Issues</b> <ul style="list-style-type: none"><li>• What are the senses</li><li>• Types of sensory issues seen in ASCs</li><li>• Associated behaviours</li><li>• Strategies to help</li></ul>
<b>Session 4: Understanding behaviour</b> <ul style="list-style-type: none"><li>• Types and functions of all behaviour</li><li>• Behaviour and autism</li><li>• Underlying difficulties behind behaviour (Iceberg principle, Schopler, 1995)</li></ul>
<b>Session 5: Managing behaviour</b> <ul style="list-style-type: none"><li>• Using the information (Iceberg principle)</li><li>• Analysing and managing behaviour (STAR (setting, trigger, action, response) analysis, Zarkowska and Clements, 1994)</li><li>• Key strategies</li><li>• Management strategies</li></ul>
<b>Session 6:</b> Group participants chose to review topics covered in previous sessions and/or focus on a new topic (for example, siblings, puberty and sexuality, transitions, sleep)
<b>Follow up session:</b> parents are invited to attend an informal follow-up session six weeks after Session 6. It has no formal curriculum.

The structure and approach of *Cygnets* is based on the Family Partnership Model (Davis & Day, 2010). This model advocates a collaborative approach to working with families in which professionals seek to combine their and parents' expertise in order to develop and build parental self-efficacy and identify effective and realistic problem management strategies. Sessions include a formal teaching element, supported by 'power point' slides/video-clips, small and whole group exercises and discussions. Parents receive copies



of the teaching materials used. Following each session parents are encouraged to carry out an activity or task before the next session which is designed to embed the learning achieved. This 'homework' is reviewed at the beginning of the following session. When sessions are missed, trainers endeavour to provide a 'catch up' session for the parent.

At least two trainers run each delivery of the programme. A set of knowledge and skills criteria is used by Barnardo's to approve a practitioner as a 'Lead Trainer'. These include: a relevant university degree or equivalent; at least three years' experience of working/living with people with autism; and, preferably, expertise in group-work. Co-trainers are required to have similar levels of experience of working/living with people on the autistic spectrum. A Trainer's manual

(<http://www.barnardos.org.uk/cygnetsprogramme.pdf>) contains guidance on setting up and running the *Cygnets* programme. Currently, there are over 100 licensed providers of *Cygnets* in the UK. Practitioners in other countries have also purchased *Cygnets* and been trained in its delivery ([http://www.barnardos.org.uk/cygnets/yk\\_cygnets-newpage.htm](http://www.barnardos.org.uk/cygnets/yk_cygnets-newpage.htm)).

Whilst a small scale pragmatic evaluation, this paper reports the findings of the most robust evaluation of *Cygnets* to date. Its objectives were to:

- compare outcomes for parents who attended the *Cygnets* programme in two localities where it was routinely offered to parents on a waiting list to attend the programme,
- explore the perceived acceptability of the programme using the proxy indicator of parent attendance,
- provide preliminary data on the costs of delivering the intervention.

A qualitative study explored the extent to which parents felt they had a better understanding of autism and the potential benefits of peer-support. The findings from this study are reported elsewhere (reference withheld).

## **2. Method**

### *2.1. Study design*

A pragmatic, two-centre non-randomised controlled study design was used within the context of routine deliveries of the intervention in two cities in northern England. Parents of children aged 5-17 in each locality were referred onto a waiting list for *Cygnnet* following their child's diagnosis. Parents were informed of upcoming deliveries of the programme and could sign up to attend a delivery that was being held at a convenient time/location. Box 2 sets out some key characteristics of these two sites and their delivery of *Cygnnet*. The study took place between September 2009 and May 2010 during which time the intervention was delivered seven times. Parents on the programme's waiting list at each site between January-March 2010 were recruited to form a comparator group (CG). Outcomes were measured using standardised instruments at pre-intervention (T0), post-intervention (T1) and three-month follow-up (T2). Equivalent time points were used for the CG. For the intervention group (IG), six-month follow-up (T3) data was also collected. It was not possible to collect this data for the CG because most of these parents had joined a delivery of *Cygnnet* by this time. During the penultimate session of the intervention (session 5), when the programme covered behaviour management (see Box 1), parents were asked to identify a behavioural goal for their child (T0<sup>G</sup>). Progress towards achieving this goal was monitored at T2 and T3. Data allowing estimates of service delivery costs were also collected.

During the study period, *Cygnnet* was delivered by five different lead trainers and six co-trainers (Box 2). All trainers had delivered the programme a number of times.

**Box 2. Delivery of *Cygnets* at site A and B**

	Site	
	A	B
Funding and Delivery	Multi-agency	Multi-agency
Administrative lead (intervention co-ordinating service)	Voluntary sector organisation delivering a suite of family support services	Child and Adolescent Mental Health Service
Venue	Community venues	Community and CAMHS venues
Lead-Trainers	Senior social workers	Clinical psychologists
Co-trainers	Educational psychologists, teachers and social workers	ASC specialist teachers and teaching assistants
Scheduling of sessions	Day and evening sessions	Daytime only

A 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*

Recruitment to the intervention Group (IG) took place at the start of Session 1. The study was introduced by a member of the research team and recruitment packs were distributed<sup>3</sup>. The recruitment pack comprised: project information leaflet, T0 questionnaire (containing outcome measures and brief questionnaire collecting socio-demographic and diagnostic information), consent form and pre-paid envelope addressed to the research team. Parents willing to take part in the study were instructed to complete the T0 questionnaire and consent form and return them, sealed in the envelope, to the Lead Trainer, at the following session. Trainers then forwarded these envelopes, still sealed, to the research team. The IG recruitment rate was 67%, affected by particularly low take-up in two deliveries of the

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<sup>3</sup> Participants were typically birth parents, but any primary carer (e.g. grandparent) was eligible to participate in the study (see Sample). For ease of reporting we refer to study participants as 'parents'.

intervention in Site B (recruitment rate excluding these deliveries was 87%). T1 questionnaires were distributed to the IG during Session 6 (or posted to non-attenders). The research team posted follow-up (T2/T3) questionnaires to all parents recruited at T0 (regardless of drop-out/attendance). Pre-paid return envelopes were provided.

The comparator group (CG) was recruited from parents (in both research sites) who were waiting to attend *Cygnnet* (n=62). These parents received a recruitment pack in the post. Thirty-two parents returned a consent form and completed questionnaire; these formed the CG (recruitment rate=52%). The CG received follow-up questionnaires after six weeks and a further three months, to correspond with the T1 and T2 data collection time points for the IG.

Reminder letters, phone calls and text messages were used to maintain response rates. An incentive (£10 high street shopping voucher) was used at each data collection time-point (provided on receipt of a completed questionnaire). Support to complete the questionnaire was offered to parents. One parent accepted this offer and questionnaires were administered over the telephone by a member of the research team.

### *2.3. Outcome Measures*

Reflecting the desired aims of *Cygnnet*, 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 measure that has been validated for parents of children aged 2-17 years (Burns & Patterson, 2001). Items describe behaviours that often cause problems for parents. It is scored on two scales: the "Intensity Scale" (IS) and the "Problem Scale" (PS). The IS rates the frequency of each problem behaviour (1=never to 7=always). The PS asks whether parents perceive the behaviours listed as a problem (yes =1; no =0).

Clinical cut-offs of 131 (IS) and 15 (PS) are suggested by the scale authors. The measure has been found to have construct validity, good reliability, with test–retest coefficients of 0.78 and internal consistency of  $r=0.94$  (IS) and  $0.93$  (PS) (Eyberg & Ross, 1978). Cronbach's alphas for the study sample were  $r=.92$  (IS) and  $r=0.91$  (PS). The scale is widely used in studies of children with autism (e.g. Ginn et al., 2015; Sofronoff & Farbotko, 2002; Whittingham, 2009) and has been found to be sensitive to change following an intervention (Webster-Stratton & Hammond, 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 the extent to which parents are satisfied with their role as a parent. A parenting efficacy subscale (PSOC-Efficacy) measures the extent to which parents feel they are managing their parenting role. A 6-point Likert scale indicates agreement with each item (1=strongly disagree to 6=strongly agree). Seven items are reverse coded so that a higher score represents increased parenting confidence. The scale has been psychometrically tested (see Johnston & Mash, 1989; Ohan et al., 2000). These papers confirmed the factor structure, assessed the scale's validity, and reported acceptable internal reliability (alpha score .75 Satisfaction Subscale and 0.76 Efficacy Subscale). Cronbach's alphas for the study sample were  $r=.78$  (Satisfaction Scale) and  $r=0.80$  (Efficacy Scale). This scale is often used to measure parenting competence amongst parents of children with autism (e.g. Estes et al., 2014; Keen et al., 2010; Malow et al., 2014) and has been found to be sensitive to change (Stuttard et al., 2014)

*Parent-identified goals:* During Session 5 (T0<sup>G</sup>), parents identified a behaviour-specific goal(s) e.g. “to eat new foods”, “Not giving hugs to everyone he sees”. A ten-point scale indicated progress (1=very far from my goal to 10=I have achieved my goal).

#### *2.4. Implementation fidelity*

A characteristic of complex interventions is that they may be designed to be adapted to the setting in which they are being delivered and the specific need(s) of a population (Medical Research Council, 2008). However, even within this notion of adaptability, or responsiveness to the particular needs of a group of parents, it remains that the core elements of an intervention should always be delivered. In order to monitor fidelity to the *Cygnets* curriculum, checklists detailing the topics specified for a session in the intervention manual were completed by trainers at the end of each session. Any deviations from the intervention, as set out in the manual, were recorded, including reasons.

#### *2.5. Sample*

*A priori* sample size calculations were carried out using 'G-Power' (version 3.1) (Faul et al., 2007). Published research which has evaluated similar parent training interventions, using the same research design and primary outcome measures as this study, reported large effect sizes (e.g. Bagner & Eyberg, 2007; Plant & Sanders, 2007). To detect a large effect size as measured by the primary outcome measure (ECBI) with a power of 80%, using the ANCOVA as the primary outcome assessment, a sample size of just over 50 was required with a minimum of 25 in both arms.

Sixty-eight parents/carers (55 mothers, 11 fathers, and a grandfather who identified himself as the child's primary carer) were recruited to the study (IG n=35, CG n=33). Fathers typically attended with their partner (n=8/11). These parents represented 59 children with a clinical diagnosis of an autism spectrum condition given by a suitably qualified practitioner (e.g. clinical psychologist), of whom 25 had been diagnosed within the past six months.

The children were aged between 5-17 years (M=10.17, SD=3.30) and the majority (n=50, 85%) were boys. Over three quarters (47/59) were in mainstream education. The IG

and CG were compared on key socio-demographic characteristics (Child factors: age, sex, type of school attending e.g. mainstream or specialist; Parent/carer factors: level of education, 2-parent family, fluency in spoken English) and T0 outcomes. There were no significant differences between the two groups. Data was not collected on those parents who did not take part in the study, however programme leads felt that the study sample represented typical attendees (E. Carrington and A. Morris, 2012, personal communication).

**Table 1. An overview of child and parent characteristics**

	IG		CG	
	N	%	N	%
<b>Child characteristics (n=60)</b>	<b>29</b>		<b>30</b>	
Age of child in years ( <i>mean, standard deviation</i> )	10	3.06	10	3.54
Male	26	90	24	80
Received diagnosis within past 6 months	8 <sup>d</sup>	32	16 <sup>d</sup>	55
In segregated specialist education <sup>a</sup>	7	24	6	20
<b>Parent characteristics (n=67)</b>	<b>35</b>		<b>32</b>	
Mother	26	74	29	91
Two parent household	30	86	21	66
Higher Education <sup>b</sup>	24	69	23	72
White British	32	91	28 <sup>d</sup>	90
English First Language	34	97	30	94
Working outside the home <sup>c</sup>	24	69	18	56

<sup>a</sup> 'Segregated specialist education' includes specialist units in a mainstream school or special school

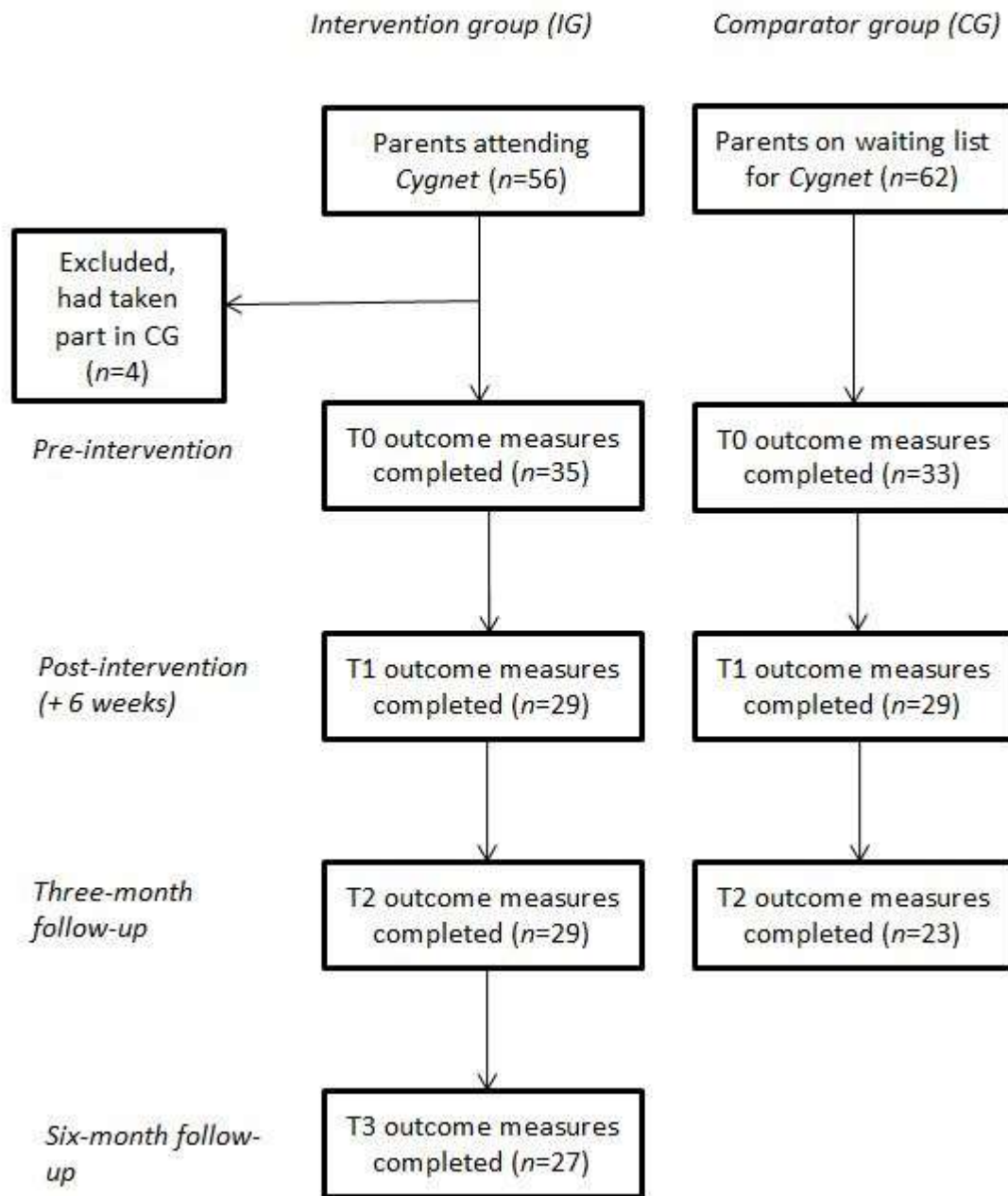
<sup>b</sup> 'Higher Education' denotes attaining qualifications *beyond* high school level/equivalent.

<sup>c</sup> This may be in a paid or voluntary capacity

<sup>d</sup> Missing data for some participants

*Retention to the research.* Retention was good; T1 response rates were: 87% (n=58), T2: 78% (n=52) and T3: 77% (n=27, IG only) (Figure 1). Given these retention rates, it is difficult to determine whether there are meaningful differences between those remaining in the study at T1 and those who dropped out. However, parents with higher/further education qualifications (e.g. gained at college or university) were less likely to drop out of the research study ( $p=.009$ ). No significant differences were found with regard to T0 scores on the outcome measures.

**Figure 1. Recruitment and data collection pathway**



## 2.6. Service delivery costs data

To estimate service delivery costs, the following information regarding delivery of the intervention was collected from the *Cygnet* intervention coordinator in each site: 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, refreshments). Trainers recorded parents' attendance at each session. 'Unit costs' (per day, per contact, etc.) were taken from a well-established annual compendium of nationally applicable unit costs (Curtis, 2010).

### *2.7. 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 managing 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.

*Short- and medium- term intervention effects.* Analysis of covariance (ANCOVA) was used to compare changes in IG and CG group mean scores on parent-reported child behaviour (ECBI) and parents' sense of competence (PSOC) between T0-T1 and T0-T2. Assumptions of the test were met unless otherwise specified. T0 scores were entered as covariates to control for baseline scores. Where both parents had attended, only the mother's ECBI responses were used as they were the more typical attendees. Bonferroni adjustments were not applied, in accordance with guidance (Perneger, 1998). Effect statistics explored the size (and direction) of change. To account for any baseline differences we used  $d_{corr}$  (see Klauer, 2001).

*Longer-term outcomes for intervention group.* Longer-term outcomes (i.e. maintained or further improvements or deterioration) as measured by PSOC and ECBI were explored using paired T-tests (T0-T3). The reliable change index (RCI) was used to examine changes in

scores at an individual level. This statistic determines the significance of change on an individual's score on a standardised outcome measure after accounting for the reliability of the measure (*Hawley, 1995; Jacobson & Truax, 1991*). Cases are classified as reliably improved if they achieve a score greater than 1.96 on the RCI. The RCI for each case was calculated by dividing the difference between T0 and T3 scores by the standard error of measurement (SEmeas) [ $RCI = T0 - T3 / S_{diff}$ ].  $S_{diff}$  was obtained by calculating the square root of double the standard error squared ( $S_{diff} = \sqrt{2(SE)^2}$ ).

*Achievement of parent-set goals.* Progress towards achieving parent-set goals was explored using a one-way repeated measures ANOVA (T0<sup>6</sup>; T2; T3). Parents' ID codes were entered as a between-subjects factor into the ANOVA as some parents had identified more than one goal. Where results were significant, pairwise comparisons, with a Sidak adjustment, identified the source(s) of difference in scores.

### **3. Results**

#### *3.1. Intervention fidelity*

Reported levels of intervention fidelity were very high (97%). The only deviation was that a small section of one session was not covered in one delivery of the programme. In addition to the standard programme materials, trainers delivering the intervention in Site B provided supplementary hand-outs and resources and also used alternative hand-outs for two topics than those provided in the *Cygnets* manual (STAR analysis, emotional thermometer, Zarkowska & Clements, 1994). The overall content, however, adhered to that set out in the manual.

#### *3.2. Indicators of acceptability of the intervention*

We have used intervention drop-out as a proxy indicator of programme acceptability.

Qualitative evidence of acceptability is reported elsewhere (reference withheld).

Attendance records were available for six of the seven deliveries of *Cygnets* included in this evaluation (n=46 parents)<sup>4</sup>. Rates of attendance were high with 80% (n=35) of parents attending at least five out of the six sessions. Just three parents attended fewer than four sessions (7%). Two parents dropped out of the programme during the study period. Trainers provided reasons for this: one found the programme's content discomforting – reporting it to be 'a bit too close to home' in terms of their own autistic characteristics, and a second suffered a bereavement.

### *3.3. Short and intermediate term intervention effects*

At T1, there were improvements in IG scores on both ECBI scales, which measured child behaviour, whilst scores had either deteriorated or remained unchanged for the CG (n.s., Table 2, Figure 2). There was significant improvement in PSOC-Satisfaction scores for the IG compared to the CG (Table 2, Figure 3). Movement on the PSOC-Efficacy Subscale was negligible. At T2, there were further improvements on ECBI scores for the IG (n.s.) whilst PSOC sub-scale scores were stable. With the exception of PSOC-Efficacy, where effect sizes were negligible at T1 and a small negative effect size was found at T2, effect sizes for the remaining scales were small to moderate.

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<sup>4</sup> Complete registers weren't received for the final group of which ten parents attended Session 1.

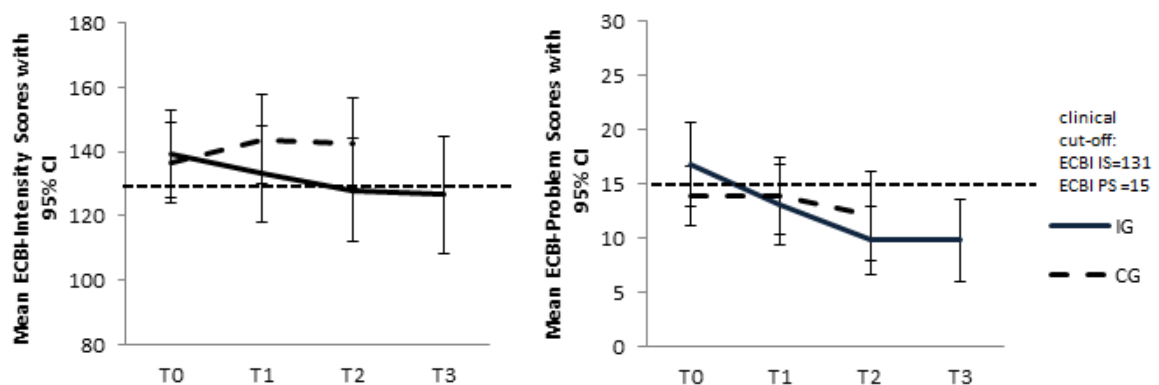
**Table 2.** Short and intermediate term intervention effects as measured by the ECBI and PSOC

Group	T0				T1				ANCOVA T0-T1	Effect size T1 (d <sub>cont</sub> ) <sup>a</sup>	T2				ANCOVA T0-T2	Effect size T2 (d <sub>cont</sub> ) <sup>a</sup>	
	N	M	SD	95% CI	N	M	SD	95% CI			N	M	SD	95% CI			
ECBI-IS	IG	27	139.07	34.45	125.45-152.70	27	133.13	34.56	118.19-148.08	$F(1,44)=2.03, p=.162$	0.4922	23	128.13	36.96	112.15-144.12	$F(1,37)=.856, p=.361$	0.1360
	CG	27	136.52	31.72	123.97-149.07	26	143.81	34.09	130.04-157.58			20	142.75	30.47	128.49-157.01		
ECBI-PS	IG	23	16.78	9.17	12.82-20.75	20	15.05	7.86	9.37-16.73	$F(1,35)=1.61, p=.213$	0.4861	21	9.81	6.87	6.68-12.94	$F(1,30)=2.95, p=.096$	0.6322
	CG	26	13.73	7.03	10.89-16.57	24	13.88	8.46	10.30-17.45			18	12.06	8.15	8.00-16.11		
PSOC-Set	IG	35	33.83	6.43	31.62-36.04	29	36.48	5.64	34.34-38.63	$F(1,55)=8.12, p=.006$	0.4856	29	37.72	5.64	35.58-39.87	$F(1,49)=4.02, p=.051$	0.2941
	CG	32	33.88	6.80	31.42-36.33	29	33.03	6.87	30.42-35.65			23	34.09	7.27	30.94-37.23		
PSOC-Eff	IG	34	27.21	4.75	25.55-28.86	29	28.24	5.19	26.27-30.21	$F(1,55)=0.199, p=.657$	0.0246	29	28.69	4.68	26.91-30.47	$F(1,49)=0.68, p=.413$	0.0477
	CG	32	26.69	6.33	24.41-28.97	29	26.90	6.37	24.48-29.32			23	28.35	6.97	25.33-31.36		

<sup>a</sup> ECBI effectsizes reversed so that a positive effectsize indicates a positive effect of the IG against the CG.

Chart Area

**Figure 2.** A comparison of child behaviour outcomes (ECBI) for parents in the IG and CG (T0-T3)



### 3.4. Longer term outcomes for the intervention group

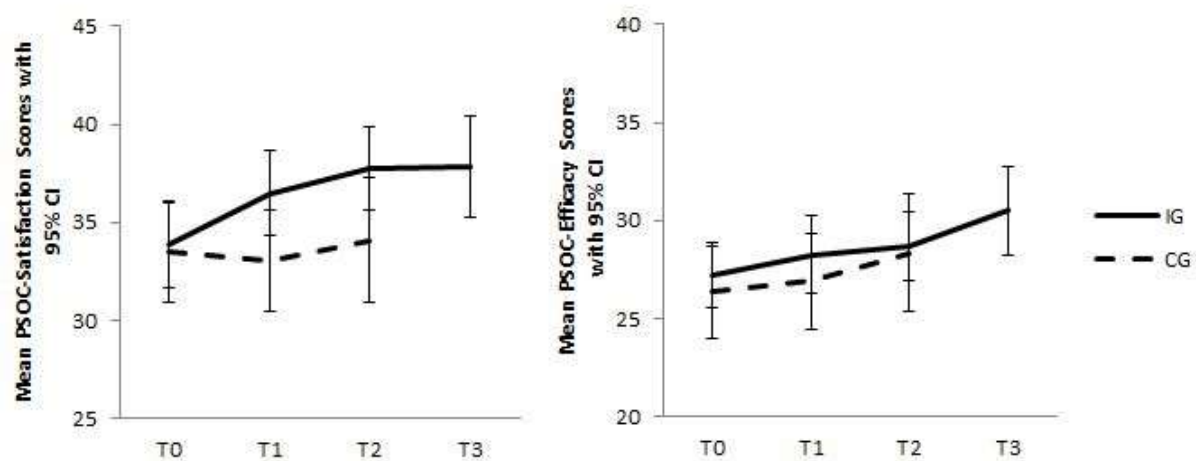
There were significant improvements in group mean scores between pre-intervention (T0) and six-month follow-up (T3) on all standardised outcome measures (Table 2). Comparisons of mean scores presented in Table 2 (see also Figures 2 and 3) indicate that improvements were maintained from three- to six-month follow-up, with further improvements made from T2-T3 for PSOC-Efficacy. For each outcome indicator, between 30% and 52% of parents

were defined (using the reliable change index (RCI)) as ‘reliably improved’. No parents’ score on the ECBI-PS had ‘reliably deteriorated’, and just one parent’s had ‘reliably deteriorated’ in terms of ECBI-IS and PSOC-Satisfaction. For the PSOC-Efficacy scale, the RCI score categorised four parents as ‘reliably deteriorated’ at T3.

**Table 3. Longer-term intervention effects measured by the ECBI and PSOC (IG only)**

	T0				T3				T(df) p	N Reliably	
	N	M	SD	95% CI	M	SD	95% CI			improved	deteriorated
ECBI-IS	20	135.95	35.61	119.28-152.62	126.45	41.17	107.18-145.71	2.75 (19), p=.013		6	1
ECBI-PS	17	16.12	9.80	11.08-21.15	9.35	7.19	5.65-13.05	2.91 (16), p=.01		7	0
PSOC-Sat	27	34.78	6.20	32.33-37.23	37.85	6.51	35.27-40.27	-3.14 (26), p=.004		9	1
PSOC-Eff	27	27.41	4.71	25.54-29.27	30.48	5.62	28.26-32.70	-3.61 (26), p=.001		14	4

**Figure 3. A comparison of parenting sense of competence (PSOC) outcomes for parents in the IG and CG (T0-T3)**



### 3.5. Achievement of parent-set goals

For the IG, mean ratings of progress towards achieving a specific child behaviour goal revealed significant improvements (Table 4). Pairwise comparisons (with a Sidak adjustment) showed significant changes occurred between T0<sup>G</sup> and T2, and T0<sup>G</sup> and T3 ( $p<.05$ ). There was no significant change between T2 and T3.

### 3.6. Costs to providers of delivering the intervention

The mean cost of delivering Cygnet was £2,390 (2009-10 costs). Costs ranged from £1,190 to £3,460 per intervention delivery. Staff time (including setting up the group, planning the sessions and travelling, as well as delivering the intervention and the de-briefing) accounted for the greatest proportion of the cost. Refreshments, course materials, and venue hire contributed around ten per cent of the total cost. The cost per session varied according to the profession and grade of trainers. In Site A (delivery coordinated and primarily run by social work staff working for a third sector organisation) the average *cost per session* was £185. In Site B (delivery led by a Child and Adolescent Mental Health Service (CAMHS)), the costs per session were between £360 and £490. The cost of delivering *Cygnet* per parent is, naturally, dependent on the number of parents receiving the intervention. Typically four-six children were represented per delivery with between six and ten parents attending.

#### **4. Discussion**

The need for robust evidence on the effectiveness of group-delivered psycho-educational interventions for parents to prevent or address challenging behaviours in children on the autistic spectrum has been called for (NICE/SCIE, 2013). This paper builds upon the emerging evidence base from earlier studies of *Cygnet*, one of the most widely delivered psycho-educational interventions for parents of children with autism in the UK. Findings are promising. However, when discussing the findings, we should keep in mind two factors regarding the representativeness of the population recruited to the study compared to the wider population of families with a child with an autism. First, the majority of children represented in the study were in mainstream education and had typically been diagnosed in middle childhood. This can be taken to indicate that the majority of the children represented did not have a severe learning disability. Second, the proportion of participants with higher/further education qualifications was higher than reported in other, similar

studies (e.g. Stuttard et al., 2014). This may be a reflection of the populations served, or that parents with more qualifications were more likely to be accessing the intervention and/or take part in the research. Retention to the study appeared associated with academic attainment.

Implementation fidelity was high, indicating that trainers were able to deliver the programme as intended. Attendance rates were good, with a lower drop-out compared to some generic parenting interventions (Lindsay et al., 2008). In addition, regardless of whether the intervention was delivered during the day or evening, attendance at *Cygnets* by fathers was higher than for other generic disability parenting interventions (e.g. Stuttard et al., 2014). This is encouraging and may reflect the perceived relevance of the autism-specific nature of the programme (Fabiano, 2007). During the study period, one parent withdrew from the programme due to unease arising from self-identification of autistic traits. Given the genetic element in the development of autism (Bailey et al., 1995), as well as poor levels of diagnosis of autism in adults (Brugha et al., 2011), this is an issue which may well be encountered and its management planned for.

Despite achieving the desired sample size, study drop-out and missing data meant the final sample was under-powered (sample size <50 for ECBI-PS T1/T2 and ECBI-IS at T2) to detect significant between group differences on the ECBI scores. We are therefore limited in our interpretation of observed changes on this outcome measure. Examination of mean ECBI scores (Figure 2) illustrated improvements in mean scores for the intervention group (IG), with little movement for the comparator group (CG). It is particularly encouraging to see that further improvements were observed following completion of the course, indicating that at least some parents appeared able to apply and generalise the knowledge and strategies received during the intervention, without ongoing supervision and support from the programme trainers at least up-to six months' post-intervention. Parents'

perceptions of whether their child's behaviour was problematic (ECBI-PS) were particularly improved over the longer term where medium effect sizes were observed at both T1 and T2.

In addition to a standardised measure of child behaviour, parents also set specific goals regarding their child's behaviour. The gains reported in terms of achieving goals were very positive and align with findings on the ECBI. However, they need to be interpreted with caution given the lack of comparator data.

Improving parents' feelings of competence as parents of a child with autism is a key aim for *Cygnnet*. In the absence of a robust autism-specific measure, we employed the generic and widely-used Parenting Sense of Competence Scale (PSOC; Gibaud-Wallston & Wandersman, 1978) to evaluate this outcome. Compared to the CG, IG parents reported significantly improved parenting sense of satisfaction (PSOC-Satisfaction). These improvements appeared to be maintained within the IG until at least six months post-intervention. The negligible effect on parenting sense of efficacy (PSOC-Efficacy) was, unexpected, contrasting with findings from an earlier (before-and-after) evaluations of *Cygnnet* (Morris, 2011; Robson, 2010). Findings from evaluations of generic disability-specific interventions received by with parents of children with autism offer a possible explanation (Beresford et al., 2012; Whittingham, 2009). These studies describe parents' reports of trepidation regarding their ability to sustain changes and learning once an intervention was complete. It is possible these concerns negatively impact parenting sense of efficacy. Indeed, Cottam and Espie (2014) go further and argue that parenting programmes may/have the potential to disempower parents.

Interestingly, when looking at changes in IG PSOC-efficacy scores over the longer-term, differences were highly significant (in a positive direction). Whilst a, sleeper effect has been observed in other evaluations of parenting interventions for parents of a child on the



autistic spectrum (Whittingham, 2009), and this offers a possible explanation for what we observed, the absence of a comparator group at T3 means we cannot explore this.

The reliable change statistic allows us to shift our perspective from group- to individual-level change. At T3, between one-third and one-half of parents were measured as having 'reliably improved' scores on all outcome measures. Notably, parenting sense of efficacy was the domain where the greatest number of parents had 'reliably improved'. It was also this scale where some parents ( $n=4$ ) were categorised as 'reliably deteriorated'. It was not possible with the current dataset to explore whether particular parent, child, or autism-specific factors were associated with an increased likelihood of improved, or deteriorated, outcomes. This is something we would strongly recommend is explored in future studies.

Given the financial constraints that services operate under, the presentation of delivery costs alongside the effectiveness data is important. Staff time was the greatest cost to the provider, with the profession and grade of those delivering the intervention affecting delivery costs. This was the main reason for the discrepancy in costs of delivery between our two research sites.

The study has several strengths: it utilised a well-matched comparator group (for T0-T2 data collection points); the sample represented typical attendees; well validated, psychometrically tested measures were used to assess outcomes; and retention to the research was good. There are also limitations. Because *Cygnnet* was already routinely offered to families in our research sites, the programme's trainers would not approve an extension to existing waiting times. This meant it was not possible to randomise the sample or retain the comparator group in the study to the 6-month follow-up time point. Whilst retention to the study was good overall, there was some evidence to suggest that parents with fewer educational qualifications were less likely to be retained to the study. Because of this, we

can be less confident that this group of parents would report similar outcomes from attending *Cygnnet*. Furthermore, it was not possible with the resources available to assess intervention fidelity beyond self-report. Some analyses were statistically under-powered due to a failure to achieve a sample size which could accommodate study attrition.

During our study period, the ethnic profile of parents attending *Cygnnet* did not reflect the local population, with very low representation of minority ethnic groups (specifically for the locations of this study, South Asian parents). As a consequence, these parents are under-represented in the evaluation. It is worth noting that, since this study was conducted, the programme's developers have engaged with community workers to promote the programme and have been delivering *Cygnnet* in Punjabi, specifically for parents of South Asian heritage (Gilligan, 2013). In these instances, an additional session covering culturally-specific issues around disability has been introduced. In the future it will be interesting, and is important, to evaluate this modification of *Cygnnet*.

In terms of future research, the findings from this study evaluation highlight a number of issues which warrant further investigation. Overall, however, and given the current widespread delivery of *Cygnnet*, a large-scale randomised controlled trial, with a cost effectiveness element, would be very useful. A larger sample size would also allow exploration of factors which moderate or mediate effectiveness such as, the cognitive profile of the children; child's age; parent characteristics; attendance by both parents; group composition; trainer qualifications etc. It would also be worthwhile to consider exploring a broader range of outcomes such as parent and child well-being, learning outcomes, observed rather than perceived child behaviour, teacher reports, and the extent to which parents practice the strategies they have been taught during the programme. We would also recommend assessing the representativeness of future work by collecting some demographic data on parents declining to take part.

## 5. Conclusions

Whilst *Cygnnet* is a widely used programme for parents of children with autism spectrum conditions in the UK, its effectiveness has not been rigorously evaluated. This study sought to address this evidence gap. Low drop-out and high attendance rates suggest it is acceptable to parents and changes in parent reported outcomes appeared promising, particularly with regard to improving parenting satisfaction. A larger scale randomised trial, including follow-up to at least six months, is recommended to further evaluate the effectiveness and cost effectiveness of *Cygnnet*.

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