



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



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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.

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## 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, Tonge, & Einfeld, 2006; Green, Gilchrist, Burton, & Cox, 2000; Guttmann-Steinmetz, Gadow, & Devincent, 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 &

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Brown, 2002; Simonoff et al., 2008; Tomanik, Harris, & Hawkins, 2004; Willey, 2003). Parents often describe themselves as feeling 'de-skilled' which compromises parenting confidence (Beresford, Sturtard, Clarke, Maddison, & Beecham, 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 *Cygnnet* 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, Birkin, Seymour, & Moore, 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.

*Cygnnet* ([http://www.barnardos.org.uk/cygnnet/yk\\_cygnnet-parents\\_carers\\_support\\_programme.htm](http://www.barnardos.org.uk/cygnnet/yk_cygnnet-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 *Cygnnet*, 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 *Cygnnet* delivered by a Child and Adolescent Mental Health Service. Statistically significant post-intervention improvements were reported for parenting confidence. More detail about the *Cygnnet* programme is given in Section 1.3.

*The Autism Spectrum Conditions-Enhancing Nurture and Development (ASCEND)* programme 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, Alderson-Day, Wright, Williams, & Urwin, 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 *Cygnnet* parenting support programme

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

<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 *Cygnnet* manual and also provides training on the programme.

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