Cygnet Psycho-educational Intervention Programme for Parents of Children on the Autistic Spectrum: A study exploring changes in the parents' perceived self-efficacy, wellbeing and their children's behaviour.

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Abstract

Aim: When a child receives a diagnosis of autism, their parents will often find it difficult to understand the condition and its impact on the child's behaviour. As a result, parents often seek help to obtain a better understanding of autism and strategies to help them address these difficulties. The Cygnet programme is a parenting intervention designed to meet such needs delivered by educational psychologists in the United Kingdom. To date, there has been little research on the effectiveness of this intervention.

Method: This study consisted of a small-scale evaluation of cohorts attending seven separate programmes within one local authority. A non-randomised, mixed methods was adopted and comprised an intervention group (n=24) of parents who attended a Cygnet programme and a control group (n=16) of parents on the waiting list to attend the programme. All parents completed standardised questionnaires of perceived parental self-efficacy, wellbeing and child behaviour at three time points (0, 6 and 18 weeks). A sample (n=6) of programme attendees were interviewed to provide qualitative data.

Findings: The quantitative data obtained did not demonstrate statistically significant differences between the two groups. However, the qualitative data found that the Cygnet Intervention was beneficial for parents of a child with autism. All the parents interviewed were extremely positive about the programme, not just for the knowledge they acquired and subsequently were able to utilise, but for the contact they had with parents in a similar situation.

The study also found statistically significant associations between perceived self-efficacy and wellbeing and perceived wellbeing and child behaviour for the Intervention group, which were not replicated in the Control Group.

Conclusions: Attendance on the Cygnet programme provided the parents with increased self-efficacy and wellbeing with some perceived improvements in their child's behaviour. Limitations of this study and areas for future research were also discussed.

Key words: Parent intervention, mixed methods, self-efficacy, wellbeing, child behaviour

I, Alison Bates, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Chapter 1: Introduction

When a child receives a diagnosis of autism, their parents will often find it difficult to understand the condition and its impact on the child's behaviour. As a result, parents may seek help to obtain a better understanding of autism and strategies to help them address the challenges they face. This current study examined the impact of the Cygnet Programme, a psycho-educational, group-based, parent intervention for parents of children with autism, which was designed to meet such needs and is often delivered by educational psychologists. To date, there has been little research on the effectiveness of this intervention and this current study sought to help fill that gap.

Children with autism, as defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM -V) (American Psychiatric Association, 2013), present with diagnostic criteria which include social and communication difficulties, restricted, repetitive behaviours and interests and a hyper-sensitivity to sensory stimuli. Autism is a developmental condition that will impact an individual's interaction with others and the way they communicate and engage with the world around them (The National Autistic Society, 2017). These challenges impact not only the child themselves, but also their parents, caregivers and all those who are involved with the child (Hastings & Brown, 2002).

One of the key needs expressed by parents of a child with autism was to be provided with support, both socially, and strategies to help them manage their stress (Weiss, 2002). More specifically, Weiss found evidence that the most helpful support was perceived to be that which promoted positive feelings of self-efficacy. It was found that social support did not necessarily need to be received, if there was knowledge of its availability, with the emphasis being placed on the benefits of the support provided by a 'family' unit.

There are many parent interventions available that seek to provide parents with knowledge and understanding of autism, and strategies that can support them in managing their child's behaviour. Cygnet is one such programme and this current study examined to what extent the Cygnet Parenting Programme, increased perceived parental efficacy and, in addition, it explored whether there were any

resulting benefits to the child's behaviour, as proposed in the programme's stated objectives. In summary, this current study explored the perceived impact of the programme on the parents as well as the child. The study sought to address a key limitation in current areas of research: that an incomplete picture was provided if the context of the child's family were not included in the study (Karst & Van Hecke, 2012).

1.1   Cygnet Parent Intervention Programme

Barnardo's[1], in partnership with parents, young people and other agencies, developed the Cygnet programme which addressed the needs of parents of children with autism aged 5 -18 years, as a follow on from programmes such as EarlyBird, which initially only catered for younger children. There was recognition that, whilst parents may have received support from other programmes at an earlier stage, the needs of the child will change as they get older (Barnardo's, 2014). This was also consistent with the National Autism Plan for Children (Le Couteur, 2003) which stated that all authorities should offer training courses for parents/ carers in the understanding and management of autism, and the training must be on-going, as individual needs change according to age and circumstances. The Cygnet programme was first delivered during the late 1990's by the City of Bradford Metropolitan District Council in response to an increasing number of children receiving a diagnosis of autism.

EarlyBird (under five years) and EarlyBird Plus (age 5-8 years) are programmes licensed by the National Autistic Society, run over eight, weekly sessions, with two home visits and a follow-up session which is held twelve weeks after the end of the programme. As for the Cygnet programme, the focus of the EarlyBird programme is to provide parents with information about autism, how to develop the child's communication skills and how to manage their behaviour (The National Autistic Society, 2017).

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[1] Barnardo's is a UK voluntary children's charity which provides support for child and family services. The charity is involved in both the production and distribution of the Cygnet programme.

The Cygnet Programme was designed to provide parents with:

- a greater understanding and knowledge of how a child with autism views the world and the impact that these views might have on their behaviour.
- practical advice and strategies which they can use to manage and support their child's communication and behaviour, such as social stories and the 'Iceberg' principle.
- a guide to appropriate resources, such as websites and forums.
- a space to meet other parents who also have children with autism, to gain support and share their experiences.

(Barnardo's, 2018)

1.2 Rationale

The following section provides a rationale for the current study, which initially arose from a personally-conducted, previous study on the Cygnet programme and evidence subsequently found in other studies of parent interventions similar to this programme which is the focus of this study. A recent DFE Green paper, Transforming Children and Young People's Mental Health Provision (2017) commented on the importance of parental involvement in such interventions. This comment was also supported by evidence in the report 'A Chance to Change', commissioned by the Centre for Mental Health (Brown, Kahn & Parsonage, 2012), which reported that family-based programmes were beneficial in improving a child's behaviour.

However, a review by Karst and Van Hecke (2012) reported that, despite the plethora of evidence which has highlighted the needs of parents of children with autism, and the number of interventions available to parents, there has been limited research on the impact of these interventions on the child with autism and their family. The Cygnet intervention is frequently used in the UK, and yet there is minimal research regarding its impact (Stuttard, Beresford, Clarke, Beecham and Morris, 2016). This current study addressed this gap by conducting a study

on the impact of the Cygnet programme on the parents who attended it in one Local Authority (LA).

The current study is a follow on to a Year 1 Research Project (2016) that the researcher conducted, which evaluated the first cohort to receive this psycho-educational programme, for parents of children on the autistic spectrum, in a local authority (LA) delivered by educational psychologists (EPs) from the Educational Psychology Service.(EPS) The EPS was particularly interested in the findings from this project as they were intending to phase out the programme they were currently running and replace it with the Cygnet programme.

The findings from the previous project helped inform the programme leaders about areas which they might want to amend or develop to improve the accessibility of the programme, and how to make it more beneficial to the parents of children who would be presenting with a broad range of needs across the spectrum of this condition. The participants in the project were very positive about the programme, both in the knowledge they acquired, and the benefits of being able to talk to parents in a similar situation and the professionals engaged in delivering the programme.

However, due to the limited scale of the Year 1 project, greater depth of analysis was not possible. Therefore, this initial project did not attempt to measure the impact that the knowledge gained from attending the programme and of 'talking to others' had had on the attendees' wellbeing. It also did not measure any change in how competent they felt about being able to manage their child's behaviour on completion of the programme, resulting from possible improved self-efficacy. These areas have been examined in the current study.

Parental wellbeing was also highlighted as an area for future research by a previous quantitative study by Stuttard et al. (2016), which evaluated the Cygnet programme. The current study examined the impact that the programme had on the wellbeing of the parents on completion of the programme.

The findings from the current study will provide valuable feedback for the LA, EPS and the programme organisers about the parents' perceived effects of the programme on their self-efficacy in managing their child's behaviour, and in their own wellbeing. It will also provide information regarding the parent's views of the impact that their attendance on the programme had had on their child's behaviour, both on completion of the programme, and in the medium to longer term.

Initially, these findings sought to provide support and information to the EPS when reviewing the delivery of the programme. In the longer term, it will provide further information when deciding on the benefits of continuing to offer this programme to parents, i.e. to support the EPS in justifying the value of continuing, or not, to run the programme. This current study sought to create a stronger rationale and evidence base for the EPs who deliver the intervention to inform the parents of the value of attendance on such a programme.

Potentially, it could also have wider implications for other Educational Psychology Services to encourage them to deliver this programme. In a more global sense, this study will add to the already substantial evidence base of the impact of parent interventions on both the child and the parent attending the programme.

The study used a mixed methods approach, first providing quantitative data via questionnaires, to more systematically assess any effects that parenting programmes had on parental self-efficacy, wellbeing and perceived changes to their child's behaviour, and to draw some conclusions as to possible associations between them. Secondly, it explored in greater depth the parents' views of their personal experience of the programme through the collection of qualitative data from semi-structured interviews, which provided a richer set of data and greater understanding for any changes observed in the questionnaires. (Preece, 2014).

1.3   Researcher's Position and Reflexivity

My interest in this topic was initially stimulated through previous work as a teacher in Special Needs Schools for children with complex needs including autism. In

addition, whilst on placement as a trainee educational psychologist (TEP), I became aware of the number of children diagnosed with autism that I was being asked to work with and the need to support their parents in coping with the challenges their children presented with.

Researcher bias was contained as I did not deliver the programme. It was run by two other Educational Psychologists (EPs) in the LA, although I did observe some of the sessions when I delivered the questionnaires. This participation which although it helped me form a rapport with some of the participants in advance of the 1:1 interview stage, might have introduced researcher bias. Additionally, researcher bias might have been introduced as, despite being an exploratory study, the specific nature of the subject matter was revealed through its title and the titles and content of the questionnaires.

As this was a mixed methods study in which there was some qualitative data, acknowledgement must also be made of the researcher's role and their influence in the direction taken by the study (Willig, 2008). My interests in this subject had been stimulated by the earlier study I had conducted on the Cygnet intervention. At this point there were no real expectations of the outcome, as there was very little previous research on this intervention. The previous study identified some key areas which I felt would be beneficial to gain further information on in the current study.

Although the interviews consisted of open-ended questions it must be acknowledged that they were substantially driven by the subject matter of the questionnaires. Whilst opportunities were provided in the first and last questions, there was reduced scope for the participants to explore their thoughts and feelings in a more unstructured way. It must also be acknowledged that, even with a semi-structured interview which focused on the specific subject matter of the questionnaires, a different researcher may have, through their responses, directed the research along a different line of discussion (Vivash, 2015).

Chapter 2: Literature Review

2.1 Background to Parent Intervention Programmes

A child's parent(s) plays a key role in the child's development and wellbeing (Olofsson, Skoog & Tillfors, 2016) and, although all parents find the role of parenting a challenging experience at times, differences will exist between parents' own internal resources, such as wellbeing and resilience. There will also be differences in their external resources, such as social disadvantage, poverty, or their support network of family or friends, which could influence their ability to carry out their parenting role successfully (Lindsay, Strand & Davis, 2011). At such challenging and difficult times, parents may struggle to carry out their parenting role, which will place additional strain on family life, and which may also be reflected in the child's problem behaviour and affect those who are directly involved with the child, such as members of their school community, for example teachers and teaching assistants. When faced with such difficulties, parents will often seek the support of outside agencies to provide them with help and guidance, for example, through intervention programmes, to help them manage their child's behaviours.

Until the 1960's, parents were not typically involved in intervention programmes to support them in managing their child's problem behaviours, and any interventions were seen to be the role of the professionals, such as 1:1 interventions delivered by clinical psychologists. During the late 1960's and early 1970's, a new approach was adopted in response to work carried out by Bandura (1969), which reported that parents could play a significant part in supporting and developing their child's behaviours. In addition, clinicians began to realise that, if parents could receive appropriate training, this would enable them to deliver psycho-educational behaviour programmes to their own children and help reduce the demand on professionals.

This next section examined studies of those interventions which were developed for parents of children without autism, such as a randomised control trial and evaluation of DELTA (Developing Everyone's Learning and Thinking Abilities) by

Miller and Harrison (2015).   The focus of this study of a parenting programme was to identify if there were benefits to the parents of attending such a programme.

The DELTA programme was offered to parents of all children aged 0-16 years, however the age range for the DELTA study was between 3 - 5 years. 334 parents of pre-school aged children were recruited from 23 mainstream primary schools. This programme is a six-week group-based parenting programme which provided parents with information relevant to the developmental age of their child.

Data was collected from pre- and post-programme questionnaires and 11 parents took part in a post-course interview. Miller and Harrison (2015) reported that the parents' self-efficacy improved in three areas: knowledge about their child's development, self-acceptance of being a good parent, and disciplining and being able to set boundaries. The participants interviewed also spoke of the importance of the social experience of the programme, as well as the knowledge gained from participation in the intervention.

The findings from the aforementioned study seemed to show that parents not only benefited from the knowledge they had acquired from the programme, but also from the social experience of being with parents in a similar situation as themselves. This current study examined if the Cygnet programme had a similar impact on parental self-efficacy, whilst also providing them an opportunity to interact with other parents of children with autism.

However, striving to become a 'good parent' of a child who is experiencing difficulties has its disadvantages, as it might put the parents' own mental health at risk, as reported in a feasibility study targeting parents of children with psycho-social difficulties who attended an intervention (Triple P Discussion Groups and Stress Control) which was a combination of a parenting programme and a cognitive behavioural intervention for mental health issues in the parents (Palmer, Henderson, Sanders, Keown & White, 2013). Key findings from this combined programme showed that there were positive changes in both parenting

management skills and parental anxiety, stress and depression. Secondary findings included improvements in child behaviour, parental self-efficacy, family dynamics and in the parents' mental health.

The study commented that the findings raised an awareness that interventions need to focus on the parent's mental health as well as the child's psycho-social difficulties. This raises the question as to whether parental mental health needs to be addressed initially, so that the parents can gain the maximum benefits from the intervention, or it may be that the parents' wellbeing is improved through the acquisition of behaviour management skills for their child.

A parent's psychological health is also likely to influence the relationship between the parent and the child, with longer term effects on the child's psychological health. (Barlow, Smailagic, Huband, Roloff & Bennett, 2014). This systematic review of group-based parent intervention programmes found evidence of short-term benefits of these programmes on depression, anxiety, stress, anger, guilt and confidence in the parents. The authors commented that follow-up programmes may be needed for the parental psycho-social benefits to continue into the longer term, i.e. more than six months after the intervention, and it also noted that parents' wellbeing was an area that needed to be continually supported.

In addition to the importance of parental wellbeing, it has been reported in a review of several studies that self-efficacy could be seen as a potential indicator of parental competence and possibly child behaviour (Jones & Prinz, 2005). Strong evidence was also found in this review that parental self-efficacy was associated with parental competence. This review explored the possible links between parental self-efficacy and child behaviour, and the parent's understanding of the behaviours and emotions that exist within such families.

These findings also provide further evidence to support the hypothesis of the association between parental self-efficacy and the impact that the child's behaviour has on the parent. The study above commented that it was as

important to consider the impact that the parent's behaviour had on the child's behaviour as vice versa, which is consistent with the theoretical model proposed by Hastings (2002), in which the child's challenging behaviour triggers parental stress, which had an impact on how the parent responded to the child's behaviour, which might then feed back to the child to trigger further challenging behaviour.

The studies above have raised some potential impacts of parent interventions for parents of children without specific difficulties. Studies of interventions designed for parents of children with specific difficulties have found similar evidence and proposed associations between the key factors. It has been proposed that interventions should include support for parents to help them develop a belief in their self-efficacy to carry out their parenting role as, for example, a child's difficulty in social communication skills might impact parental self-efficacy. If a parent feels unable to understand or address their child's needs, this could result in a lowering of their self-efficacy (Karst, Van Hecke, Carson, Stevens, Schohl, & Dolan, 2015). It could be hypothesised that, by increasing a parent's knowledge of being able to communicate with their child more effectively, this might also increase their self–efficacy to manage their child's behaviour.

In their meta-analysis, comparing parental stress in parents of children with or without autism, Hayes and Watson (2013) found evidence that early interventions which focus on reducing parental stress can be supportive in bringing about positive changes in the child's behaviour.

Karst et al. (2015) proposed in their review a model for intervention evaluation which included assessment of parent and family issues as part of the evaluation as, even if significant improvements were made with the child, this would not necessarily impact the stresses and strains that the parents and family were experiencing. The authors also stressed the importance, in their view, of having a greater understanding of the impact of the interventions and the changes they might bring about, both in the relationship between the interventions and the impact of them on both the parents and the child.

Evaluations of parent interventions often focused on the outcomes for the child, and there was not always a clear and specific focus on the impact that they might have on the parents and family, both in the immediate term and long term (Karst et al. 2015). The authors of the previous study commented that it was important that this factor was considered, because it cannot be assumed that by improving child behaviour parental stress would also improve.

This would seem to suggest that improvement in parental wellbeing is not dependent on improved child behaviour, but other factors are also involved. Therefore, it could be said that, through having a better understanding of the parent's wellbeing, further clarity could be acquired as they could be supported. This study of the Cygnet programme sought to address some of these limitations by focusing on the parents' perspectives of their wellbeing and self-efficacy, as well as their views of their child's behaviour.

All the studies described above have found evidence that parental self-efficacy and wellbeing were key factors to support parents of all children, whether they have specific difficulties or not. The studies of interventions for parents of children with specific difficulties also seemed to suggest that the most effective way to help parents was to support them increase their self-efficacy in managing their child's behaviour, and to provide them with stress management strategies.

More directly related to the current study, a wealth of literature has explored the use of intervention programmes for those parents with children with autism. It has already been mentioned that, when faced with a diagnosis of autism for their child, parents may feel guilty and unable to cope with their child's behaviours and in addition, they might feel socially isolated due to a lack of understanding from other family members and the general public, who might perceive their child as being just 'naughty' or 'spoilt' (Shields, 2001). The child's challenging behaviours can result from difficulties with regulation of their emotions often leading to frustration, anxiety and in some cases a 'meltdown' in which the child loses

control and may use verbal, such as shouting or crying, and/ or physical means, such as hitting or biting, to express themselves (National Autistic Society, 2017).

Many parents find this behaviour challenging to manage and are more likely to experience negative psychological outcomes, such as depression, stress or anxiety, than those parents with typically developing children, or even those parents with children with other developmental disabilities such as cerebral palsy (Mugno, Ruta, D'Arrigo & Mazzon, 2007; Weiss, 2002). Other studies showed that parents of children with autism were more likely to experience higher levels of stress (Baker-Ericz, Brookman-Frazee & Stahmer, 2005; Dabrowska & Pisula, 2010; Duarte, Bordin, Yazigia & Mooney, 2005).

The next three sections examined what the literature reported were the impacts of such interventions for parents with children with autism. They explored in more depth the key factors identified above, i.e. the parent's perceived self-efficacy and wellbeing, the benefits of the programme to the child, and the possible impacts that the interventions have on both the parents and the children themselves. The first to be examined was self-efficacy.

2.2 Perceived Self-efficacy

Bandura (1982) defined self-efficacy as an individual's perceived abilities to be successful in specific contexts. Therefore, an individual's self-efficacy might change from context to context and could be said to be context specific. The focus for this current study was the context of parenting. Johnston and Mash (1989) defined self-efficacy in more specific terms as: the perceived confidence and competence the parent feels in managing their child's behaviours.

Self-efficacy was the term primarily used throughout this study, although other terms such as competence and confidence were used as a proxy for self-efficacy in some of the studies reviewed where the term self-efficacy was not used. Self-efficacy has been used throughout the study except where a particular study had used an alternate term.

One of the key aims of parent intervention programmes, including the Cygnet intervention which was the focus of this study, is to provide parents with knowledge which, in the Cygnet programme, includes having a better understanding of autism, practical advice about strategies to help them manage their child's behaviour and information about other resources they can access. Although the type and range of knowledge provided may vary between programmes, depending on the focus of the programme, there are certain common themes which are similar to all intervention programmes for parents of children with autism, thus making it more relevant to draw comparisons between each intervention.

Studies, such as the one by McAleese, Lavery and Dyer (2014), evaluated the benefits of acquiring knowledge by attending a psycho-educational parent group intervention for parents whose children had recently received a diagnosis of autism. A total of 83 parents attended the programme and were assigned to one of two groups, either a pre-primary school age group, or a post-primary age group. Analysis of the results from the questionnaires completed both at the beginning and end of the course by the participants showed that, because of their attendance on the programme, the parents had significantly increased their knowledge of the social deficits and the cognitive and behavioural difficulties linked with autism. Evidence from the study also found that the parents' acquired knowledge of strategies that could be used to support a child with autism had also increased their self-efficacy significantly. Whilst these findings are interesting, they are based on a short 3–week intervention which might have had less impact than a longer intervention and therefore be less sustained over the longer term. The intervention in the current study had a 6-week duration with a 12-week later follow-up. Measures were taken at the start and end of the intervention and at the follow-up session.

The authors hypothesised that improved parental self-efficacy might be the result of their increased ability to manage their child's behaviours, as they now had the knowledge and skills to help them better manage their child's behaviour.

The acquisition of knowledge can be seen to help parents improve their self-efficacy. Evidence was found in a study (Cutress & Muncer, 2014) where parents reported that, by knowing about specific strategies to help them manage their child, they became more confident and competent. The study focused on the EarlyBird Plus Programme, which is a psycho-educational group-based programme for parents of children with autism aged 5-8 years. As mentioned earlier, it was developed by the National Autistic Society as a follow-on programme to the EarlyBird Programme for parents with pre-school children with autism. The main aims of this programme were to help develop the parents' self-efficacy. The content of programme was divided into three sections: understanding autism, the difficulties that children with autism have with social and communication skills, and strategies which support the parents with their child's behaviour.

Data was collected through a post-group questionnaire, which also provided the parents with an opportunity to give qualitative feed-back about their experiences, and general comments about the programme. The questionnaire was only given post intervention, so there was no pre-post intervention comparison to more clearly identify any changes that might have occurred as a result of the intervention and, in addition, there was no control group to compare to the intervention group. Both issues are addressed in the current study by having a measure 12 weeks post completion and a control group.

However, the key themes reported by the parents in Cutress and Muncer's (2014) study were interesting in that they showed that by being given specific strategies to support their child and, in addition, being provided with other coping strategies, the quality of family life was improved.

An earlier evaluation of the EarlyBird programme (Clubb, 2012) reported similar findings that, through attendance on the programme, parents reported that they had a better understanding of autism and increased problem–solving skills and knowledge. These included strategies they could try with their own children, such

as modifying their language to help develop positive communication between them and their child.

As described earlier, parents of children with autism are often faced with having to deal with challenging situations, which can range from their child being unwilling to engage in a suggested activity, to having to manage threatening and aggressive situations. A study by Preece (2014) examined the benefits of a programme which had been designed to address specific needs. The study explored the benefits of providing physical intervention training to a small group (n = 11) of parents of children aged 7-11 years who attended the same special school. This training programme focused on providing support to parents in understanding the concept of challenging behaviour and the emotional state of the child, as well as teaching parents how they might respond to behaviours such as biting, hair pulling and fighting by using techniques such as safe holding or escorting.

Parents were asked to complete questionnaires post the training and at the 12-week follow-up session. This data was triangulated with data collected from semi-structured interviews with the trainer and the specialist autism practitioner immediately after the training, as well as after the 12-week follow-up session. The purpose of these interviews was to gain further information about the interaction between the trainers and the parents and the relationship between the school and the parents.

The data showed that the participants' confidence had increased in all the areas that had been explored in the training, such as understanding, managing and being able to predict challenging behaviour in their child, and being confident in using physical interventions, immediately post the training. In the 12 weeks post completion of the programme, the parents' confidence in their ability to manage their child's behaviour continued to increase, although their confidence in their ability to understand and predict their child's behaviour was slightly decreased. However, the study reported that participants maintained a level of confidence in other areas, especially in the use of physical interventions and being better able

to manage situations without having to use such interventions. It was noted that none of the parents had used physical interventions between the end of the training and the 12-week follow-up session.

It could be suggested from the evidence found in Preece's (2014) study that such training could be empowering in providing parents with self-efficacy to enable them to engage in very specific interventions if needed. This enabled them then to confidently carry out their daily lives without necessarily having to resort to further support, either immediately post the training programme, or in the longer term. An aim of this study of the Cygnet Programme was to explore if there were any longer-term benefits for the parents who attended it.

Confidence was not only acquired through having an increased knowledge base, but it was commented that it could be a reflection of the positive feelings of support that the parents had received by attendance on a group-based intervention (Pillay, Alderson-Day, Wright, Williams & Urwin, 2011). Pillay et al. evaluated a parent intervention - Autism Spectrum Conditions – Enhancing Nurture and Development (ASCEND) which was run from 2004 to 2007 and included 79 parents. The data was collected from course satisfaction questionnaires, a developmental checklist, and a parental knowledge questionnaire, both pre-and post the course.

The evidence found that the parents' knowledge about autism and the difficulties that their child was experiencing had increased and the parents reported that they had acquired knowledge about new strategies that they could use to support their child. In addition to the benefits of increased knowledge, the parents mentioned the importance for them of being able to attend a group- based programme and the authors commented that it could be argued that parental confidence had increased due to both the acquired knowledge and the positive support that they received from the group.

Improvements in parental self-efficacy were found post attendance on a group-based parent programme in which there was a specific focus in a pilot study

carried out by Grahame et al. (2015). Grahame et al. explored more specific areas of autism, such as restricted and repetitive behaviours (RRB). The study focused on an intervention for managing repetitive behaviours in young children with autism using videos to record potential triggers of RRB. In addition to improved self-efficacy of the parents, reported that there were improvements in the child's overall functioning, and a reduction in restricted and repetitive behaviours.

The evidence from Grahame et al.'s (2015) study would seem to suggest a possible association between self-efficacy and improvement in the child's behaviour. This was explored in this study of the Cygnet Programme.

Parents also reported an improved sense of self-efficacy post attendance of an intervention, with improvements in parenting satisfaction and support to manage their child's behaviours (Stuttard, Beresford, Clarke, Beecham, Todd & Bromley, 2014). Stuttard et al. conducted a study of another group-based parent intervention for parents of primary aged children with autism – Riding the Rapids. This was a non-randomised controlled study which consisted of an intervention group (n=48) and a control group (n=28). The programme was delivered over ten weeks in two-hour sessions. In addition to completing the Eyberg Behaviour Inventory (1999), the parents were also asked to complete the Parenting Sense of Competency Scale (1989) post intervention and at a six-month follow-up. Improvements were also reported at the six-month follow-up session. The evidence also showed an association between child behaviour and parental self-efficacy.

The authors commented on the difficulty in obtaining a truly random sample, which was also ethnically and gender representative of the population as a whole, in a study of this type, which was reliant on volunteer participants from a closed group. This is likely to be a limitation in any study of parent intervention programmes and might impact the findings as study participants are likely to be volunteers, so are self-selecting rather than random. For example, participants of different ethnicities might have a different perspective of autism and respond

differently to being invited to attend the intervention. Although the current study had a small sample it included a number of participants of different ethnicities.

As has been described earlier, parents of children with autism are at risk of feeling socially isolated, which can result in a breakdown of family dynamics. Schultz, Stichter, Herzog, McGhee and Lierheimer (2012) explored this feeling of social isolation in their study of the effects of a social competence intervention for parents. This intervention was delivered alongside a social competence intervention (SCI-A) which targeted young people aged 11-14 with autism. The focus of this programme was primarily to provide strategies to support the parents to teach social skills development to their children. The children received similar sessions to the parents which ran at the same time.

Schultz et al. (2012) used a quasi-experimental design to explore the effectiveness of a social competency programme which was carried out after school through hourly sessions, twice a week for 10 weeks, for parents with children aged 11-14 with a diagnosis of autism.

Data was collected from questionnaires which were given to a sample group (n=16) both pre and post the intervention. The findings showed that there was a positive trend for parental self-efficacy from pre- to post-intervention.

Interventions that target self-efficacy have benefits for mothers by reducing maternal stress, and for fathers, lead to improvements in self-efficacy by reducing how they are affected by their child's challenging behaviour. Such interventions could be seen as acting in a mediating way for the mothers, and in a moderating way for the fathers (Hastings & Brown, 2002). Hastings and Brown also reported that, although the parents were still concerned about their child, their self-efficacy had increased in managing their concerns, which was a result of the skills and knowledge they had acquired from the programme. It also commented that attendance on intervention programmes could have an impact on parental wellbeing.

The literature above has shown that intervention programmes provided parents of a child with autism with knowledge about autism. This knowledge was beneficial in supporting them in both the understanding of autism and providing them with strategies to manage their child's behaviour. The parents reported that the acquired knowledge increased their self-efficacy in being able to be a 'good parent.' Pillay et al. (2011) commented that parental self-efficacy might be acquired through the positive support that they received from other parents in the group in addition to the knowledge they had acquired.

Although the focus of this section was to examine the impact that the acquisition of knowledge acquired from a parent intervention had on parental self-efficacy (Hastings & Brown, 2002; Schultz et al., 2012), the literature also found evidence that there was an association between self-efficacy and child behaviour (Stuttard et al., 2014). The next section examined if literature had found further evidence of improved parental wellbeing post their attendance on a parent intervention. It also explored if literature had found associations between increased parental skills and knowledge and a decrease in parental stress and anxiety.

2.3 Perceived Wellbeing

For the purpose of the current study, the World Health Organisation's (WHO) (2001) definition was used, which stated that an individual has a sense of wellbeing when they are aware of their own abilities which enable them to cope with the stresses and strains of everyday life and in the long term, their mental health.

Several studies have reported on parental wellbeing in parents of children with autism (with some using the term 'parental stress' as a proxy for wellbeing). One such review (Da Paz & Wallander, 2017) focused on wellbeing and mental health. This review examined the impact that therapeutic interventions, such as mindfulness training, positive psychology and relaxation therapy, had on the wellbeing of parents of children with autism. They commented that there were promising indications that the interventions they reviewed had a positive improvement on the parents' mental health and wellbeing. Such programmes

could, they reported, in the long term, help reduce the mental health costs that might ensue in the future if the parents continued to struggle to cope with their child's behaviour. The authors commented that most of the studies examined had small sample sizes and relied on self-reporting both which limit the generalisability of their findings. They also noted that further research in relation to wellbeing was needed, to explore this area in greater depth.

The above review found evidence of the benefits of therapeutic interventions to parental wellbeing and this would seem to suggest that all parent interventions should include a wellbeing focus in the programme. This would benefit the parents with possible long-term impacts on society as a whole. Although in this current study of the Cygnet programme, wellbeing was not the specified focus of the intervention, parental wellbeing was examined through the questionnaires and the semi-structured interviews, to explore the impact that the intervention had had on the wellbeing of participants.

Mindfulness was also the focus of an eight-week programme for parents of children with autism where it was found to be a more effective way to enhance wellbeing and reduce parental stress than a cognitive skills/ behavioural skills intervention (Ferraioli & Harris, 2013). In this feasibility study, carried out in the US, parental wellbeing was the focus, parental stress was shown to be significantly reduced post attendance on a mindfulness intervention.

The authors commented that it was not possible to make any meaningful conclusions due to the small sample size of the group (n=21). However, it was noted that high levels of satisfaction were reported by parents of both interventions. The authors reported that the evidence showed that it was beneficial to include specific skills in an intervention that helped parents manage their stress. The study also commented that it would be beneficial if future studies explored the impact of interventions on child behaviour which focused particularly on the most effective mediators in the programmes.

Another study (Kowalkowski, 2013) of a therapeutic approach, Acceptance and Commitment Therapy (ACT), which is an intervention offering an alternative to traditional skills training, using psychotherapy to address depression and anxiety, was delivered to a group of mothers of a child with autism. Kowalkowski found evidence of an association between maternal stress and child behaviour, but the author warned that, due to the subjectivity of the data collected, it was not possible to determine whether the parents were viewing their child's behaviour as more challenging than it actually was, due to their stress, or whether their stress caused their child's challenging behaviour.

Whilst there are benefits for parents to attend therapeutic intervention programmes, evidence of an association between wellbeing and child behaviour have also been found in a US study. Tonge, Brereton, Kiomall, MacKinnon, King & Rinehart (2014) examined the benefits of providing parents with specific strategies to help them understand and manage challenging behaviour, as well as being given the support to help develop their child's communication and social and play skills. Tonge et al. carried out a parallel-group comparison between two parent interventions to explore their impact on parental mental health. A sample of 70 parents of children aged 2.5 - 5 years who had a diagnosis of autism were randomly allocated to a group that, either received just a written, manual-based education programme, or a group that also received skills training in addition to the manual-based programme. Data was collected from three questionnaires covering adaptive behaviour, emotional and behavioural problems and autistic symptoms, and cognitive and language developments pre-, post- and six months after the intervention.

Tonge et al. (2014) acknowledged that, even with a sample of 70, which was recruited from two metropolitan regions and two rural ones, the sample was unlikely to be truly representative of the wider population due to possible differences between the regional services and the demographics of the different areas. The authors also commented that the reliance on self-reporting might also have impacted the overall reliability of the findings. However, they found evidence that showed that both groups of parents benefited from the intervention received,

and improvements were also made to their mental health and wellbeing - this was particularly so if the parents had already experienced mental health difficulties.

The demographic of where the study is taking place and the criteria for taking part in the intervention might limit the constituency of the possible sample in any such study of a parent intervention of this type. The issue of self-reporting is addressed in the current study by the use of measures which had been specifically designed to acquire self-report data and had been independently standardised and validated in this field. The key focus of this study was to gain an understanding of the parental perspectives, irrespective of what more 'objective' observation methods might demonstrate.

The findings from Tonge et al.'s (2014) study would seem to suggest that parents do not need specific support to manage their wellbeing, as improvements to parental stress might also occur if they are provided with the knowledge and understanding which enabled them to communicate with their child, as they then had the strategies to manage their child's behaviour more effectively and therefore reduce the child's challenging behaviour. In the current study of the Cygnet programme this was the approach adopted, as there were no formally targeted sessions on parental wellbeing, which is similar to the hypothesis above.

If parents' self-efficacy is increased, parental stress is decreased and there are improvements to family life (Cutress & Muncer, 2014). Cutress and Muncer conducted a study of an intervention programme focused on seeking the parents' views on the extent to which an intervention programme increased their self-efficacy. The authors of this study of the EarlyBird Plus programme, which has been discussed earlier, commented that interventions that target parental stress might help improve the way that the parent perceived their child's behaviour, even if the behaviour of the child did not change markedly. This association between parental wellbeing and child behaviour was examined in the current study, to identify if there were evidence of possible links.

However, even if wellbeing has improved, it is difficult to measure, as it may not be possible to determine the reason why it had occurred, as improvements to wellbeing might occur if parental self-efficacy were increased, or because of improvements in the child's behaviour, or because of both (Roberts, Brophy & Bacon, 2009). Despite these reservations, the report found that parenting programmes increased wellbeing, in that they found that parents developed a trust in themselves and others, relationships between the parents improved, they were able to develop links within a community of parents in a similar situation and developed a sense of belonging. They also began to enjoy their children, as it will often break the cycle of poor parenting that they themselves might have received as children. The report commented that wellbeing should be one of the key objectives for all parenting programmes, and such programmes need to be designed to boost both parents' and children's wellbeing, which was a comment that had been made earlier by Palmer et al. (2013).

Whilst parental wellbeing was not a key objective of the Cygnet programme, in this current study, in addition to the participants providing quantitative data regarding their wellbeing at different times, a sample of parents were also asked to discuss their feeling of wellbeing and the impact that the intervention might have had on it.

Parents have reported that wellbeing was a difficult topic to discuss, as most of their time was spent focusing on their child's needs (Dababnah & Parish, 2016). Evidence of this was found in a qualitative study in the US of The Incredible Years, a group-based pre-school parent programme which had been adapted to meet the needs of parents of children with autism. This programme had originally been developed for parents of typically developing children with severe behavioural problems to help them manage their child's challenging behaviours and improve their mental health. It was noted by the authors that participants may have reported overly positive outcomes due to social desirability bias resulting from their emotional investment within their intervention group. The current study utilised independently standardised and validated questionnaires, which had been designed to acquire self-reported data, to obtain quantitative data to

compare to the qualitative data obtained from participants with the aim of mitigating this issue.

Dababnah and Parish commented that the programme was also particularly relevant to parents of children with autism, as they often experienced similar, significant parental stress, which resulted from their child's behaviours. Dababnah and Parish found that participants benefited from the session on self-care and how to reduce stress. There were suggestions from the participants that parenting needs and self-care should perhaps be run as a separate programme at a later date.

These suggestions were different from those made earlier by Da Paz and Wallander (2017) and Tonge et al. (2014) where it was commented that parental wellbeing could improve even if there were no specific focus on it in the programme. It could be suggested that the social component of the programme, i.e. the interaction between the parents on the programme, provided enough support to allow parental wellbeing to improve.

As mentioned in the above study, parents can become totally focused on their child however, evidence was found in a study of the Parents Plus Early Years (PPEY) intervention that, those parents who observed improvements in the behaviour of their child, were also less stressed, and they had greater satisfaction with their role (Gerber, Sharry & Streek, 2016). The PPEY programme is designed to support the parents of children with behavioural, emotional and developmental difficulties, though not specifically for children with autism. Questionnaires were completed both pre- and post- the intervention by the parents of the children. The programme was not based on a structured teaching format but, by building on their strengths, the parents became empowered to seek their own solutions to their child's problem behaviour.

These findings could suggest that, by providing a structure for the parents, this removed some of the parenting stress, such as the continual questioning of 'am I doing the right thing?' Therefore, by supporting the parents to develop a more

collaborative and assertive parenting style, this then encouraged the child to become more responsible and self-determining through the use of choices and consequences.

The theme of increasing self-efficacy having possible implications for reduced parental stress was also hypothesised by McAleese et al. (2014) in their study of a group intervention for parents of children with autism. The evidence for this hypothesis was taken from qualitative information provided by the participants at the end of the questionnaire. The parents made comments about the workshops being secure and nurturing and everyone felt relaxed. Comments were also made about being provided with strategies to support difficult situations, such as bedtimes, which resulted in these situations being less stressful.

Similar evidence of increased parental self-efficacy having an impact on parental wellbeing was found in a study by Schultz et al. (2012) which focused on Social Competence Intervention for Parents (SCI-P), a group-based parenting programme for parents of young people with autism. The study found evidence that, post this intervention programme, participating parents showed improvements in parental wellbeing and had less perceived stress. Schultz et al. also reported that, although parental stress levels were reduced, the level of stress connected with the young person was not. The authors commented that the data showed that, although parents continued to remain concerned about their child, they were empowered with their newly acquired skills to help them deal with their concerns. It could be suggested that the empowerment created by this acquisition of knowledge and skills had enabled the parents to deal with the difficulties that they were faced with more competently, and they experienced less stress in doing so.

The studies above have found evidence that parents of a child with autism are likely to have a reduced wellbeing as they experience stress, anxiety and depression on a regular basis. Associations have been found between wellbeing and fatigue and low self-efficacy for such parents in a study of fifty mothers of children with autism aged 2-5 years (Giallo, Wood, Jellet & Porter, 2011). Further

evidence of this association was also found in a study by Estes, Munson, Dawson, Koehler, Zhou & Abbott (2009) which found evidence that associated high levels of parental stress in mothers to the challenging behaviours in their children with autism. This evidence was however consistent with the theoretical model proposed by Hastings (2002) that parental stress could trigger further challenging behaviour from the child as discussed earlier.

Both these studies focused on mothers of children with autism and, as a result, there can be no generalisation of the findings to the fathers or other carers. The current study mitigated this to some extent, as data was collected from a small sample of fathers as well as mothers attending the intervention. But, overall, the participants in the intervention were largely female, as it is generally easier for the mother to attend an intervention run during normal business hours. However, no other carers (e.g. grandparents) participated in the intervention being studied.

In a small-scale US study of an intervention which addressed feeding difficulties linked with children with autism, whilst it was not a focus of the programme, participants reported a significant decrease in their stress post attendance (Sharp, Burrell & Jaquess, 2014). It was suggested that, through the involvement of the care-giver in the intervention, there was a greater possibility that their wellbeing also increased. The authors commented that, by reducing parental stress, it was more likely that the intervention would be more effective, with the possible added benefits of improving interactions between the parent and child. It could be suggested that, through the acquisition of proven support strategies, the parents felt less stressed and were able to implement the strategies more effectively.

A positive association between parental wellbeing and parental management of their child's behaviour was also commented on in a small-scale study of The Incredible Years Programme (Roberts & Pickering, 2010). This is a parenting programme to support parents of children with autism and in this study, eight parents whose children had a mean age of 8 years, participated in the 12-week programme. Both scales on the Eyberg Child Behaviour Inventory (1999) (the

measure used to assess both the severity and rate of occurrence of the behaviour) showed reduced scores from pre- to post- questionnaires. This reduction indicated that the parents were able to manage their child's behaviour more effectively, and they also did not perceive it as being as difficult to manage. The authors also noted that the programme seemed to have a positive influence on the parents' mental health.

Improvements in parental wellbeing, as well as a reduction in the child's challenging behaviour over the long term, were also shown in a large study of the parent intervention programmes: The Incredible Years, Triple P and Strengthening Families, Strengthening Communities (SFSC). (Lindsay et al., 2011) The study focused on children with problem behaviours, including, but not specifically, autism in six Local Authorities.

Mancil, Boyd and Bedesem (2009) stated in their US-based literature review that, although there was enough evidence in support of increased levels of stress in parents of children with autism, there was still a need for further research into the coping strategies that these parents engaged in to help them manage their stress, which this current study addressed by examining if the Cygnet programme were beneficial in reducing the levels of stress in the parents. This comment seemed to suggest that, as parental coping strategies vary, it could be helpful to have an initial measure of parental stress, as this could be beneficial in seeking out the most appropriate strategies to support them and, in turn, their child.

Throughout the studies reviewed so far, there has been a strong theme that has emerged which has suggested that, by being provided with the relevant knowledge and skills about their child's difficulties and how to manage them more effectively, parents not only feel empowered, but they also felt less stressed and, as a result, it could be hypothesised that their wellbeing improved. Some of the studies reviewed (Cutress & Muncer, 2014; Gerber et al., 2016) reported that when the parent felt less stressed this could lead to changes in how they view their child's behaviour, as the improved parental wellbeing was a result of their

newly acquired knowledge of the strategies they could adopt to manage their child's behaviour.

The current study explored to what extent the Cygnet programme addressed the parents' wellbeing and, if it did, had the newly acquired knowledge been influential in reducing their stress, and if so what impact did this have on the child's behaviour? The final section examined evidence the literature has found which showed the impact that interventions have on the child. It also examined if there were associations between parental wellbeing and parental perceptions of their child's behaviour and their management of that behaviour.

2.4 Benefits to the child

The previous sections have focused on studies (Gerber et al., 2016; McAleese et al., 2014; Roberts & Pickering, 2010) which have discussed the effectiveness of parental interventions for the parents themselves, however, there have also been some studies which have focused on exploring the effect that these programmes have on the children. Typically, this may be linked to areas which many children with autism will experience difficulties with, such as social communication, and other autistic symptoms including repetitive and restrictive behaviours.

One such study (Gerber et al., 2016) found evidence that parent interventions provided benefits to the child whose parents attended the PPEY pre-school parent intervention programme. The parents in this study reported a significant improvement in the behaviour of their child. These improvements were identified on the Strength and Difficulties Questionnaire (Goodman, 2001) as a decrease in emotional symptoms, conduct problems, hyperactivity and peer problems, and there were significant increases in pro-social behaviour. Gerber et al. commented that, as the children were so young, there were potential benefits of attending an intervention programme soon after receiving a diagnosis of autism for their child. Similarly, in a review of 17 studies (Oono, Honey & McConachie, 2013) it was suggested that those children whose parents had participated in a

parent intervention presented with a reduction in symptom severity compared with those in the control group.

The positive impact of a parent programme on child behaviour was also found in the study by Stuttard et al. (2014), which has been discussed earlier in this literature review. The study collected data from the Eyberg Child Behaviour Inventory (1999) which although it showed an improvement immediately post intervention, there were some variations in the parents' ability to continue with this improved behaviour six months later. The authors hypothesised that this may be that parents found it difficult to adapt the strategies to new challenging behaviours which developed post intervention

This hypothesis differed from evidence found in a US study which showed that there were long-term implications for parents in that, once they had received appropriate training, they could effectively deliver an evidenced–based social skills programme to their children (Radley, Jenson, Clark & O'Neill, 2014). The study, which explored the outcomes of a social skills programme for parents of children with autism, found that the children showed an increased engagement in social skills in a free play setting following the intervention.

The findings from Radley et al.'s study would seem to suggest that, when parents have been provided with appropriate training, they could have a positive influence on their child's behaviour. However, there was some disparity between the findings of Stuttard et al. (2014) and Radley et al. (2014) as to how effective parent interventions were in supporting the parents to generalise and adapt strategies to new and different situations possibly due to the very short gap before the follow up measure was obtained in the Radley et al.'s study. This suggestion was examined in this current study in the questionnaires and interviews completed 12 weeks after the end of the intervention, to identify if this sample of parents were able to continue to adapt and generalise the strategies they had acquired from the intervention.

Some intervention programmes can support parents more specifically, by providing additional skills training that can improve their child's communication, socialisation and day-to-day living skills and autistic symptoms are decreased (Tonge et al., 2014). In this randomised group study, which has been previously discussed, a comparison was made between a parent education and counselling intervention and a parent education and behaviour management skills training intervention to explore the benefits to the child. The data collected showed that a manual-based intervention with additional skills training could be linked with improvements in the child's communication, socialisation and day-to-day living skills, and a decrease in autistic symptoms. The manual-only based intervention only showed improvements in socialisation skills.

Studies such as a randomised control trial carried out by Whittingham, Sofronoff, Sheffield and Sanders (2009) in Australia hypothesised that, by improving parenting skills, there could be changes to the parents' perceived behaviour of their child. The authors would seem to be suggesting that, by improving parenting skills, parents were more likely to perceive their child's behaviour more positively, possibly because they now have the strategies to manage their child's behaviour more effectively. This current study also explored this area to identify if there were evidence to support this hypothesis.

Whittingham et al. (2009) evaluated Stepping Stones, which is a variation of the Triple P parenting programme and had been specifically designed for parents of a child with a range of disabilities including autism. The focus of this programme was to support the parents in managing their child's behaviour in a positive and constructive way by suggesting alternative ways that the parent could respond to the behaviour of their child.

The sample size for Whittingham et al.'s (2009) study was n = 59, with 29 in the intervention group and 30 in the control group. The participants were parents of children aged between two and nine years old who had been diagnosed with autism. The study provided evidence of a reduction in their child's challenging behaviour for parents in the intervention group compared to the control group.

Further follow-up data showed that this trend was continued six months after completion of the programme. The limitations of Whittingham et al.'s study, as the authors reported, were that the data collected was dependent on parental responses, so they were aware of the 'treatment' effect of the intervention which could have influenced their responses. Therefore, the authors noted that it would have been beneficial to have had some independent observations in support of the reported findings of the parents. Additionally, as the parents had reported that their children were verbal, and some had been diagnosed with Asperger's Syndrome, generalisations could be made that these children were both verbally and intellectually able and therefore more able to express themselves. Further studies would be needed to explore if similar evidence were found with parents of non-verbal and/ or intellectually less able children. Despite these limitations, the authors hypothesised that parent interventions provided benefits to both parents and their children with possible long-term impacts, which was an area also examined in this current study.

Other evidence has also shown that attendance on a parent intervention programme can result in a significant reduction in the parents' perception of their child's challenging behaviour (Pillay et al., 2011). Pillay et al. evaluated the ASCEND programme, which has been discussed earlier, showed that the improvement in the child's behaviour was connected to three of the learning targets in the programme, which included parental understanding of the behaviour, developing ideas of how to cope with challenging behaviour, and being able to plan strategies to manage the behaviour.

It could therefore be suggested that, by providing parents with knowledge and understanding of their child's behaviour, their perceptions of their child's behaviour changed, as they now felt better able to manage it, which was a point that Cutress and Muncer (2014) raised and was commented on in the previous section. This current study examined to what extent parents' increased knowledge had an impact on the way they viewed their child's behaviour.

The authors of the ASCEND study commented that there could be an association between the parents' perceived improvements in child behaviour and their increased confidence and knowledge of how to manage their child's behaviour. The authors also noted, as in the previous study (Whittingham et al., 2009), that the data relied on parental perceptions, and therefore the association between their perceptions of challenging behaviour and ability to manage was not unexpected as, even if the behaviour were still challenging, the parents now have increased self-efficacy in managing the behaviour.

These findings could suggest that perceived parental self-efficacy are pre-requisites for managing their child's challenging behaviour more effectively. This association between parental self-efficacy and child behaviour was examined in this current study to explore if parental self-efficacy was beneficial in helping parents manage their child's behaviour.

Pillay et al. (2011) also reported that their study did not have a comparison with a control group and, as there had been no independent evaluations made of the child's behaviour both pre- and post–course, any reported changes in the child's behaviours were the parents' perceptions. Though this is important, it cannot offer independent evidence of any actual change.

This theme, of providing parents with support strategies, was explored by Preece (2014), described previously, who found that, post attendance on the programme they received, parents did not need to use physical restraint on their child during the 12 weeks after the training. Prior to the training, physical intervention had been used as often as several times each week without the parents having received any training or support re safe handling techniques, or other strategies which support behaviour management. Preece commented that their study supported findings in other studies, such as the US study by Karst et al. (2015), which reported that, if appropriate training were provided, there were benefits to the parents, in that their self-efficacy and wellbeing were improved and, additionally, their perceived view of their child's challenging behaviour decreased. An interesting observation in this study was that, as the control group were not

prevented from accessing other interventions to the one which was the focus of the study, this might have affected the between groups analysis results.

In Karst et al.'s (2015) study the control group showed a small, but not significant, negative result (child behaviour became more challenging) however, over the period of the study a small number of control group participants had accessed pharmacological support to help manage their child's behaviour, potentially affecting the accuracy of the control group findings. In the current internet age, the issue of control group access to websites, forums, and other forms of information and support is close to impossible to prevent. It is not ecologically valid to try and prevent the control group participants from seeking out support from other sources, such as the internet, during the course of the study. The key is to look at what an intervention adds over and above any such ad hoc support that the control group might have accessed.

Associations were shown between the young person's social and behavioural difficulties, as perceived by the parents who have attended the parent intervention programme SCI-P, and parental wellbeing (Schultz et al., 2012). It must be noted that the programme delivered to the parents was based on the same programme that their children had received and, in this way, the parents were focusing on a set of targets directly connected to the children's programme.

The discussion above has focused on studies that included a measure of child behaviour, however in the following study this was not the case. Even though a measure of the child's behaviour was not included in a study of the parent intervention EarlyBird Plus, parental responses indicated that the programme had helped them manage their child's behaviour better (Cutress & Muncer, 2014), This evidence was collected from qualitative comments which were provided in addition to the responses to the closed questions. The parents also reported that they were better able to prevent any challenging behaviours occurring. It could be hypothesised that, by managing and preventing problem behaviour, that there would also be fewer occurrences or extremes of such behaviour. Although the authors saw this as an area for future research, they commented that, if parental

stress were improved, parents' views of their child's behaviour might also improve. The current study of the Cygnet Programme aimed to address this gap in research by collecting both quantitative and qualitative data on any changes in the parents' perception of their child's behaviour following the intervention.

This possible association between parental stress and child behaviour was explored further in the following study which found that through involvement of parents in a parent intervention programme, by helping parents to manage their stress, this supported them in managing their child's challenging behaviour (Osborne, McHugh, Saunders & Reed, 2008). Osborne et al. also found evidence that increased parental stress had an impact on a child's challenging behaviour and, therefore, there was an association between parental stress and child behaviour.

Higher stress levels could be linked to a lack of change in the social skills of the child (Stadnick, Stahmer & Brookman-Frazee, 2015). In this US pilot study of the Project ImPACT, discussed earlier, it was commented that, in cases where there were high levels of parenting stress, the programme might also need to be adapted to include a better understanding of the parents' level of stress. The authors emphasised the importance of addressing parenting stress in an intervention programme, as the parents' stress might have a direct impact on the outcomes for the child.

It could be suggested that, as stated earlier, to enable the child to receive the benefits from the programme too, there is the need to provide strategies to support parents with stressful situations, which again raises the question whether parents should have an assessment of parental stress prior to the start of the programme. Additionally, it could be suggested that the acquisition of knowledge improved parental wellbeing and also supported the parent in managing their child behaviour, thus creating an association between wellbeing and child behaviour. This current study of the Cygnet Programme explored the impact of the programme on parental stress (wellbeing) and the link to perceived changes

in their child's behaviour to examine if there were evidence in support of this hypothesis.

In summary, from the literature reviewed above, both children and parents benefited if the intervention included the provision of supporting strategies, skills and knowledge to help the parents to understand and manage their child. This newly acquired self-efficacy provided the parents with a greater sense of wellbeing and enabled them to more effectively manage or prevent problem behaviours in their children.

The majority of the research discussed in this literature review was carried out in the UK, USA and Australia, with individual articles also originating in Brazil, Canada, Ireland, Italy and Poland which might reflect cultural differences from the authors or the results. The meta analyses may also have covered research conducted in countries other than where the analysis was conducted. The articles discussed in the first section were primarily concerned with the value of parent interventions in general, rather than those with a specific focus of group interventions or interventions for parents of children with autism, to provide context for the current study. The articles in the other three sections (self-efficacy, wellbeing and child behaviour) were focused, where possible, on group interventions for parents of children with autism. Where there was a limited amount of research covering both criteria additional research on parental wellbeing in general and non-group interventions focused on child behaviour in general have been included.

This current study explored these areas, i.e. perceived parental self-efficacy, wellbeing and child behaviour, in relation to participation in the Cygnet Programme, to identify if equivalent benefits were delivered by the programme. Findings from the current study provided further evidence to the suggested areas of future research by previous studies (Karst et al. 2015; Stuttard et al., 2016) and to provide further evidence to support other studies in this field.

It also explored the possibility of links between these three areas: perceived parental self-efficacy, wellbeing and child behaviour; and initiated further discussions into potential associations between the areas which have been mentioned above, to identify the possible benefits that there might be in ensuring that all parent interventions address all three areas in their key aims.

From the literature examined above, there were several limitations and challenges that were common to a number of studies. Some of the studies (Dababnah & Parish, 2016; Kowalkowski, 2013; Radley et al., 2014) employed small sample sizes which might limit the reliability of any identified effects, both between and within groups, and therefore the findings need to be interpreted with caution. A small sample size would also limit the range of participants that were involved in the study, which may therefore not be representative of the wider population (Schultz et al., 2012). In one study, the small sample was specifically selected by the headteacher of the school, which again did not represent the wider population (Preece, 2014).

In addition to small sample sizes potentially affecting the validity of the findings, the absence of a control group in a number of studies meant that any changes identified in the intervention group could not be shown to be different from any changes that might have occurred without the intervention, as no comparison group was available (Cutress and Muncer, 2014; Gerber et al., 2016; McAleese et al., 2014; Schultz et al., 2012). Although in a study by Kowalkowski (2013), a control group was initially set up, it was disbanded part way through the study due to lack of interest from the participants and therefore no comparison was possible.

The literature review also found a number of studies where the measures used did not seem to have been independently validated or standardised (Cutress & Muncer, 2014; McAleese et al., 2014) or, in one instance, clearly identified (Preece, 2014), which, potentially, limits the reliability of the findings, as there

was no independent evidence to demonstrate that the measures themselves were reliable and capable of producing valid and unbiassed results. In Pillay et al.'s (2011) study, two of the questionnaires had been developed by two of the participating researchers, which potentially might have introduced researcher bias.

Standardisation and validity was not the only limitation relating to the measures used, as several studies did not have a follow-up measure at a point in time some months after the end of the intervention, so there was no evidence of any continuing impact beyond the end of the intervention (Lindsay et al., 2011; Pillay et al., 2011; Schultz et al., 2012). In Radley et al.'s (2014) study, although a follow up measure was obtained, this was only two weeks after the end of the intervention, and therefore the longevity of the impacts identified could not be confirmed over the longer term.

It was also interesting to note that there was a substantial drop-out of participants from the study sample in some of the studies examined. In the study by Lindsay et al. (2011), even though it started with a large sample, only about half the original participants completed the post-course questionnaire, reported by the authors as being due to socio-economic disadvantage and other difficulties. A high drop-out rate could reduce the generalisability of the findings. A relatively high number of parents dropped-out between the end of the programme and the follow-up session in studies by Preece (2014) and Stuttard et al. (2014), which did not allow a comparison to be made between the intervention group and the control group beyond the end of the intervention in some areas of the study.

Drop-out is an extremely difficult factor to manage in studies of parent intervention programmes, where participants in both intervention and control groups are self-selecting volunteers. Those who drop-out may be those who are struggling the most, or those who have busy and potentially stressful lives, which might affect either, or both, of their ability or willingness to continue to participate. Conversely, those who feel the need for further support might continue to participate in the study, thereby potentially understating the results, as such participants are

potentially likely to score their perspectives lower than others who might feel less in need of support. Significant drop-out post intervention will affect the potential validity of the impact of the intervention over the longer term, as the sample size will have decreased.

The current study has specifically addressed a number of these limitations and challenges through the use of independently validated and standardised measures, the inclusion of a control group, and the inclusion of a follow-up measure a significant period (12 weeks) after the end of the intervention. However, as the current study was a small-scale study carried out in one LA, the issue of a small sample size and therefore the creation of a truly representative sample could not be addressed. The drop-out rate could also not be easily managed where participants are all volunteers, as was the case in this current study.

The current study provided evidence, not just for the EPS in which this study was conducted, but for other services, of the benefits of parent interventions to both the parents and their child and, more specifically, the effect that the parents' self-efficacy and wellbeing has on the child long term. It also filled a gap in research by examining the impact that parent interventions have on the three areas of focus and to explore in a single study the associations that there might be between them, such as, does a positive feeling of self-efficacy or wellbeing link to a positive view of their child's behaviour, or even an improvement in that behaviour?

2.5 Research Aims

This study aimed to explore the impact that the Cygnet intervention had had on three areas (perceived parental self-efficacy, wellbeing and child behaviour), which had not previously been investigated in a single study.

2.5.1 Research hypothesis

My hypothesis is that: when parents are provided with background information and skills/ strategies to support them in understanding and managing their children's behaviours resulting in improvements in perceived self-efficacy and wellbeing. If the parents' self-efficacy and wellbeing improve, there may well be associated benefits to the child. The parents may observe, or just perceive, that their child's behaviour has improved, i.e. that their child's behaviour has become less challenging, either through fewer occurrences of challenging behaviour, or it is less intense, as they now have the knowledge and strategies to help them understand and manage their child.

2.5.2 Research questions

- Does the Cygnet intervention have an impact on the parents' perceived self-efficacy to manage their child's behaviour, and in what way?
- Does attendance on the Cygnet intervention have an impact on the parents' perceived wellbeing, and in what way?
- Do the parents' views of their child's challenging behaviour change post attendance on the intervention?
- Are there any correlations between perceived self-efficacy, wellbeing and child behaviour?

2.6 Epistemological Perspective

The focus of the research questions and, ultimately, the research design was stimulated by the researcher's interests in an exploration of individual's interpretation of their experiences, in this instance, their perceived views of the impact of attending this parent intervention.

Taking this into consideration, this study followed a pragmatic approach as the research questions explored the relationships between their responses and the intervention. This enabled the researcher to move between methods to explore the research questions in greater detail. The pragmatic paradigm enabled the researcher to conduct the study using a variety of methods to answer the research questions.

Johnson and Onwuegbuzie (2004) identified some other characteristics of pragmatism which stated that, as individuals throughout their daily lives interacted with their environments, truth and meaning are constantly changing over time, and individuals are constantly adapting to new situations and different environments.

The philosophical stance of pragmatism, with its view of exploring a middle ground of inquiry is an attempt to seek a solution which could be workable for many, whilst also providing a way of responding to the research questions in the most effective manner.

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Chapter 3: Methodology

3.1 Research Design

This study of the Cygnet parent intervention programme followed a pragmatic paradigm and a mixed methods approach was used to acquire the data. The focus of this study was on the participants' perceptions of the impact that the programme had on their self-efficacy, wellbeing and, ultimately, the benefits to their children. It explored the impact that the intervention had on groups of parents, to identify if there were any shared perceived experiences between them.

The research design used the mixed methods approach to collect both quantitative and qualitative data at various points throughout the study, therefore it was able to benefit from the strengths of both approaches. The main rationale for adopting a mixed methods design was that, by using both qualitative and quantitative methods, it was hoped that a broader and richer range of information would be obtained.

Feilzer (2009), in a review of the implications of carrying out mixed methods research using pragmatism as the research paradigm, commented that the pragmatic approach allowed for a variety of methods to be used to explore the range of questions that are raised. Therefore, pragmatism frees-up the researcher to explore multiple lines of enquiry, some of which may be unexpected, through the most appropriate method. Most of the studies examined in the literature review had used a quantitative design to collect the data. As this study was adopting a fieldwork approach in that the quantitative data was being collected in the sessions, it seemed appropriate to acquire a broader holistic picture of the parents' views from qualitative data obtained through an interview. In this way, the participants would be given the opportunity to provide further detail and explanation to their answers (Brannen, 2005).

Brannen (2005), in her paper on using qualitative and quantitative approaches in research, discussed the various phases of the research including interpretation and contextualisation of the findings, particularly in qualitative analysis, which

were not often commented on. As the context played a significant part in the participants' views, not just from the context of where the programme was being delivered, but the context of their lives before they arrive at the programme, i.e. how was their wellbeing on that particular day, contextualisation seemed particularly relevant to the current study.

The use of qualitative and quantitative approaches facilitated an approach which enabled data to be collected from a range of questions which could still be scrutinised and interpreted whilst taking into consideration the context of the participants who had provided the original data (Brannen, 2005).

Tashakkori and Teddlie (2003) identified two categories of research which used both quantitative and qualitative data, which either used a mixed methods or mixed model. The mixed methods design seemed to fit better with this study, as the data was collected throughout the intervention and then integrated at the final stage of the analysis.

A mixed methods design also enabled the data to be triangulated and to provide supporting information for the findings collected. In this way the quantitative data was complemented by qualitative data providing a richer and deeper understanding to the final analysis. In addition, the research questions could be explored from different perspectives.

The quantitative data captured the parents' perceived self-efficacy and wellbeing and if there were any perceived changes in their child's behaviour following the parent attending the programme. The quantitative data was compared with qualitative data collected from a sample of the parents. Using this design, the qualitative data was able to explore in greater depth why (if relevant) the participants felt there had been changes to their perceived self-efficacy and wellbeing, and what impact this had, if any, on their child's behaviour. It therefore provided a richer and broader understanding to the numerical data collected from the questionnaires.

As one method, i.e. quantitative, complemented the other (qualitative), it has been argued that the mixed methods design is now being more widely used in educational studies (Howe, 2003). It is even more valuable where the context is likely to be more complex (Mertens, 2014) such as in this study. Further areas for future studies and/ or issues that would need to be addressed through the programme delivery were also revealed through a broader and more extensive approach.

3.2 Ethics

Care was taken to ensure that the study adhered to the ethical requirements of the British Psychological Society's Code of Ethics and Conduct (2009). An Application for Ethical Approval (Appendix B) was prepared which, after review and amendment, was submitted for ethical approval from the UCL Institute of Education Ethics Committee, which was granted in November 2016. The study focused on working with adults in environments which had been deemed to have passed the appropriate standards for health and safety for the Cygnet Programme to take place in that building. All the parents had agreed to take part in the intervention programme, which focused on a topic that could raise sensitive issues which could be attributed to their child.

All the participants were volunteers and were informed that they could withdraw at any time during the study. The questionnaires used had been previously validated, thus eliminating any ambiguities and over personalising the responses was avoided, as the participants were asked to respond to the question using a Likert scale. At the beginning of the interview the researcher reminded the participants that they could ask for clarification of any question. Where the researcher asked for more specific details in the answer the participant was reminded that they only need to provide specific details if they wanted to. There was also a pause half way through the interview where the researcher asked if the interviewee were happy to continue with the interview.

3.2.1 Consent

All participants completed a consent form prior to taking part in the study and those parents who agreed to be interviewed completed an additional consent form covering the interview. Participants were reminded at each contact point of their right to request to be withdrawn from the project.

3.3 Participants

The Educational Psychology Service (EPS) in the LA was initially approached to gain an understanding of their willingness for a further study on the Cygnet Programme to be carried out to identify in greater depth the benefits of this programme to parents of children with autism. Once agreement from the EPS had been obtained, a meeting was held with the University and Research Tutors to discuss a proposed research design of the study.

Alongside this process, the LA Autism Outreach Centre was contacted to identify where and when Cygnet Programmes were running in each of the LA quadrants and to provide access to parents of children with autism who had not attended the programme to form the Control Group. As the programme had just started in one of the quadrants that cohort was used as a pilot study for the questionnaires.

The participants were recruited from the seven groups of parents who attended the Cygnet Programme in the LA between September 2016 and March 2018. The size of the sample was determined by the number of parents attending the programmes run in the LA which totalled 35, of whom 24 were willing to participate. All the participants in the intervention group had one child, aged between 5 and 8 years who had been diagnosed with autism, apart from two participants whose children were in the age range 11-13 years.

The sample of parents (n = 6) who were willing to participate in the semi-structured interview were all female. They were recruited from the parents who had completed a full set of questionnaires at all three time points from the seven Cygnet programmes run in the period of the study.

The Control Group was recruited from parents on the waiting list to attend the Cygnet programme who had indicated that they were not receiving, or had not received, any other kind of structured support to help them with their child's autism. In total, 16 parents participated in the Control Group.

3.4 Materials

3.4.1 Cygnet Parent Intervention Programme

The Cygnet Programme was based on the Family Partnership Model (Davis & Day, 2010), which advocated working collaboratively with both parents and professionals to develop the parents' self-efficacy and support them in identifying strategies which are appropriate for their child. The Cygnet programme was run over six, weekly sessions of three hours duration and, in this LA, it was run twice yearly in each of the four quadrants of the authority. The programme was delivered by two EPs presenting together.

The Cygnet programme initially provides general information about autism and diagnosis. In later sessions other topics such as communication, sensory issues and understanding and managing behaviour are covered. Further details of the content of the Cygnet sessions are provided in Appendix C. A voluntary, informal session was also held 12 weeks after the completion of the programme to review the parents' current situation.

The sessions included formal teaching using PowerPoint slides, video clips and group activities and less formal discussions. Each parent received a set of session notes to take away and was encouraged to complete an activity related to the latest session before the next session, to help embed the session's learning. The parents were asked to complete an evaluation form at the end of each session.

Table 1 below is an example of the content of one of the Cygnet programme sessions:

Session 2: Communication			
Topics:	Number of slides	Time	Delivery format (i.e., in addition to discussion, this section includes):
Welcome	2	10 min	
Understanding communication	2	20 min	• "What-How-Why" Activity
Building blocks of communication	3	20 min	• "The Messages Children Send" Activity • Video clip
What is different in ASCs	2	10 min	
Understanding communication	5	15 min	• "Language Too Complex" Activity
Using communication	7	15 min	• Video clip
Break	1	15 min	
Strategies & resources	12	60 min	• "The Importance of Visual Supports" Activity • 2 Video clips
Thank you and completion of evaluation forms	1	15 min	• Evaluation forms

Table 1: Example of the content of a Cygnet programme session

3.4.2 Questionnaires

The questionnaires used in the study are described below. The focus of the three questionnaires were to gain an understanding of the parents' perceived competency scale, wellbeing and child behaviour. The questionnaires consisted of Likert scales which used words ranging from 'strongly agree' to 'strongly disagree' or 'none of the time' to 'all of the time'. A copy of each of the questionnaires is provided in Appendices D-F The questionnaires used in the study are described in further detail below and examples are given of the types of questions that were asked.

3.4.2.1 The Parenting Sense of Competency Scale (PSOC) (Gibaud-Wallston & Wandersman, 1978; Johnston & Mash, 1989).

The PSOC consists of 16 items including two subscales. The first is the parenting satisfaction subscale (PSOC-Satisfaction), which measures how satisfied parents are with their parenting role. The second is a parenting efficacy subscale (PSOC-Efficacy), which measures how parents perceive they are managing their role as a parent for example. The Satisfaction subscale also reflects parental frustration, anxiety and motivation, and the Efficacy subscale reflects their competence, problem solving ability and capability in the role as a parent (Plant & Sanders, 2007).

Parents were asked to endorse statements such as: 'Being a good parent is manageable, and any problems are easily solved.' A 6-point Likert scale was used to measure the individual's agreement with each item (1 = strongly agree to 6 = strongly disagree). Seven of the 16 statements are coded in reverse (and so the scoring of these is also reversed), so that a disagreement with the statement represents increased parenting confidence. The sum of the scores given for each question provides the total score for the questionnaire, with separate sub-totals calculated for the statements relating to Efficacy and Satisfaction. The minimum scale total score is therefore 16 and the maximum is 96.

The scale has been psychometrically tested (Ohan, Leung, & Johnston, 2000). Ohan et al. confirmed the factor structure, assessed the scale's validity, and found that the questionnaire had acceptable internal reliability - Cronbach's alphas for the study sample were $r = 0.78$ (Satisfaction Scale) and $r = 0.80$ (Efficacy Scale).

This questionnaire had been used in a range of parent intervention programmes, including the DFE (2012) study mentioned previously, so it was not only relevant because of this, but it had proven validity and reliability.

3.4.2.2 The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) (Stewart-Brown & Janmohamed, 2008)

The Warwick-Edinburgh Mental Well-being Scale was funded by the Scottish Government National Programme for Improving Mental Health and Well-being,

commissioned by NHS Health Scotland, developed by the University of Warwick and the University of Edinburgh, and is jointly owned by NHS Health Scotland, the University of Warwick and the University of Edinburgh.

This questionnaire had UK validation in 2008 for those aged 16 and above (Stewart-Brown & Janmohamed, 2008). WEMWBS is a 14-item scale of mental wellbeing, covering subjective wellbeing and psychological functioning, which include optimistic feelings, happiness, relaxation and self-acceptance, for example, 'I've been feeling optimistic about the future.'

The responses to each item are answered on a 1 to 5 Likert scale (1 = none of the time to 5 = all of the time), The sum of the scores given for each question provides the total score for the questionnaire. The minimum scale score is therefore 14 and the maximum is 70.

The construct validity was found to be moderately high in comparison with other wellbeing scales, and the high coefficient of Cronbach's alpha r = 0.89, suggested that there was a good level of internal consistency. The test-retest reliability score was also high, with scores for individuals stable over a one-week period.

3.4.2.3 The Child's Challenging Behaviour Scale (CCBS) (Bourke-Taylor, Law, Howie & Pallant, 2010)

The Child's Challenging Behaviour Scale (CCBS) was first used in a study to measure mothers' reports of challenging behaviours shown by their child with disabilities that could compromise maternal mental health and difficulties with care-giving.

The CCBS is an 11-item set of statements answered on a 1 to 4 Likert scale (1 = strongly agree to strongly disagree). The sum of the scores given for each question provides the total score for the questionnaire. The minimum scale score is therefore 11 and the maximum is 44. An example statement is: 'My child never has tantrums.'

The CCBS has a high internal consistency (Cronbach's alpha = 0.89) and its uni-dimensionality was supported by factor analysis. Correlations with the Pediatric

Quality of Life Inventory (PedsQL) Psychological Psychosocial Health Summary Score (rho = - 0.51) supported construct validity. (PedsQL is a modular approach to measuring health-related quality of life (HRQOL) in healthy children and adolescents and those with acute and chronic health conditions.) The CCBS scores were significantly different between those groups of children with, and those without, either autism or psychiatric conditions.

This questionnaire had been used in the DFE (2012) study. This questionnaire seemed to be an appropriate one to be used in the current study to explore similarities or differences in the findings.

3.4.3 Semi-structured Interviews

The questionnaires were followed up with a semi-structured interview with a sample (n = 6) of the participants, three months after completion of the programme. The interview questions were based on an analysis of the interviewees' responses to the questionnaires. An example question is: 'How did you feel the programme affected your overall sense of self-efficacy in being able to manage your child and why?'

A pilot study of the interview questions was carried out with two participants to check their reliability and the appropriateness of the wording of the questions. As only minor changes were required to provide additional clarity to the meaning of the questions, these interviews were included into the final analysis of the qualitative data.

The semi-structured interview explored in greater depth the participants' views of the effect that the intervention had had on their self-efficacy and wellbeing and explored further why they thought this was so. They were also asked if, and to what extent, the programme had had an impact on their child's behaviour.

The semi-structured interview lasted 20-30 minutes and consisted of six to nine questions and had some specified prompts. The interviews were held either on the telephone, or in a location that was convenient and appropriate for both

parties, with the proviso that it needed to be private and fairly quiet for recording and confidentiality reasons.

A copy of the question prompts is provided in Appendix G. The questions ranged from exploring if they felt more confident in supporting their child post intervention to, more specifically, asking what had contributed to an improved/ decreased score in the final questionnaire. The questions were open-ended to allow the participant to respond freely, whilst also providing the interviewer with opportunities to ask further questions as appropriate (Willig, 2008).

3.5 Procedure

The study utilised three short questionnaires, each taking less than ten minutes to complete, which the participants in the Intervention Group were asked to complete pre- and post- the intervention, and again twelve weeks later (follow-up session).

At the start of each programme the EPs provided all parent attendees with a background information sheet (Appendix H) on the research study which also stressed that anonymity would be maintained at all times, and that, even if they participated initially, they could withdraw at any time during the study. Those parents who agreed to participate in the study were asked to complete the consent form (Appendix I) and the three questionnaires at the start of the first Cygnet session. These were collected and returned to the researcher.

The participants were then asked to complete the same set of questionnaires at the end of the six-week programme, and again at the 12-week follow-up session. At this session the participants were asked if they would be willing to participate in the semi-structured interview. A further consent form (Appendix J), specific to the interview, was completed by those willing to participate. Arrangements were then made for the location, date and time of the interview to take place, which was at their convenience. They were also offered the option of a telephone interview.

The semi-structured interviews, apart from one which took place at the participant's home, were carried out via telephone. The interviews were recorded using a digital audio recorder to ensure that there was a reliable and semi-permanent record of the data. A back-up voice recorder was also made on a mobile phone. The data was immediately transferred to a secure laptop and the other data was deleted. As previously mentioned no names were used during the recordings.

An email (Appendix K) was sent out by the Cygnet programme organiser in March 2016 and October 2017 to parents on the waiting list, asking them to email the researcher if they would like to participate in the study and be part of the Control Group. The only criteria that was stipulated was they had not attended an intervention similar to the Cygnet programme nor were they receiving any other form of structured support for their child.

When they had signed the Consent Form the parents in the Control Group followed a similar procedure to the Intervention Group, by firstly completing the three questionnaires at a baseline date, and then again at 6 and 18 weeks later, which replicated the time-frame between the start of the Cygnet programme and the 12-week post-programme follow-up session.

A de-brief sheet (Appendix L) was given to all participants (both in the Intervention Group and the Control Group) at the end of their participation in the study. They were provided with the opportunity to ask any questions, either at that time, or at a later date, if they wanted to. The participants were also reminded of their ability to withdraw from the study up to fourteen days from the date of the interview and thanked again for their participation in the study, and this was followed up by a thank you email or letter.

After initial analysis of the data from the Control Group, it was decided to ask for further information from the participants who had completed three sets of questionnaires to ascertain whether they had received any form of support to help them manage their child during the period of the study. (A copy of the email sent

to the parents can be seen in Appendix N.) The email was sent to 12 participants, 11 of whom responded.

Confidentiality was maintained throughout the study as each questionnaire was coded with the participants' unique identifier and there were no names mentioned at the beginning of each tape apart from the participant's unique identifier for transcription purposes.

3.6 Data Analysis

3.6.1 Quantitative Data Analysis

The quantitative data obtained via the questionnaires was analysed using the Statistical Package for the Social Sciences (SPSS v25: IBM) to look for correlations between data sets and statistically significant differences within data sets. The data was analysed to compare the participants' views of their competency, wellbeing and child's behaviours pre, post and 12 weeks after the intervention, to identify any changes in their views that had occurred, and the results from the control group were compared to those from programme participants.

An analysis was made of the further information obtained from the Control Group to identify any potential link between additional support that they might have received and the data that had been collected via the questionnaires.

3.6.2 Qualitative Data Analysis

At participant level, the quantitative data was used to inform the semi-structured interviews of a sample of participants to obtain qualitative data. This was particularly important as some of the interview questions were linked to the responses given by individual participants, for example, 'You have indicated via the questionnaires completed that your perception of your (competency, wellbeing, child's behaviour) has changed (in some way) – why do you think this is so? This was done at whole questionnaire level, subscale level, or individual question level, depending on the recorded changes, either positive or negative, in each individual participant's answers.

An analysis was made of the qualitative data obtained in the interviews, which explored the reasons why the participant felt that changes had/ had not occurred in the three areas of parental competence, wellbeing and child's behaviour, over the period from the start of the programme. Data from the semi-structured interviews was analysed thematically and comparisons and links were made to the results obtained from the quantitative data.

The data collected from the semi-structured interviews was analysed using thematic analysis, which was informed by a pragmatic epistemology. Whilst recognising there are some potential disadvantages to thematic analysis, in that the data analysis can be interpreted too broadly and focused on being just descriptive, which may have limited value in providing insight to the study. Another potential disadvantage was that it was more difficult to maintain continuity and consistency throughout an individual's dialogue (Braun & Clarke (2006). Braun and Clarke commented that the advantages of using thematic analysis were that it can be used to summarise key points from data. It can also be used for the interpretation of data from both a psychological and social perspective and, in addition, can provide unexpected observations and, as a result, the authors commented that the advantages of acquiring a richer set of data from a more flexible approach seemed to outweigh the disadvantages.

Initially, a verbatim transcript was made of all the audio recordings. Each of the transcripts was read several times, and a detailed analysis was made using the procedure set out by Braun and Clarke (2006). This procedure comprised familiarisation with the data and identification and generation of initial codes. This was followed by collation of the codes into possible themes which were then reviewed to confirm that they 'worked' within the transcripts. When the themes had been identified the transcript data was coded into sub-themes, which were either individual words, or phrases with similar meanings, that were used in multiple transcripts. The next phase comprised a collation of quotes from the transcripts, which were analysed to ensure that they provided supporting evidence to capture the key focus of the main themes.

Further reviews of the extracts connected to the main themes and quantitative data collected from the questionnaires were made to ensure that there was a consistent and interactive link between the themes, extracts and quantitative data. Before further refinement was made of the themes, they were reviewed and discussed with a colleague and a Senior Educational Psychologist in the LA to ensure that impartiality was maintained, and the possibility of researcher bias was reduced (Boyatzis, 1998). A final analysis was performed, and the themes were named prior to the report being written up. An example extract of a transcript featuring codes and subthemes can be seen in Appendix M.

3.6.3 Qualitative/ quantitative comparison for interviewees

An additional analysis was conducted to compare the quantitative and qualitative data provided by the interviewees, to identify any inconsistencies and obtain a greater understanding of their thinking at the time they completed the questionnaires and at the time of the interview.

Chapter 4: Results

4.1 Introduction

This current study aimed to explore parents' perceptions of changes in their self-efficacy (competence), wellbeing and their child's behaviour post attendance on a parent intervention programme for parents of a child with autism. A mixed methods research design was used to acquire a richer data set as most of the studies examined in the literature review only collected quantitative data.

The current study aimed to address a deficit of research on parent intervention programmes for parents of children with autism (Karst et al., 2015). The study also explored perceived parental wellbeing as suggested by Stuttard et al. (2016) and as the literature review revealed there had been little discussion within a single study of parental self-efficacy, wellbeing and child behaviour together.

4.2 Quantitative Data

As described in the Methodology, the study obtained quantitative data from two groups:

- An Intervention Group comprising 24 parents attending the Cygnet intervention.
- A Control Group of 16 parents with children diagnosed with autism who were on the waiting list to attend the Cygnet intervention and were also not receiving any structured support to help them with their child.

All participants completed the questionnaires at Time 1 (week 0, the start of the intervention) and Time 2 (week 6, the end of intervention), however eight participants from the Intervention Group, and four from the Control Group did not complete the third set of questionnaires at Time 3 (18 weeks/ 12 weeks post intervention).

The analysis below examined the scores for each measure in each group across each time point. The intervention period (pre-post) and maintenance phase (post-

follow up) are considered separately, before considering the overall changes across the study period.

4.2.1 Perceived Competency

4.2.1.1 Change in scores: Intervention Period

To determine whether the intervention had an impact on the perceived competency scores during the intervention period, a mixed ANOVA was performed with time points (T1: pre-intervention, T2: post-intervention) as within-subject factor and group (Intervention and Control) as a between-subject factor. The ANOVA revealed a significant main effect of time ($F_{(1, 38)} = 4.203$, $p = .047$), but not of group ($F_{(1,38)} = 1.857$, $p = .181$). There was also no significant interaction between group and time ($F_{(1, 38)} = .991$, $p = .326$). Mean perceived Competency scores and Standard Error for each group at each time point can be seen in Figure 1.
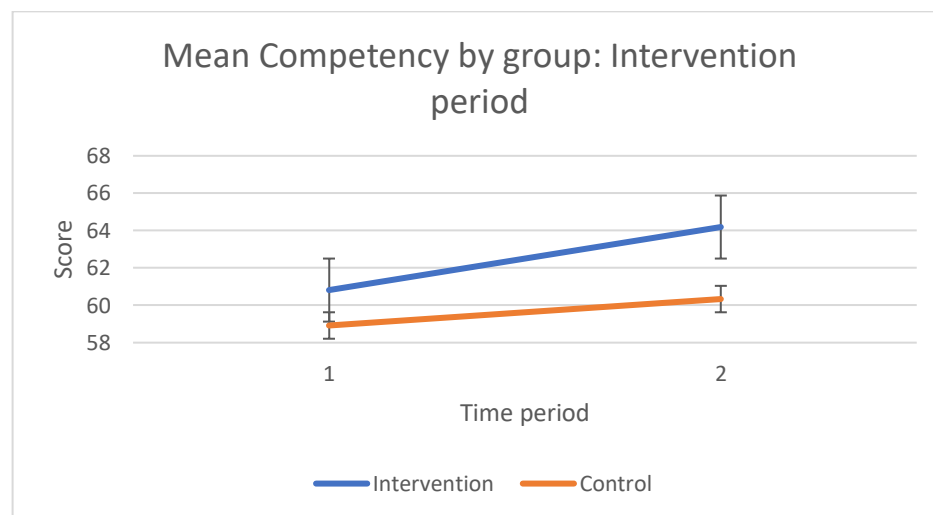
Figure 1: Mean Perceived Competency for each Group at start and end of intervention

4.2.1.2 Change in scores: Maintenance Period

This was followed with an analysis of the period between the end of the intervention and the 12-week follow-up. A mixed ANOVA was carried out on the competency scores with time point (T2: post-intervention, T3: 12-week review) as within-subject factor and group (Intervention and Control) as a between-subject factor. The ANOVA revealed no effect of time ($F_{(1, 26)} = 2.127$, $p = .157$), nor of

group (F (1,26) = .722, p = .403). There was also no significant interaction between group and time (F (1, 26) = .226, p = .638). Mean perceived Competency scores and Standard Error for each group at each time point can be seen in Figure 2.
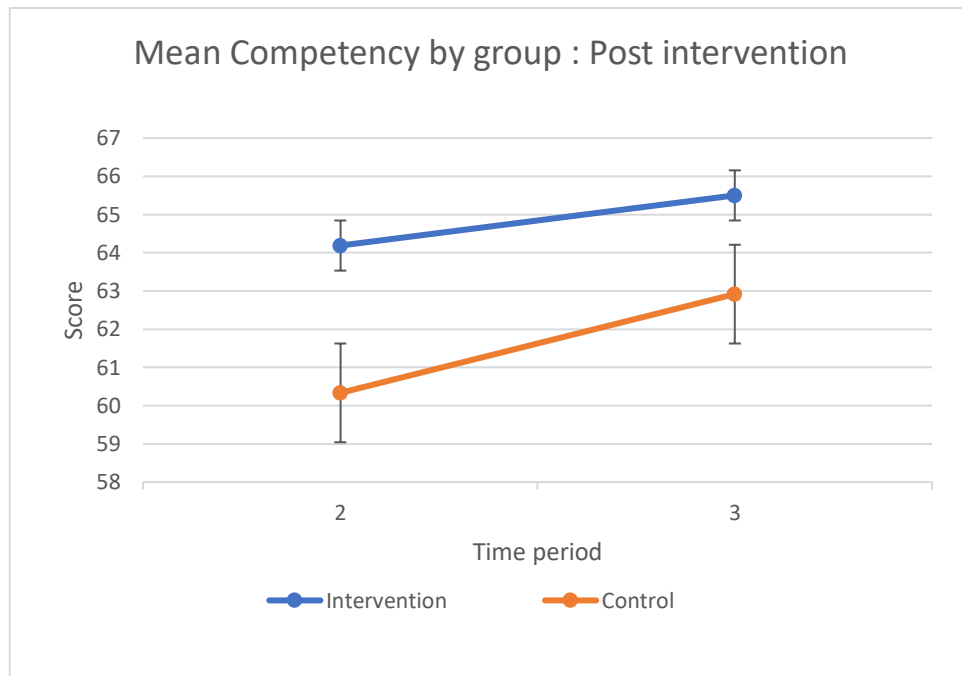
Figure 2: Mean Perceived Competency for each Group from end of intervention to 12-week follow-up

4.2.1.3 Change in scores: Entire Study Period

A further mixed ANOVA was then conducted to examine the competency scores across the whole study period, with time point (T1: pre-intervention, T2: post-intervention, T3: 12-week review) as within-subject factor and group (Intervention and Control) as a between-subject factor.

The ANOVA revealed a significant main effect of time (F (1, 26) = 9.170, p < .01), but not of group (F (1,26) = .586, p = .451). There was also no significant interaction between group and time (F (1, 26) = .057, p = .812). Mean perceived Competency scores and Standard Error for each group at each time point can be seen in Figure 3.

Counter-intuitively, repeated measures ANOVA's for each group separately indicated that there was a main effect of time for the Control Group but not the

Intervention Group (though the result for the Intervention Group was approaching significance at the .05 level). For the Intervention Group the ANOVA revealed no significant main effect of time (F (1, 15) = 3.991, p = .064. For the Control Group the ANOVA revealed a significant main effect of time (F (1, 11) = 14.466, p < .01).

Paired t-tests revealed that the change in the Control Group was driven by a significant increase from T1-T3, pre-intervention to follow-up (t (11) = -3.803, p < 0.01), however, no changes in scores during the intervention or maintenance phases separately were significant.

An improvement in Intervention Group scores over time had been anticipated however, the improvement in Control Group scores was not expected at the start of the study. The possible reasons for the change in Control Group means was examined in the Additional data collection and analysis 4.2.5 below.
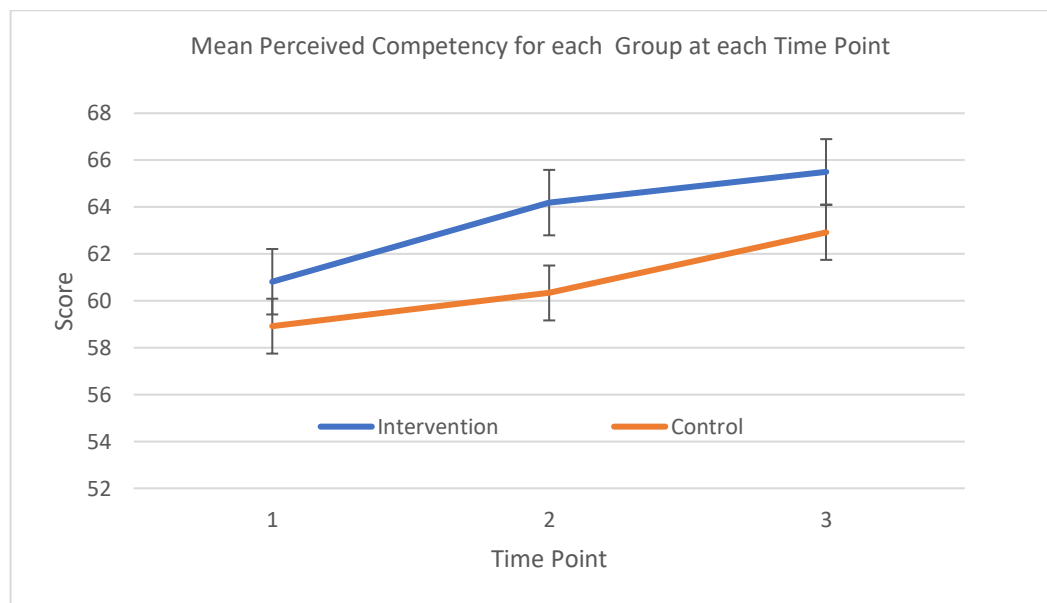

Figure 3: Mean Perceived Competency for each Group at each Time Point

Data: those respondents completing questionnaires at all three time points (Intervention Group n = 16, Control Group n = 12).

4.2.1.4 Change in subscale scores

Given that the competency measure comprised two subscales, repeated measures ANOVAs were run for the Efficacy and Satisfaction scales separately.

For Efficacy scores, a repeated measures ANOVA revealed a significant main effect of time ($F_{(1, 26)}$ = 8.942, p < .01), but not of group ($F_{(1,26)}$ = .503, p = .485). There was also no significant interaction between group and time ($F_{(1, 26)}$ = .080, p = .780).

Repeated measures ANOVAs, for each time period separately, again revealed that significant changes were seen only in the intervention period. There was a significant main effect of time pre-post intervention (T1-T2) ($F_{(1, 38)}$ = 6.195, p = .017)), and a significant interaction between group and time ($F_{(1, 38)}$ = 4.253, p = .046). There was no main effect of group ($F_{(1,38)}$ = 3.400, p = .073). For the follow-up period, there was no significant main effect of time ($F_{(1, 26)}$ = 1.040, p = .317), nor of group ($F_{(1,26)}$ = .652, p = .427), and no significant interaction between group and time ($F_{(1, 26)}$ = 1.719, p = .201).

T-tests demonstrated that the significant main effect and interaction were driven by an increase in Efficacy scores in the Intervention Group during the intervention period (t(23) = -3.04, p < 0.01), without an accompanying change in the Control Group (t(15) = -.45, p = .66).

For Satisfaction, the ANOVA revealed a significant main effect of time ($F_{(1, 26)}$ = 4.955, p = .035), but not of group ($F_{(1,26)}$ = .454, p = .506). There was also no significant interaction between group and time ($F_{(1, 26)}$ = .331, p = .570). ANOVAs for each time period separately did not reveal any significant main effects or interactions (all p values > .2), suggesting that any change was marginal and did not reach significance within the smaller, underpowered, groups.

As such, it appears to be the Intervention Group's change in Efficacy during the intervention period that is driving the main effect of time over the study period.

4.2.1.5 Range of Competency scores

Perceived Competency scores at the start of the intervention for the Intervention Group ranged from 39 - 74. (The lowest possible score for each participant for all 16 questions is 16.) This group had a mean perceived Competency score of 59.75, and a median score of 58.5. Perceived Competency scores for the Control Group at Time 0 ranged from 35 – 77, with a mean of 56.75 and a median of 56.5.

An independent samples t-test was conducted to identify if there were a significant difference in the means for perceived competency between the Intervention and Control Groups at Time 1. The difference was not statistically significant, $t(38)=.872$, p=.389.

Perceived Competency scores for the Intervention Group, at the end of the intervention ranged from 52 – 74 with a mean of 63.54 and a median of 64.0. Perceived Competency scores in the Control Group (Time 2) ranged from 36 – 83, with a mean of 58.06 and a median of 58.5. There was no significant difference in the means for perceived competency between the Intervention and Control Groups at Time 2 ($t(38)=1.682$, p=.101).

Perceived Competency scores 12 weeks later (Time 3), for the Intervention Group range from 47 – 80, with a mean of 65.5 and a median of 66.5. Perceived Competency scores for the Control Group range from 41 – 77 with a mean of 62.92 and a median of 65.0. A further independent samples t-test showed no statistically significant difference in the means between the groups, $t(26)=.621$, p=.540.

The Means were calculated on all responses received at each time point and includes data for those participants who only responded at Time Points 1 and 2, so differs from the results shown in Figure 1 above, which only reflects data from participants who completed questionnaires at all three time points.

4.2.2 Perceived Wellbeing

4.2.2.1 Changes in scores

To determine whether the intervention had an impact on level of perceived wellbeing, a mixed ANOVA was performed with time (start, end, 12-week review) as within-subject factor and group (Intervention and Control) as a between-subject factor. Mean Wellbeing scores for each group at each time point can be seen in Figure 4.

The ANOVA revealed no statistically significant main effect of time ($F_{(1,26)}$ = 2.518, p = .125) or group ($F_{(1,26)}$ = .040, p = .906) on the wellbeing scores. There was also no significant interaction between group and time ($F_{(1, 26)}$ = .0, p = 1.000).
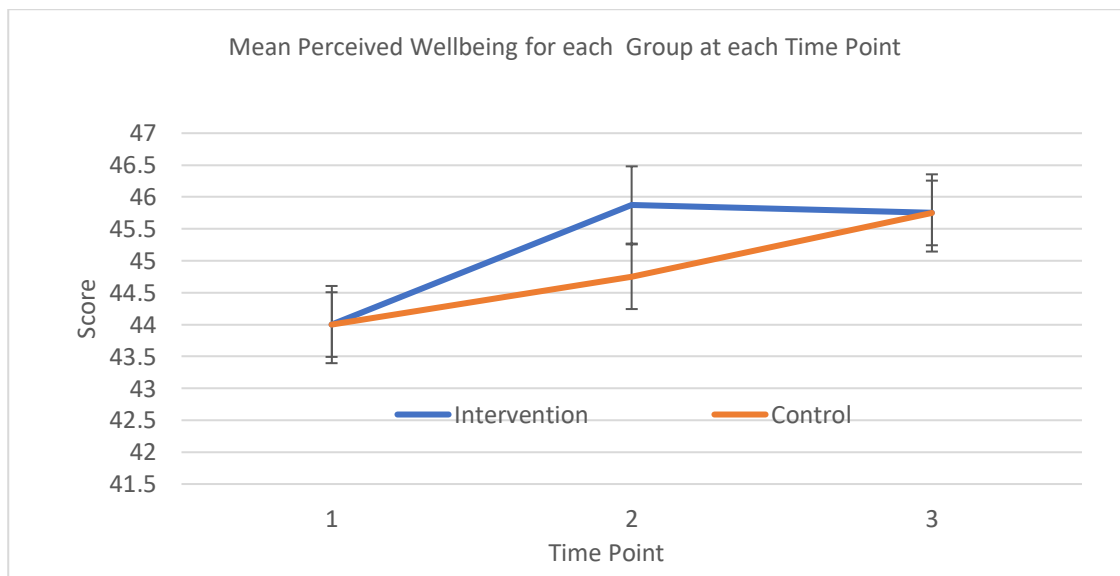
Figure 4: Mean Perceived Wellbeing for each Group at each Time Point

Data used is: those respondents completing questionnaires at all three time points (Intervention Group n = 16, Control Group n = 12).

In summary, whilst there was observationally a slight improvement in the mean Wellbeing score for the Intervention Group, there was a similar improvement in the mean Wellbeing score over the time period for the Control Group and there was no statistically significant difference over time, either within the groups, or

between the two groups. This could suggest that attendance on an intervention has no additional benefit than non-attendance.

4.2.2.2 Range of Perceived Wellbeing scores

Perceived Wellbeing scores at the start of the intervention for the Intervention Group ranged from 31 - 54. (The lowest possible score for each participant for all 14 questions is 14.) This group had a mean perceived Wellbeing score of 43.58, and a median score of 43.5. Perceived Wellbeing scores for the Control Group at Time 0 ranged from 20 – 60, with a mean of 41.75 and a median of 42.0.

An independent samples t-test was conducted to identify if there was a significant difference in the means for perceived wellbeing between the Intervention and Control Groups at Time 1. The difference was not statistically significant, $t(38)=.660$, p=0.513.

Perceived Wellbeing scores for the Intervention Group, at the end of the intervention ranged from 30 – 58 with a mean of 44.96 and a median of 45.5. Perceived Wellbeing scores in the Control Group (Time 6) ranged from 22 – 60, with a mean of 42.88 and a median of 43.0. There was no significant difference in the means for perceived competency between the Intervention and Control Groups at Time 2 ($t(38)=.717$, p=.478).

Perceived Wellbeing scores 12 weeks later, for the Intervention Group range from 28 – 58, with a mean of 45.75 and a median of 45.5. Perceived Wellbeing scores for the Control Group range from 24 – 63 with a mean of 45.75 and a median of 46.5. A further independent samples t-test showed no statistically significant difference in the means between the groups, $t(26)=.000$, p= 1.000.

The Means were calculated on all responses received at each time point and includes data for those participants who only responded at Time Points 1 and 2, so differs from the results shown in Figure 2 above, which only reflects data from participants who completed questionnaires at all three time points.

The Control Group had a wider range of scores and lower means than the Intervention Group across the first two time points, and an identical mean at the third time point. This wider range for the Control Group may be related to the self-selection of individuals wanting to take part in the Control Group for the study, as it may be that some individuals 'had something to say', either negative or positive.

4.2.3 Perceived Child Behaviour

4.2.3.1 Change in scores: Intervention Period

A mixed ANOVA was conducted to identify whether the intervention had an impact on the level of perceived Child Behaviour during the intervention period, with time points (T1: pre-intervention, T2: post-intervention) as within-subject factor and group (Intervention and Control) as a between-subject factor. The ANOVA revealed no main effect of time ($F_{(1, 38)} = 1.276$, $p = .266$), nor of group ($F_{(1,38)} = 2.181$, $p = .148$). There was also no significant interaction between group and time ($F_{(1, 38)} = .013$, $p = .909$). Mean perceived Child Behaviour scores for each group at each time point can be seen in Figure 5.
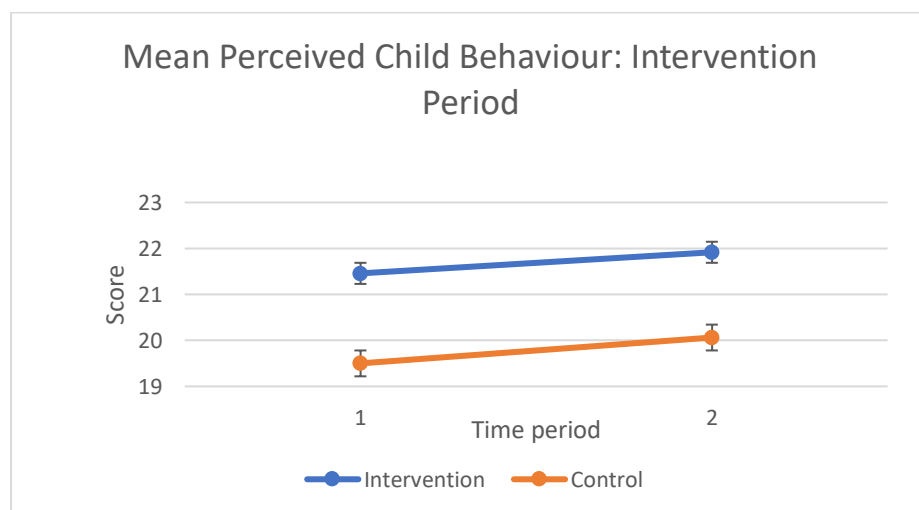

Figure 5: Mean Perceived Child Behaviour for each Group over the intervention period

4.2.3.2 Change in scores: Maintenance Period

The period between the end of the intervention and the 12-week follow-up was analysed using a mixed ANOVA with time point (T2: post-intervention, T3: 12-

week review) as within-subject factor and group (Intervention and Control) as a between-subject factor. The ANOVA revealed no effect of time (F (1, 26) = 2.584, p = .120), nor of group (F (1,26) = 2.380, p = .135). There was also no significant interaction between group and time (F (1, 26) = .000, p = 1.000). Mean perceived Child Behaviour scores for each group at each time point can be seen in Figure 6.
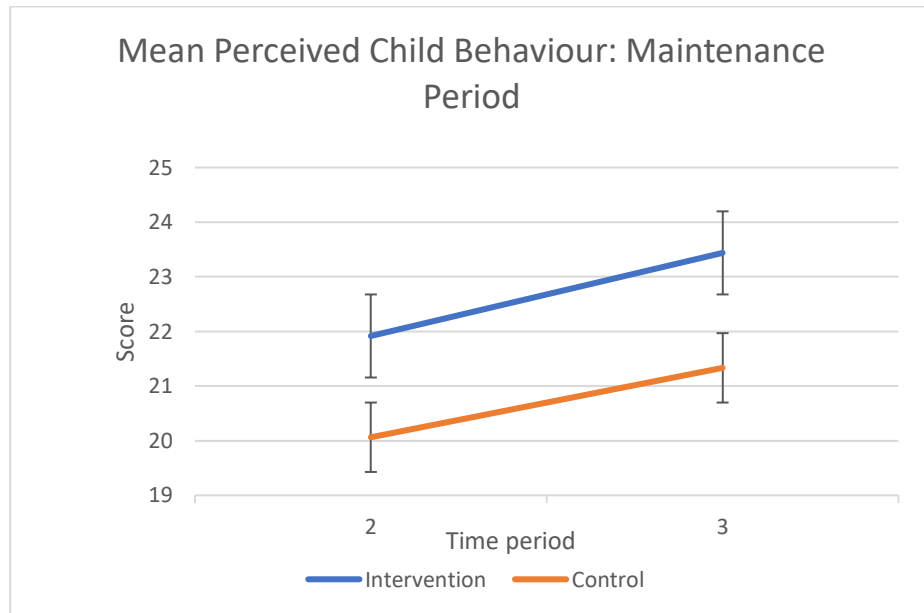
Figure 6: Mean Perceived Child Behaviour for each Group over the maintenance period

4.2.3.3 Changes in scores: Entire study period

The impact on the level of perceived Child Behaviour over the entire study period was examined using a mixed ANOVA, with time (T1: start of intervention, T2: end of intervention, T3: 12-week review) as within-subject factor and group (Intervention and Control) as a between-subject factor. Mean perceived Child Behaviour scores for each group at each time point can be seen in Figure 7.

The ANOVA revealed a marginally significant main effect of time (F (1, 26) = 4.692, p = .040), but not of group (F (1,26) = .2.795, p = .107). There was also no significant interaction between group and time (F (1, 26) = .008, p = .932). The effect of time seen in the overall results is not replicated in the results of the separate time periods.
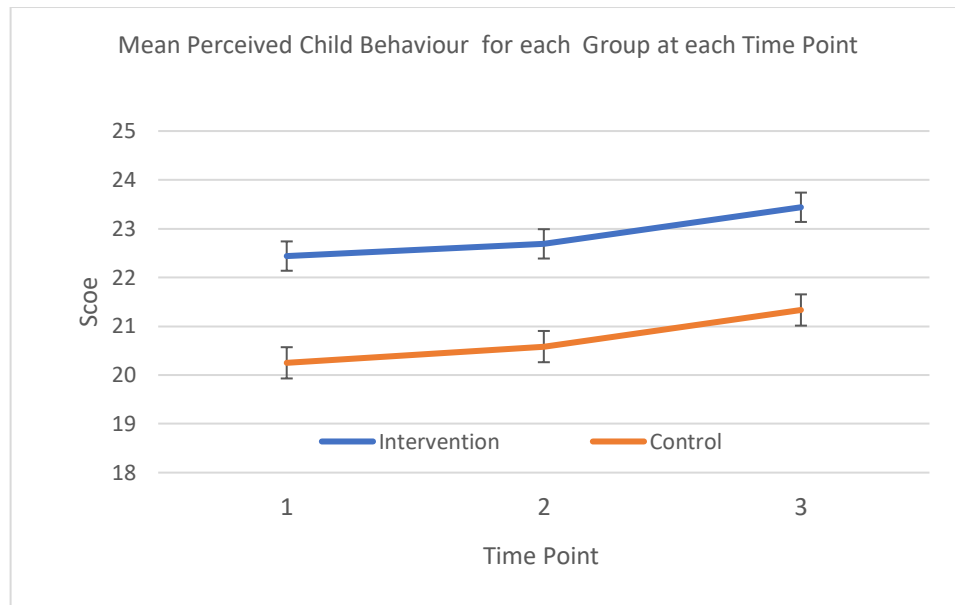
**Figure 7: Mean Perceived Child Behaviour for each Group over the entire
study period**

Data: those respondents completing questionnaires at all three time points
(Intervention Group n = 16, Control Group n = 12).

An improvement in Intervention Group scores over time was anticipated however,
the similar improvement in Control Group scores was not expected at the start of
the study. The possible reasons for the change in Control Group means was
examined in the Additional data collection and analysis 4.2.5 below.

Repeated measures ANOVA's for each group separately indicated that there was
no main effect of time for either group. For the Intervention Group the ANOVA
results were (F(1, 15) = 3.000, p = .104), and for the Control Group (F(1, 11) =
1.824, p = .204).

To further examine whether the change in means was significant within each
group, paired-sample t tests were carried out looking at the change in means
between Time 1 (start of intervention) and Time 2 (end of intervention) and Time
2 and Time 3 (12 weeks post intervention) and over the entire study T1-T3. The
detailed results are shown in Table 4 below.

Group Time Period	t	df	p
Intervention Group Child Behaviour			
T1-T2	-.701	23	.490
T2-T3	-1.007	15	.330
T1-T3	-1.732	15	.104
Control Group Child Behaviour			
T1-T2	-1.107	15	.286
T2-T3	-1.827	11	.095
T1-T3	-1.351	11	.204

Table 2: Perceived Child Behaviour paired sample t-test results

There were no significant changes in scores identified within either Group over the different time periods.

In summary, there was no statistically significant difference either within the groups or between the two group over time, though there was a significant effect of time overall for both groups data combined. However, there were no significant changes in the underlying data to suggest from where the overall effect of time derived. The small individual groups may be underpowered to detect any significant changes.

4.2.3.2 Range of Perceived Child Behaviour scores

Perceived Child Behaviour scores at the start of the intervention for the Intervention Group ranged from 14 - 29. (The lowest possible score for each participant for all 9 questions is 9.) This group had a mean perceived Child Behaviour score of 21.46, and a median score of 22.0. Perceived Child Behaviour scores for the Control Group at Time 0 ranged from 12 – 25, with a mean of 19.5 and a median of 21.50.

An independent samples t-test was conducted to identify if there was a significant difference in the means for perceived child behaviour between the Intervention

and Control Groups at Time 1. The difference was not statistically significant, $t(38)=1.488$, p=0.145.

Perceived Child Behaviour scores for the Intervention Group, at the end of the intervention ranged from 15 - 30 with a mean of 21.92 and a median of 22.5. Perceived Child Behaviour scores in the Control Group (Time 6) ranged from 12 – 26, with a mean of 20.06 and a median of 20.5. There was no significant difference in the means for perceived competency between the Intervention and Control Groups at Time 2 ($t(38)=1.308$, p=.199).

Perceived Child Behaviour scores 12 weeks later, for the Intervention Group range from 19 - 29, with a mean of 23.44 and a median of 22.5. Perceived Child Behaviour scores for the Control Group range from 13 - 28 with a mean of 21.33 and a median of 22.0. A further independent samples t-test showed no statistically significant difference in the means between the groups, $t(26)=1.599$, p=.122.

The Means were calculated on all responses received at each time point and includes data for those participants who only responded at Time Points 1 and 2, so differs from the results shown in Figure 3 above, which only reflects data from participants who completed questionnaires at all three time points.

Overall, the Intervention Group mean is consistently slightly higher than that of the Control Group, though this is not statistically significant, and the ranges are similar.

4.2.4 Correlation within groups

In addition to analysing the data within questionnaire type, further analysis was performed to test for the existence of any correlation between the change in participant scores for each questionnaire type (Competency, Wellbeing and Child Behaviour) over time, and the change in the other two questionnaire scores. This was carried out for each pair of potential relationships by group for all participants completing three sets of questionnaires.

4.2.4.1 Intervention Group

Change in scores over time: Competency – Wellbeing

Figure 8: Intervention Group: Competency - Wellbeing Change plot

A correlation was run to explore whether there was a statistically significant relationship within the data plotted above, that is, whether changes in perceived competency and perceived wellbeing for each individual appeared to be associated over time. The results show that there is a statistically significant positive correlation at the .05 level within the Intervention Group between the change in Competency and Wellbeing scores over time, r = .609, p = .012.

There would therefore appear to be a link between the perceived parental competency and wellbeing scores within the Intervention Group. This will be discussed later.

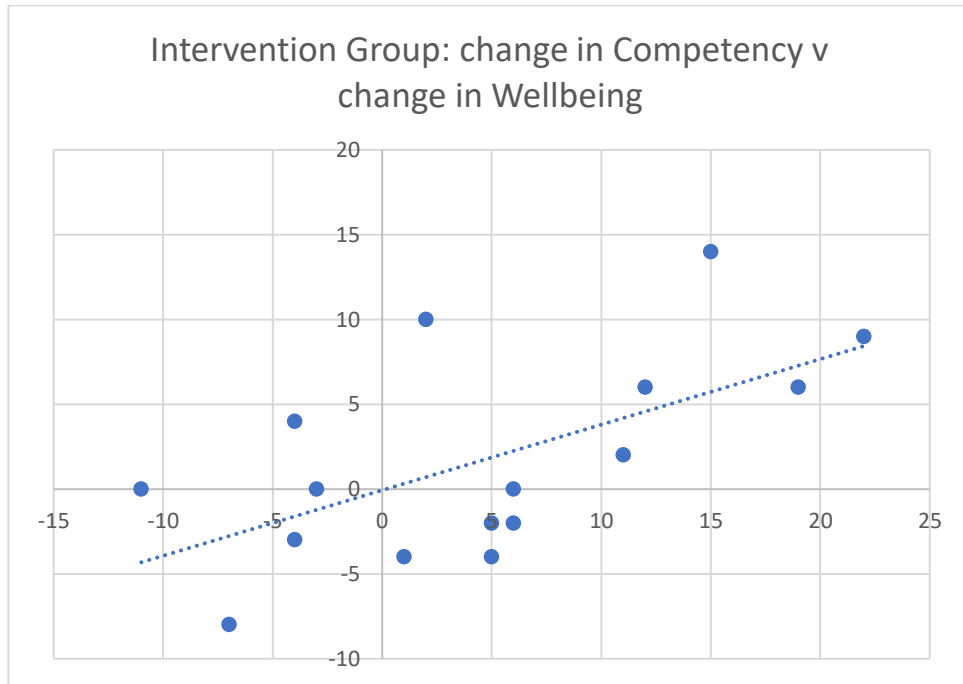*Change in scores over time: Competency – Child Behaviour*

Figure 9: Intervention Group: Competency - Child Behaviour Change plot

A correlation was run to explore whether there was a statistically significant relationship within the data plotted above, that is, whether changes in perceived competency and perceived child behaviour for each individual appeared to be associated over time. The results show that there is no statistically significant correlation within the Intervention Group between the change in perceived Competency and Child Behaviour scores over time, r = .4, p = .125.

There is no apparent link between the parental competency scores and the perception of their child's behaviour for the Intervention Group.

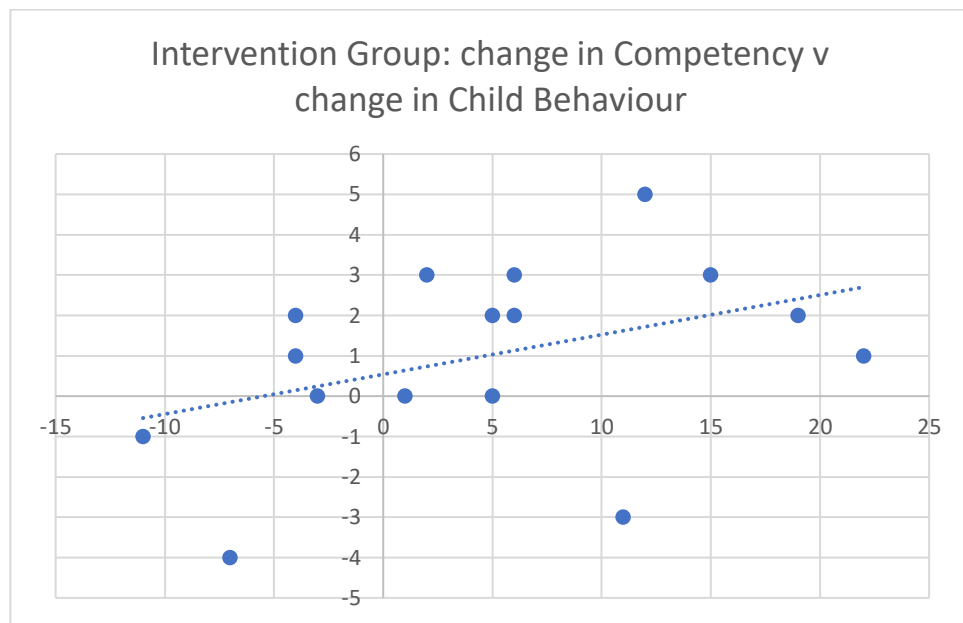*Change in scores over time: Wellbeing – Child Behaviour*

<u>Figure 10: Intervention Group: Wellbeing - Child Behaviour Change plot</u>

A correlation was run to explore whether there was a statistically significant relationship within the data plotted above, that is, whether changes in perceived wellbeing and perceived child behaviour for each individual appeared to be associated over time. The results show that there is a statistically significant correlation at the .05 level within the Intervention Group between the change in perceived Child Behaviour and Wellbeing scores over time, r = .542, p = .03.

There would therefore appear to be a link between the parental wellbeing scores and their perception of their child's behaviour within the Intervention Group This will be discussed later.

4.2.4.2 Control Group

Change in scores over time: Competency – Wellbeing

Figure 11 Control Group: Competency - Wellbeing Change plot

A correlation was run to explore whether there was a statistically significant relationship within the data plotted above, that is, whether changes in perceived competency and perceived wellbeing for each individual appeared to be associated over time. The results show that there is no statistically significant correlation within the Control Group between the change in perceived Competency and Wellbeing scores over time, r = .394, p = .205.

There is no apparent link between the parental competency and wellbeing scores for the Control Group.

Change in scores over time: Competency – Child Behaviour

Figure 12: Control Group: Competency - Child Behaviour Change plot

A correlation was run to explore whether there was a statistically significant relationship within the data plotted above, that is, whether changes in perceived competency and perceived child behaviour for each individual appeared to be associated over time. The results show that there is no statistically significant correlation within the Control Group between the change in perceived Competency and Child Behaviour scores over time, r = .198, p = .538.

There is no apparent link between the parental competency scores and their perception of their child's behaviour for the Control Group.
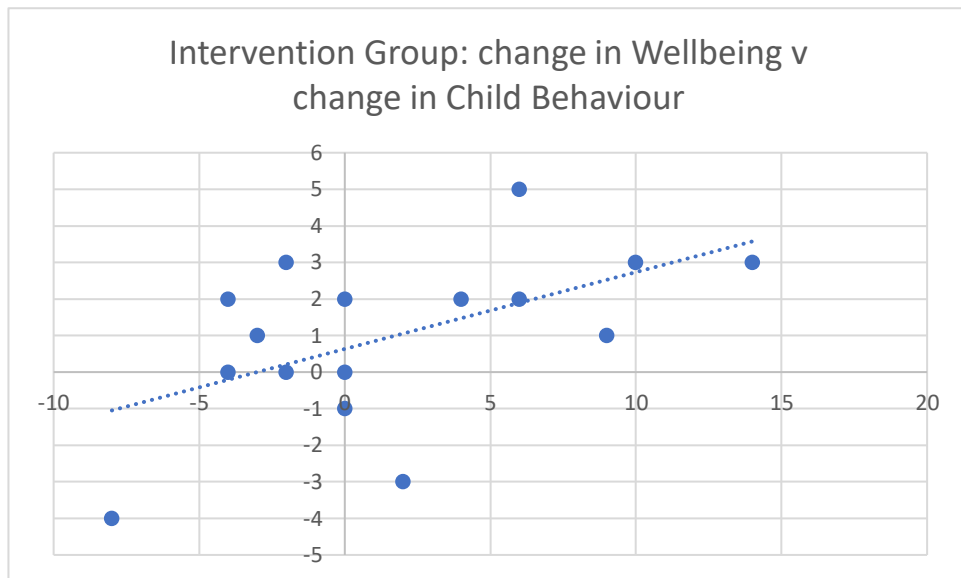
Change in scores over time: Wellbeing – Child Behaviour

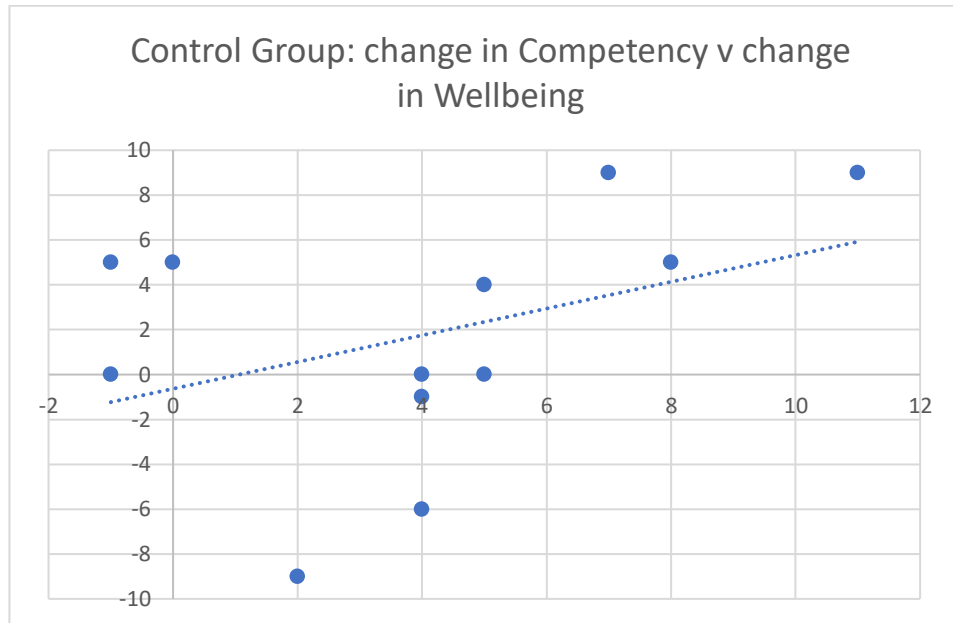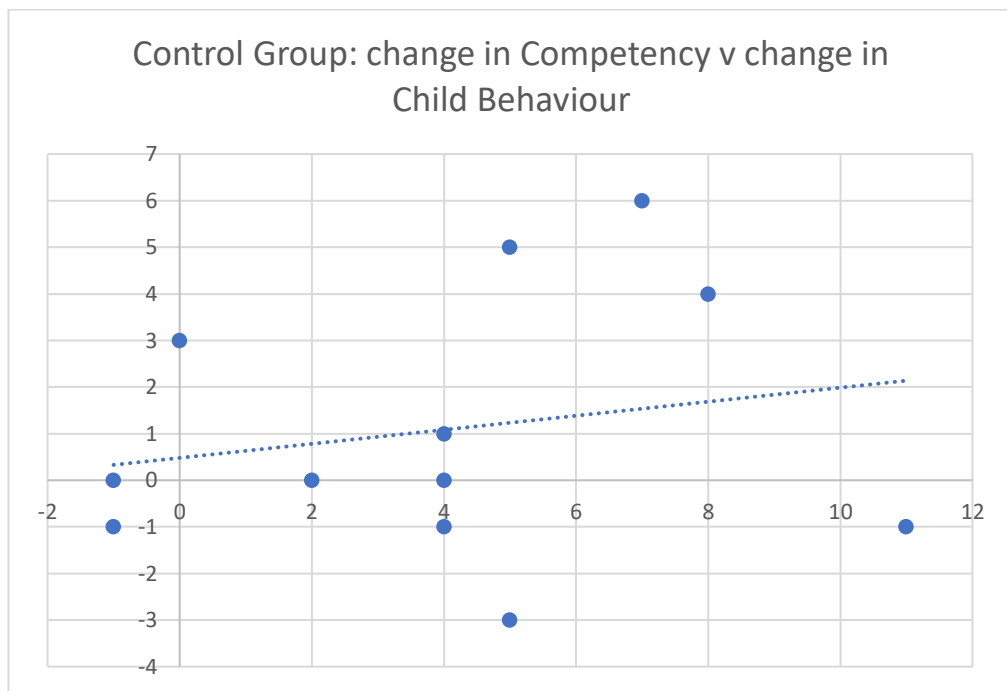Control Group: change in Wellbeing v change in Child Behaviour
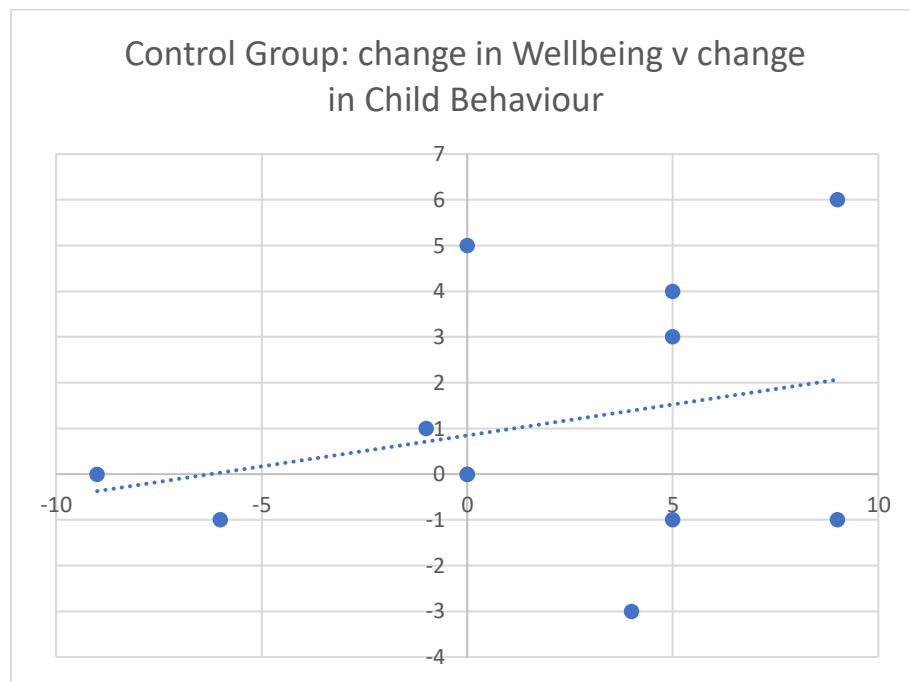
Figure 13: Control Group: Wellbeing - Child Behaviour Change plot

A correlation was run to explore whether there was a statistically significant relationship within the data plotted above, that is, whether changes in perceived wellbeing and perceived child behaviour for each individual appeared to be associated over time. The results show that there is no statistically significant correlation within the Control Group between the change in perceived Child Behaviour and Wellbeing scores over time, $r = .269$, $p = .399$.

There is no apparent link between the parental wellbeing scores and their perception of their child's behaviour for the Control Group.

4.2.5 Additional data collection and analysis

The improvement in Control Group means (statistically significant for perceived competency, but not statistically significant for perceived wellbeing and child behaviour) over time found above was unexpected. To help gain a better understanding of why this might have occurred, it was decided to contact all of the participants in the Control Group who had completed the 18-week

questionnaires (n = 12) with one further question. The purpose of this question was to clarify if these participants had received any other form of support, such as friends, websites, or online forums, during the period that they were responding to the questionnaires. 11 out of 12 participants responded to the question (see Appendix N).

It was found that, despite having indicated at the start of the study that they were not receiving any structured support to help them with their child, 10 of the Control Group had sought and received some support during the period, most from more than one source:

No. of parents	Nature of support
7	Informal discussions with other parents of ASD children
5	ASD Facebook group
2	Online ASD support forum
6	Researched related websites
5	Some other form of support

Table 3: Control Group support sources

Out of the 10 participants who had received some form of support:

Questionnaire	Improved score	Score stayed the same	Reduced score
Competency	7	1	2
Wellbeing	5	3	2
Child Behaviour	4	2	4

Table 4: Change in questionnaire scores for Control Group members receiving some form of support

Overall, out of the 10 participants who had received some form of support, 9 had an improved score in at least one questionnaire type at 18 weeks, but 6 also had a reduced score in at least one questionnaire type at 18 weeks.

This might suggest that the acquisition of 'unstructured' support, or obtaining support in an unstructured way, does not lead to a general improvement for each individual across the three questionnaire areas. This could explain why, whilst the mean scores for the Control Group improved for each questionnaire type, there was no correlation found between the change in each individual's scores between questionnaire types. Individual's responses (as measured by the questionnaire scores) to obtaining unstructured support appeared to vary widely.

The scores of the participant who said that they had received no support during the period improved slightly in Competency, stayed the same in Child Behaviour, and reduced in Wellbeing.

4.3 Qualitative Analysis

After the 12-week follow-up session, and completion of the final set of questionnaires, all participants in the intervention group were invited to take part in a semi-structured interview, although only six accepted the invitation. The purpose of the interview was to capture their views of the impact that the intervention had had on their self-efficacy, wellbeing and their child's behaviour. The interviews were transcribed and analysed using thematic analysis, as has been described in the Methodology chapter. Six interviews were carried out and ranged from seventeen to thirty-five minutes long. (An example of an extract from a transcript can be seen in Appendix M.)

During the interviews, it became clear that these parents were highly emotional about their child's diagnosis of autism, and the impact that the diagnosis had had on them and their family. This was apparent in the honesty and passion of the comments shared in the interviews. One explained:

> *When you are given a diagnosis that your child has autism, it's like the end of the world, but really it isn't, and I think going on that course helps you realise that, no, it isn't the end of the world. (Parent C)*

They were also all extremely positive about the programme itself, irrespective of how they had scored themselves in the questionnaires, with one parent stating that:

> *"I thought it was a brilliant programme, I would actually think I would benefit from doing it again." (Parent H)*

These views were supported by similar comments made by other parents, which included, 'really valuable course,' 'it was all very useful' and would 'advise other parents to attend.' Another parent commented that:

> *"It was an extremely positive experience…I can't think of anything negative." (Parent S)*

One parent commented that the programme's content was 'really good and not too heavy.' The other key factor for the parents was the timing of the course, which, for this parent, was soon after their child's diagnosis of autism.

> *At the precise time I was on the course I did not feel at all confident. I was overwhelmed, under-informed and, yeah, all the stuff that goes with that. So, the timing of the course was great from that point of view. (Parent H)*

Analysis of the transcripts identified three main themes: 1. A challenging experience. 2. Feeling more competent and confident. 3. Need for collaboration and support. Each of these were further split into two or three subthemes, details of which are shown below in Figure 10.

Theme 1

A challenging experience

➡ **Subtheme 1**
Being on a roller coaster

➡ **Subtheme 2**
Understanding reasons for child's behaviour

Theme 2

Feeling more competent and confident

➡ **Subtheme 1**
Acquiring tools knowledge and information

➡ **Subtheme 2**
Parenting in a different way

➡ **Subtheme 3**
Increased confidence

Theme 3

Need for collaboration and support

➡ **Subtheme 1**
Talking with others in a similar situation

➡ **Subtheme 2**
Working together

➡ **Subtheme 3**
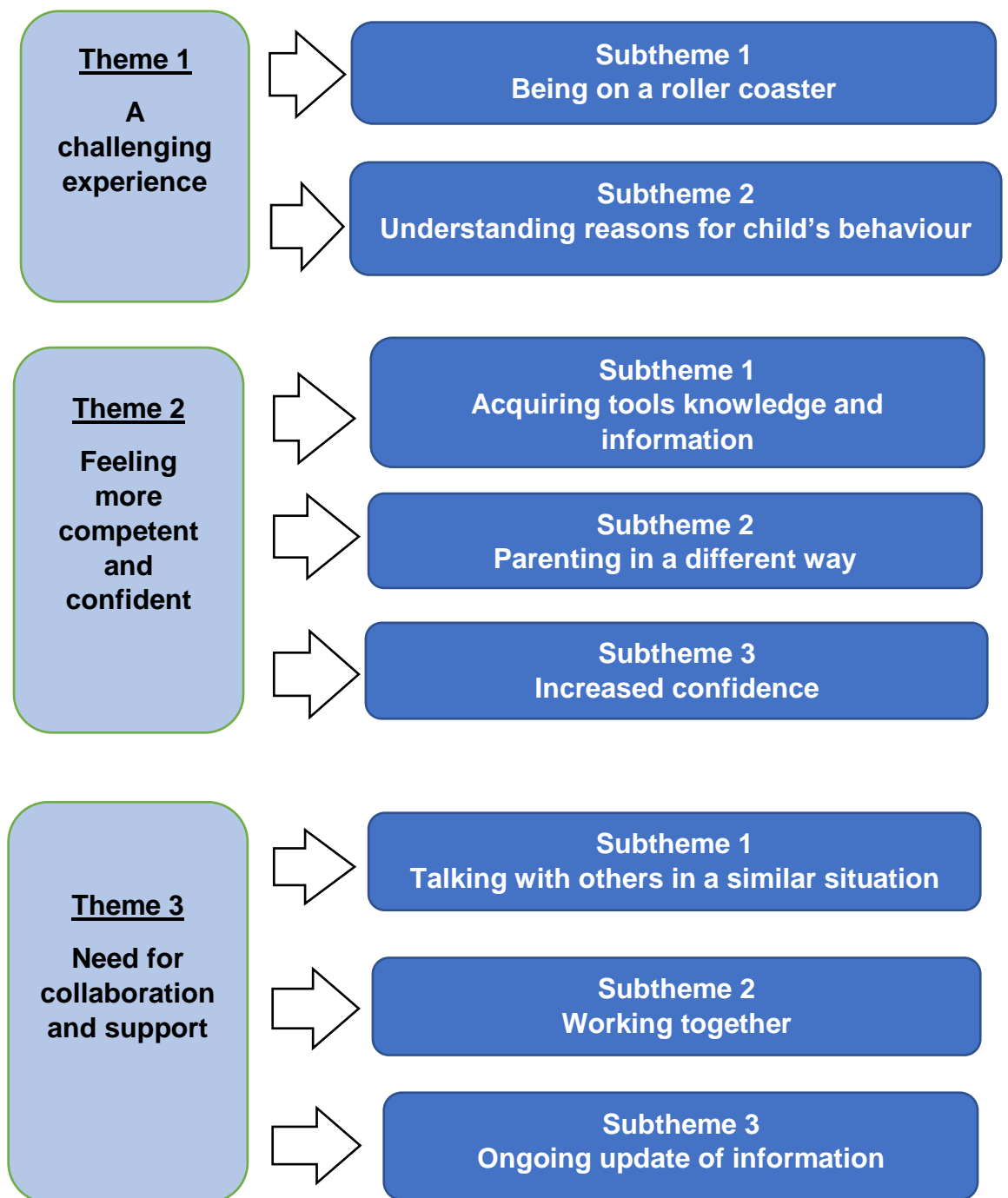**Ongoing update of information**

Figure 14: Themes and sub-themes

4.3.1 Theme 1: A challenging experience

Through analysis of the data, a theme emerged of how challenging the experience of being a parent of a child with autism was. It has already been reported that, after their child was given a diagnosis, two of the parents felt 'overwhelmed' and, as the start of the programme came shortly after they had received the diagnosis, the timing of it was particularly appropriate for them. One parent admitted that they felt 'anxious a lot of the time,' and they explained why in the following quote:

> *"I don't think it's purely because I'm a parent [of a child with autism] that I'm anxious, it's outside influences that have an awful lot to do with it."* *(Parent C)*

Within this theme two subthemes emerged from the interviews. The first highlighted the volatility of life as a parent of an autistic child, the second highlighted how understanding the reasons for the child's behaviour helped them with the challenges they faced.

4.3.1.1 Being on a roller coaster

The role of a parent of a child with autism is not easy, as it is so unpredictable, particularly in the early days when they are still learning about their child's needs and difficulties. Parents can find the role exhausting and hard work, particularly when they do not understand the reason for their child's behaviour. This situation is escalated if their child has limited or no language, or outside influences, such as domestic or financial problems, are adding to what is already a stressful time and may, in the words of one parent, feel like "I am banging my head against a brick wall."

One parent described life with their child as like 'being on 'a roller-coaster', as their emotions will fluctuate widely depending on whether they were having a good or bad day. The impact of this roller-coaster of emotions was evidenced in the variable responses to their questionnaires which one parent was able to explain in this quote:

"It's a lot about what's influencing me - will influence me on the day...That's probably why there is a disparity between the answers to the questions." (Parent C)

This changeable emotional state was echoed by other parents as either 'depending on the kind of day you are having,' or 'just where you are emotionally' at that particular moment, or their child 'was getting more demanding.' These were given as possible reasons for the potential differences between their answers to the questionnaires and their responses in the interview. As one parent summarised:

"[The response] just depends on the time when the question was asked." (Parent N)

This variation in responses to the questionnaires being dependent on how the respondent felt on the day was echoed by another parent more specifically. They admitted that, at the time they were responding to the final set of questionnaires, they were dealing with a lot of outside personal pressures, in addition to having a child with autism, which led to a deep state of 'fed-upness'. The parent felt that these outside pressures explained why they responded to the final set of questionnaires very negatively. The following quote provided further evidence of how volatile their lives were:

"In between there were some good weeks, so if you had asked me [the questions] in a different week you would have got a different response [to the questionnaires]." (Parent H)

This concept of good and bad weeks, or even times of the day, was often the result of an accumulation of negatives issues and feeling fed-up, which contributed to the low emotional state of the parents. One parent commented that this state of mind was not permanent and could easily change which the following quote illustrated:

If you've had a bad week and you're thinking, is this ever going to get better … and then you have a good week. Then, you know, you get home and his [their child] behaviour is great, and you can see improvement on last year when you're doing the same thing you think, actually, we are getting

somewhere, and there is light, and this is achievable so… at that point you are going to feel more optimistic. (Parent H)

This parent's comments highlighted the emotional stress of their lives, which could go from feeling very low to having very positive feelings, and also showed how emotionally fragile they might be. One parent said that, even if they were feeling 'really low', but they were able to see that something was going to change, such as the child making improvements in some area, they would begin to 'feel up again.' The above quote also demonstrated how the child's emotional state and behaviour had an impact on parental wellbeing, as another parent said, their child will have 'periods where he finds things a little more difficult than other times.' During these difficult periods the parent was not in a 'happy place.' The parent explained this further in the following quote:

We do go through great ups and down with our son and … we were going through a tricky period with him … and you look at things in a lot more negative light when you are going through those difficult periods. (Parent S)

Feeling unhappy about themselves can produce negative feelings, which could then have an effect on how they felt about themselves, as one parent described:

If I feel I have been a failure that day ... just lost my temper … or I just didn't know how to handle that [situation] … I'm going to feel rubbish about myself. It's generally going to affect my overall mental health. (Parent K)

This roller coaster effect had other negative impacts which were more personal to the parents, as several of them mentioned a 'sense of guilt' they have in relation to their child's behaviour, for which they blame themselves. The programme helped them overcome the guilt by providing them with a better-informed understanding of autism. Parents commented that the knowledge and understanding that was provided by the intervention empowered them to place less blame on themselves for their child's behaviour, as one parent explained:

You blame a lot of the bad behaviour on yourself and your own incompetencies. The programme makes you realise that, actually, it's not

me, unfortunately, it's down to my son's difficulties and needs rather than my own incompetencies. (Parent S)

Attendance on the programme helped the parents place less blame on themselves for their child's behaviour and it also enabled them to feel more positive about themselves as this quote explained:

Before he was diagnosed I was just beating myself up and I had a sense of guilt that the reason why he misbehaved was that I should have said better things to him, as he doesn't understand and, obviously, the course did make me feel more positive, educate me as well. (Parent A)

A parent also commented that the programme supported them in understanding that they were not alone in their experience as there were other parents in a similar situation. This gave them a renewed strength in the knowledge that, as there was no blame attached they, as the parent, could take a more positive and proactive role in supporting their child.

"It [the programme] made you actually understand that other people have been through it … it was actually empowering me to realise that, actually, it's not down to anyone else, this is down to me as a parent." (Parent H)

Negative feelings were not necessarily directly linked with their child's behaviour, but the outcomes were the same, i.e. their reduced wellbeing would be likely to have a negative impact on the child, which could possibly result in an increase in poor behaviour from the child. Therefore, if parental wellbeing was low, and the parent was having a bad day, the situation was not likely to improve as this parent explained:

"If I'm having a bad day for whatever reason … this ends with a messy downwards spiral." (Parent K)

In summary, this section has shown that these parents led very volatile and highly emotional lives. This highly emotional state was not necessarily directly caused by their child's behaviours, but could be the result of other, external or internal familial stresses and pressures. This could have a negative impact on their mental health and could also lead to an increase in their child's adverse behaviour. However, it was mentioned that this could work in both directions, i.e.

in that, if the parent observed positive behaviour in their child, their state of mind would be lifted, even if they had previously been having a bad day.

4.3.1.2 Understanding reasons for child's behaviour

Within this subtheme the parents discussed how the intervention enabled them to understand their children better, as they now recognised that this behaviour was the child's means of communication. The initial sense of feeling over-whelmed, which many parents experienced, was lessened as their understanding increased.

> *"The course has helped me, and you found out about their behaviour, you found out about a lot about why they do things." (Parent A)*

> *"Understanding the cause of his behaviour - when I'm alive to his behaviour …. I'm trying to find the cause why that behaviour happened." (Parent N)*

Overall, the parents felt that the intervention had been beneficial as, by giving them an understanding of the reasons for their child's behaviour, this helped them avoid or mitigate adverse behaviours thus, potentially, reducing the stress that this might cause to both parent and child. As one parent said:

> *"After having the sessions, it sort of clicked sometimes, the reasons behind those behaviours, and how to maybe prevent the melt downs before they are happening … because I knew the trigger." (Parent S)*

Comments were also made that, by having knowledge about the behaviours, they were able to look for similar patterns of behaviour, which then enabled them to pre-empt the result of a similar situation. By predicting the possible outcomes of a stimulus, they now were able to mitigate the situation if it occurred again. This parent explained further:

> *"You start looking back and you do see patterns after time, and then you can therefore pre-empt that - if that happens again, you are going to get the same reaction" (Parent H).*

The following parent developed this concept further by commenting that, through the acquisition of knowledge to understand the child's world better, they became

better informed about how and why their child might respond to certain situations or stimuli in a way that might not be acceptable to others, as this parent explained:

> *"Generally, about why they behave the way they behave, as well as …. understanding that a bit more, and getting into their world - understanding, and that was really good." (Parent A)*

Another parent agreed with the above quote and commented that by having an enlightened understanding of the reasons behind their child's behaviour family life had become less stressful as they explained:

> *It's actually made family experiences like days out a lot easier and a lot more pleasurable … it was a real insight and has definitely made life at home easier ... by having a better understanding of triggers and how to manage them. (Parent S)*

The concept of 'going back to basics' and having a better understanding of their child's world helped the parents understand the reasons and triggers for certain behaviours was reflected in comments made by several parents. One parent expanded on why they felt that the acquisition of the skills and knowledge had been beneficial to them.

> *"It's going back to the basics, as there is a reason for the behaviour." (Parent H)*

Although one parent commented that they would not have said their child was 'a naughty child', by having a better understanding, they were able to pro-actively manage the behaviour, with the focus on encouraging 'good behaviour', using strategies that had been provided by the programme, as a quote from another parent explained:

> *Once you have a reason for it, you can do something about that … if you know that going to the supermarket is just going to be a nightmare, then it's OK, just don't do it, or minimise the trip. (Parent H)*

Another parent recognised that, as parents, they were on a continual learning curve, and that the programme on its own was not going to solve all their problems, and this they explained as:

"OK, it's [the programme] not going to solve everything, but it can be a starting point for growth." (Parent K)

In summary, this concept of a 'starting point for growth' seemed to capture the benefits of the intervention programme, which may not be able to solve all the parents' difficulties but, for these parents whose life had been turned upside down, leaving them feeling helpless and unable to cope, the intervention gave them a sense of why their child was behaving in a particular way. They became more aware of similar patterns in the behaviour and, because of this, they were better able to predict their child's possible responses to similar situations, and possibly avoid difficult situations altogether, or pro-actively mitigate their child's response to a situation and make family life 'more pleasurable.'

4.3.2   Theme 2: Feeling more competent

The previous theme described the volatility of the parents' lives and how the intervention gave them a better understanding of autism and the reasons for their child's behaviour. The next theme which emerged from the interviews explored the impact that the intervention had on the parents' self-efficacy, and why the intervention helped them feel more competent and confident and able to fulfil their parenting role in a more positive way.

Within this theme three subthemes emerged from the interviews. The first highlighted the importance of acquiring knowledge about their child and their child's behaviour, the second highlighted how they needed to adapt their style of parenting to respond to their child's needs, and the third reflected the overall gain in their confidence to carry out their parenting role more effectively.

4.3.2.1 Acquiring tools, knowledge and information

This subtheme described in more detail how the intervention supported them by providing them with information about strategies they could use to help manage their child's behaviour. One parent commented about how they used their acquired knowledge of what triggers certain behaviours when planning family outings.

"All behaviours are trying to communicate something … so we're trying to see in advance what …… would then improve their behaviour … and to be able to already have the strategy [ready] when you see the problem coming." (Parent K)

This parent's comments highlighted the benefits of having a better understanding of autism and the impact that this might have on their child's behaviour, which this parent explained was because they had 'the strategy.' The benefits of having strategies were echoed by other parents, and some of them identified those they felt were particularly helpful to them and their child.

"Where they describe the Iceberg technique, where you are kind of digging around the trying to find out the cause, more than the issue." (Parent H)

This parent had identified a specific strategy which they had used and was appropriate for their own child. Other strategies linked with supporting sensory issues were also mentioned.

"I really enjoyed the sessions regarding sensory issues, because that's quite a big issue that impacts my son." (Parent S)

Some parents commented that, having knowledge about autism, was also beneficial in helping them manage their child's behaviour, either for pre-empting those situations which might be more challenging for their child, or when they had to respond immediately to a difficult situation that had occurred. A parent in the following quote discussed why having this knowledge had been empowering for them and what impact it had on them as a parent.

"It's giving you the tools, knowledge and information in order to be a better parent." (Parent H)

One parent gave reasons why it was beneficial to keep building on new information each week of the programme, which can then be put all together as they explained:

"So, we got the knowledge … we'd go away and try it at home all the time … it just means I can apply it and keep on learning." (Parent K)

The quote above takes the view that the intervention provided parents with information and strategies to support them, which they also acknowledged would not provide solutions for every occasion. However, for this parent the programme provided them with a sound foundation of information for them to build both their knowledge and skills to support them in managing their child. Therefore, the knowledge they received from the programme, which they built on each week, gave them a perspective which helped them understand the reasons for their child's behaviour and the focus was no longer on their perceived poor parenting skills. This parent explained it further in that, for them, it was the ability to take the knowledge they had acquired and apply it practically with their child, as this quote explained:

> *"The fact is, that it was very well learning stuff, but it was the practical application that you take away and … you could try and apply to actual situations." (Parent K)*

Another parent was still finding it difficult to apply their knowledge and strategies practically. They explained that the reason for their sense of frustration was because they were not content with how they were supporting their child and wanted to strive for more as they explained:

> *I think I am always quite critical about myself, and I always think that I'm not doing enough for him … why can't I make you feel better, why are you [the child] still feeling like that … I want to make it better for him I'm failing because I can't. (Parent A.)*

For some parents, ensuring that their partner was able to share in this acquisition of knowledge was also important. Although the programme was mainly attended by mothers, one of the fathers was able to attend a couple of sessions, which they felt was very beneficial and 'made a real impact', as it gave him an understanding for the triggers and reasons behind the challenging behaviour. The mother, who attended all the sessions, expanded on this in this quote:

> *He's at work and only here at the weekends, so he's not used to certain behaviour so, for him, it was a real insight and it has definitely made life at*

home a lot easier for us both, having a better understanding of the triggers of certain behaviours and how to manage them. (Parent S)

Some parents were not able to observe specific improvement in their child's behaviour, but were able to comment that, when they became more aware of the triggers for their child's behaviour they then began to look at 'the bigger picture'.

"After being on the course it makes you look at it from another level and a different way of dealing with it and resolving it." (Parent C)

By being able to pre-empt possible difficult situations, or more effectively manage specific behaviours, the parents were potentially experiencing fewer, or less extreme, challenging behaviours. One parent described their use of the 'Social Story' as helping their child manage change which supported their child, not just for this particular time, but for any other occasion when a similar change could occur. They gave their reasons for this in the following quote:

Our children need to be secure about what is going to change, or what is going to happen… I try to keep it as I explained [it to him] so D [child] feels more secure and he knows what's going on. It's easier for me as well, relaxing for him and easy for all of them. (Parent N)

By providing the child with information about future events or changes to routine gave the child a sense of security when they knew they were going somewhere or doing something which was not completely unfamiliar to them. This was beneficial to the child and parent as it avoided unnecessary stress to both of them.

4.3.2.2 Parenting in a different way

The tricky and stressful periods experienced with a child with autism can, for some parents, be linked with specific situations. For one parent, meal times were difficult, and often resulted in the parent getting 'really upset' and the child becoming really upset as well. Through using strategies provided by the programme, and 'listening to other parents in how they deal with challenging meal times' the parent was able to respond in a calmer way when their child did not like a particular food, as they explained:

I don't put pressure on him and upset him to try it [the food] either… I'm not going to force it, and that I definitely picked up from the course… I hope one day in the future he will try it. (Parent C)

For some parents, bedtimes can be difficult for them and their child, as one parent described:

"Just constantly trying to find another way of doing things. It's draining me and I need the rest now and to start again tomorrow." (Parent A)

This parent, as with the parent before, recognised that to support the child as well as reducing their stress, they needed 'to get into their (child's) world, into what's he's thinking', which is something that they had not addressed or thought about before and can be very tiring but, as this parent recognised, they now have the background knowledge to support them.

"I'd say, when something happens, I've got the background to be able to handle it differently." (Parent K)

The knowledge that the parents received from the programme enabled them to change what could have been a stressful experience into one which is less highly charged:

The course really helped me think about how to adapt situations … so that they worked for [child]… without blaming myself [for] being a bad parent and blaming him as well. He is really frustrating me, but to actually turn it around and think 'he's different' … so he's got to be parented in a different way. (Parent C)

Another parent explored this area further by saying that, by having a better understanding of the triggers for their child's behaviour, they have changed their strategies in dealing with certain incidents:

Just by changing certain things, especially at home, we find that with, say, melt downs, quite often they are not as bad as they used to be because we have taken on board some of the advice from the organiser [the EP delivering the programme]. (Parent S)

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These parents have identified specific strategies which they have used which were relevant to their own child. This was clearly very important to the parents when planning outings, such as a family outing to a theme park. A parent in the following quote talked about using this knowledge to prepare the child for an outing with the intention of reducing any negative impact on the child.

> *"If it's a bigger event, if you say something the day before, so they know what's coming. Even if I can say something five seconds before sometimes, you can calm it before it happens." (Parent K)*

This parent commented that certain events, such as Christmas, were now 'much more peaceful', as they had given more thought to it and taken some time to predict and plan for stressful moments.   They explained this further in the following quote:

> *"I'm trying to reduce their stress, so it's that thing of, they're behaving that way, that's because they're stressed about something, and we want to bring that stress down… so we are addressing that." (Parent K)*

Parents commented that the benefits of both the knowledge and strategies provided them with the support which they could use if an unexpected situation arose that they had to respond to immediately. One parent described how they had acquired a 'mental agility', particularly if their child were in a situation to which they could react negatively, as they had to think so fast to decide which strategy to apply, or whether or not to intervene at all.

Another parent, who described their son as 'a very shy boy', had used specific strategies, particularly around communication and language, with their child. They mentioned that they had been giving their child too many long questions and, by simplifying the content and language, not only does their child understand better, but they were now communicating more, and this had also improved the child's behaviour. Another parent commented that, when they are going somewhere new, they would always prepare their child by showing them pictures of where they are going. They explained this further in this quote:

He'll [their child] still ask a lot of questions, but his behaviour is a lot different, he's a lot calmer, he's a lot more settled, and he'll understand what we're going to do. That's changed his behaviour a lot…. You understand their feelings a bit more as well. (Parent A)

Although, in the above quotes, the parents were not clearly identifying an improvement in their child's behaviour, they all seemed aware that it was important for them to be able to plan for and predict possible situations which may be stressful for their children. Many of them were doing this successfully on a regular basis and, in this way, the child's behaviour had improved, as the parents were using strategies to avoid or modify a scenario that had in the past been 'a messy situation.' The parents were aware of the efforts that they had made but did not seem to fully recognise the actual outcome of their efforts, which was not only an avoidance of a meltdown but, by not having a meltdown on that occasion their child's behaviour had actually improved as they were parenting in a 'different way.'

4.3.2.3: Increased confidence

A parent can be empowered when they feel confident that the way they are managing their child is best for their child at that moment. One parent explained that it helped them by seeing other parents in a similar situation to themselves as this quote demonstrated:

"I think it [the programme] really boosted me … it was good to be around other parents who were going through a very similar situation and actually made me think maybe it's (the situation) is not as bad as I think it is. (Parent C)

This parents' confidence was improved when they had been given knowledge about autism and, more specifically, strategies which they could use to manage or even pre-empt their child's challenging behaviours.

"It empowers you to know - this is acceptable, and this is not - which should make you confident as a parent … It is a combination of strategies and confidence." (Parent H)

One parent said, by having the information from the programme, they felt more confident and more likely to approach a difficult situation 'with a patient voice' and calm attitude, rather than panicking; which they admitted was not easy to maintain but did 'make a big difference.' Parents described the frustration, prior to the programme, of not being knowing how to manage their child's behaviour. Once they had acquired the knowledge they had a sense of empowerment when they realised that they had not caused the behaviour. This sense of empowerment enabled them to become more confident as parents and with managing their child's behaviour.

> *Having that understanding gave me the confidence of being able to manage them [behaviours] in a different way, where before, it could be quite frustrating not knowing how to deal with a particular meltdown that my son was having. (Parent S)*

For one parent their confidence developed once they had a better understanding of their child's behaviour and they no longer placed the blame on themselves.

> *I feel more confident. I think to myself, this is the reason why he struggles to do this, and not because of anything I've done, and it's not because of anything he's doing, it's the way he's wired, [his] biological make-up. (Parent C)*

The following quote recognised the importance of the group-based delivery, which provided the opportunity and benefit from seeing other parents having similar experiences to them, especially when their confidence was being challenged. This parent likened her parenting role as a journey which, to them, was long and involved many ups and downs.

> *"This journey is kind of long. Sometimes you feel confident, sometimes you feel really down, but what helped me is that you can see other parents in the same situation." (Parent N)*

It has already been mentioned that these parents' lives are very volatile, which could influence how confident they feel. Despite their volatile lives, parents seemed to be making a connection between understanding their child's behaviour and their own confidence, and this is explored further in comments

from other parents who describe it as a 'grounding', or 'background', which gave them an increased self-confidence that they have 'done a good job.'

> *"I think it [the programme] gave me a bit more confidence in how to deal with the daily challenges." (Parent S)*

The quote above highlighted the challenges that parents faced on a daily basis and how their perceived views on how well they had engaged with their child impacted their confidence. This parent explained how their self-confidence depended on how well they had been able to manage their child that day.

> *"So, if I feel I have done a good job that day, and I feel more self-confident and generally happier with myself." (Parent K)*

The importance of having knowledge and understanding was also recognised as a key factor to increasing confidence. In the following quote, the parent commented that the knowledge they had acquired from the programme had empowered them to be able to talk to others about autism, which they believed supported both their understanding and acceptance of it.

> *Because of the course … I am able to explain it better to people, so I'm educating them, as well, my friends and family understand it more. I think that people are getting educated, understanding it as well and accepting it [autism]. (Parent A)*

Parents also talked about their increased confidence in being able to explain to family and friends why they were managing their child in a certain way. Their confidence has developed from the knowledge they have acquired from the intervention.

> *I can pass that information on to other family members who may be putting pressure on us to say that it is just naughty behaviour, and I can say, it's absolutely not naughty behaviour and, I'm afraid, if you don't like it, then that's the way it's going to be. (Parent H)*

One parent mentioned that their confidence can fluctuate, and outside influences can have a significant impact on their confidence and leave them feeling out of control.

I lack confidence about them [outside influences] making me feel less confident that I'm doing a good job with my son. It's outside influences, it really is, and things that are beyond your control and you feel out of control. (Parent C)

Another parent commented that attendance on the programme had increased their confidence. This they felt had enabled them to rise above the 'outside influences' and ignore the 'judgemental looks' from other people in the soft play area, or the lady who had given them 'a nasty look' as their children had started arguing as to who should sit in the buggy. The parent commented:

"No-one knows my children the way I do. So, I've 'kinda' got the self-confidence to say 'that's why I'm doing it' … and that's kind of OK." (Parent K)

Increased confidence can be shown in different ways. One parent mentioned that the EPs who delivered the programme had encouraged them 'to take care of ourselves.' This gave the parent the confidence to think about themselves and more positively manage their own wellbeing. This parent explained:

"I'm going to do something for myself only. I started to take care of myself, sport helped me. What I do now is I take regular exercise, so this has helped me." (Parent N)

In this section it has been shown that the programme can have a positive impact on parental confidence in being able to manage the day-to-day difficulties as well as having the confidence to explain their child's behaviour to others. This resulted in a perceived improvement in parental wellbeing, with 'guilt' being removed from the parents themselves, enabling them to feel more confident.

4.3.3 Theme 3: Need for collaboration and support

Collaborative support, ether from a partner, other family members, or school was seen to be beneficial to the child. The key issue for this support was to create a set of appropriate strategies for that child, which were then used on a consistent and regular basis by all of those who were involved with the child. If both parents

collaborated and discussed which strategy they would use in certain situations this was seen by some parents to be the most beneficial course of action to support the child. This theme explored how important parents felt that collaboration was between family members and all those who play a significant role in the child's life.

Within this theme three subthemes emerged from the interviews. The first highlighted the benefits of talking with other parents in a similar position to themselves, the second highlighted the benefits of collaborative working, and the third their need for ongoing support and information.

4.3.3.1: Talking with others in a similar situation

As the interviews were recorded after the follow-up session of the programme, this sub-theme came out of the interview question which asked the parents if there were anything else that they would like to share. In response, parents made some very positive comments about being in a group of people in a similar situation to themselves, who were both understanding and supportive and, as one parent mentioned, were not 'judgemental' of how you were managing your child, and another one commented:

> *"The most I got out of it [the programme] was the sharing with other people that had children with autism." (Parent C)*

Through sharing their worries and concerns they were also able to discover the strategies that other parents had used for similar behaviour, which left them feeling less isolated and different.   Other comments were made about the benefits of sharing information with other parents whose children were experiencing similar issues.

> *"Coming back every week and talking … Each week you can have a catch-up with the teacher or whoever. Generally getting things out of every parent, that was good as well." (Parent A)*

"I also think it's good to know that you're are not alone, and you know my son's problems are not unique, and that other children are facing the same difficulties." (Parent S)

One parent, when commenting about the 12-week follow-up session, said that this session had been useful and emphasised the value of engaging with other parents.

It was quite nice to come back after being away from the sessions for a while… and also catch up with the other parents to find out how they'd got on. I found that session very helpful. (Parent S)

Parents also provided more specific positive support for each other. One parent described a comment that had been made by another parent about giving their child a mental picture of the place they were planning to visit. This comment had helped them with supporting their child as they expressed in this quote:

"I started thinking about that particular comment …. [and] changed how I was approaching a lot of things." (Parent K)

It was suggested by one parent that it would be beneficial if there were opportunities for parents to periodically meet each other in the future, as a continuing part of the programme/ support, to enable the initial 'bond' that had been developed during the programme to continue, and to share experiences, or talk about difficulties they were experiencing.

At challenging times, as well as being provided with knowledge, parents were gained support by having the opportunity to talk to other parents in a similar situation to themselves, which enabled them to make comparisons and realise that others were also having similar experiences. The following quote emphasised the importance of being able to talk and share with others who were experiencing a similar situation to them.

It was good to be around other parents who were going through a very similar situation ... actually made me think, well maybe it's not as bad as I think it is. I think there are others that are going through the same thing if not worse … that I'm going through … I talk to other people as well about

it in a more positive light. It was all very doom and gloom in the beginning, but now it's not as bad. (Parent C)

For this parent, by talking with other parents in a similar situation, they seemed to be able to reassess and view their situation from a different and more positive perspective.

4.3.3.2: Working together

When both parents were able to attend some of the sessions together they were able to work more effectively together as a result, through shared knowledge and understanding. One mother saw this as being particularly beneficial to her husband as through attendance on the programme, they have made changes to their strategies, which has made family experiences more pleasurable. This is explained further in the following quote:

"And it's actually made family experiences, like days out, a lot easier and a lot more pleasurable, because of that. I think it has probably helped my husband a lot more than me because I'm the primary carer." (Parent S)

For some parents, as it was not possible for them to both attend the programme, one parent commented that she shared the 'most significant bits' of the programme with her husband, and then they 'would both work at that' together. They tried to set aside time on a regular basis to discuss, either past situations, or pre-empting possible issues, and planning strategies for future events. As a result, this parent believed that they were handling specific events, such as holidays, or someone coming to visit, in a more positive way. The following quote expanded their thoughts:

I'm talking to my husband about it and saying, how are we going to handle this? Do you think we should do this, or should we take them [the child] there as they are going to be unsettled… so we're trying to see in advance what things would then improve their behaviour, when we actually do whatever it is. (Parent K)

The same parent and their partner were finding time, usually when their children had gone to bed, to discuss specific issues that had arisen during the day and

how they could have managed them differently or better next time. This initiative seemed a very positive way for the parents to undertake a collaborative role in supporting their child and also in supporting each other, when the children are in bed and 'the day is over and they have the time to stop' and are able to 'both work at it.' The parent was keen to emphasise that these times were for a positive discussion where the focus was:

"Not to make it into an argument ideally, but where we can both learn and do it differently next time. We know it's positive, but it doesn't always happen." (Parent K)

In addition to the collaboration of family members, the school, i.e. teachers and teaching assistants, were also viewed as being part of the support team in helping improve the child's behaviour. One parent thought it was 'essential' that a member of the school staff attended some of the programme sessions, whilst another parent felt that school staff attendance should be made compulsory. Collaborative support and working as a team was seen as an important part of the programme. Those school staff who attended sessions were seen to be a valuable addition to the child's support team. One parent expressed their positive feelings about some feed-back from a parents' evening at school about improvements in their child's behaviour, which they said was 'really good news', and which they recognised was not just due to their parenting but:

"The fact is he's gone from Reception to Year 1, but it's the strategies they [the school] put in place, the strategies we put in place, the routines, etc.' (Parent H)

This parent felt that this collaboration between schools and home had been the reason why they had seen positive changes to their son's behaviour and they endorsed in this quote:

"There is 'a huge improvement in his behaviour" (Parent H)

4.3.3.3 Ongoing update of information
Although parents were generally very positive about the programme, several comments were made about the need for regular information and updates post

the programme, to maintain 'a continuous programme of support.' This parent felt a need for ongoing support and gave their reasons why:

There has been a void since then [completion of the programme] and I'm sure there is, actually, heaps out there, but when you're busy every day, it's very difficult to find the time to research it. I think if it were pushed out to you it would be easier. (Parent H)

In addition, another parent said that they would like a soft copy of the sessions, which they could refer back to, and it was suggested that the course could benefit from being lengthened, to help develop parental confidence, or to provide further information about other forms of support. A suggestion was also made for 'tips and techniques', for example, about transition time between schools, to be sent to those who have previously attended the course, or information about intervention support for their child, such as Applied Behaviour Analysis (ABA). One parent explained that ongoing support could be delivered in different ways and:

"It doesn't have to be a face to face meeting." (Parent H)

Whilst reflecting on this observation, one parent commented that, as parents of children with autism are on a learning curve, they would continue to need support long after completion of the programme. As they explained, it was important to think about:

"What you are doing after [the completion of the programme], as there is a possibility of losing it [knowledge]." (Parent K)

The programme had empowered parents to confidently speak out for the needs of their child, and it was felt that ongoing support was needed to guide parents to where they could get support and guidance for their child on an ongoing basis.

4.4 Comparison of qualitative and quantitative data for the parents interviewed during the study

For the six parents interviewed, a simple, non-statistical analysis was performed comparing the qualitative data obtained with the quantitative data from their individual questionnaires.

All six interviewees made positive comments about the Cygnet programme and how valuable and useful they had found it. All made at least one positive comment about each of self-efficacy (understanding and knowledge acquired), wellbeing (how attendance on the programme had helped them to feel better about the way they managed their child's behaviour) and their perception of their child's behaviour (avoidance of problems, reduced impact when problems arose).

However, for their quantitative data, 2 parents had shown a reduction in competency over the period of the study and 2 recorded a degradation in their child's behaviour (one parent was common between the two sets). All but one showed an improvement in wellbeing with one parent showing no change.

It should be noted that the parent showing a reduction in both competency and child behaviour admitted that their scoring of the questionnaires was probably influenced by a long-running problem that they had been experiencing with an external support provider for their child, which had made them quite upset over a long period. This 'outside influence' may well have impacted the underlying accuracy of responses to the questionnaires which were attempting to assess the impact of the intervention.

For the parent who showed a reduction in competency, their comments on this area during the interview were all positive and they were unable to explain why their scores came out this way. Similarly, the parent who showed a reduction in perceived child behaviour could not explain why the scores had come out this way.

For the remaining 3 parents, each showed improvement in all three areas over the period of the study.

No. of parents	Competency	Wellbeing	Perceived Child Behaviour
3	+	+	+
1	+	+	-
1	-	+	+
1	-	0	-

+ = Scores improved, **-** = Scores declined, **0** = Scores stayed the same

Table 5: Summary of changes in interviewee's quantitative scores over the period of the study

The differences between the two sets of data for the same participants emphasised the point, noted in the qualitative analysis above, that the quantitative data obtained in a study such as this, where the participants are living on a 'roller-coaster', can be significantly influenced by the participants' feelings and emotional state at the time of completion, i.e. where on the roller-coaster they happen to be, rather than necessarily be a true measure of the 'underlying' position at that time.

Chapter 5: Discussion

This mixed methods study aimed to explore parents' views of their self-efficacy (competence and confidence in managing their child), wellbeing and their child's behaviour post attendance on an intervention for parents of a child with autism. This chapter will discuss the various findings and also considers whether the qualitative data was consistent with, and provided explanations for, the quantitative analysis. Where this was not the case, further discussion was undertaken to examine why this might be so.

5.1 Research Question 1: Does the Cygnet intervention have an impact on the parents' perceived self-efficacy to manage their child's behaviour?

Evidence obtained from the Intervention and Control Group questionnaires showed that, throughout the intervention, the parents' perceived level of competency improved. There was a significant main effect of time when looking at the data for the Intervention and Control groups combined over the study period however, there was no significant effect of group, or interaction between group and time. When analysed further, there was a significant main effect of time for the intervention period (T1-T2), but not for the post intervention period (T2-T3). There was also a significant interaction between group and time for the intervention period.

Further analysis showed a significant improvement in the Intervention Group's Efficacy scores over the intervention period, but this effect was not sustained over the entire period of the study. There was also a significant main effect of time over the study period (T1-T3) for the Control Group separately, and for Satisfaction for the combined data for both groups, but further analysis was unable to identify any significant effects, either by time period (T1-T2 or T2-T3), or within group that might have driven these effects.

The fact that the control group increased in self-efficacy over the period of the study to a significant degree, but the intervention group did not (though it was approaching significance at the .05 level), was an unexpected and unusual result. Possible reasons include the fact that the Control Group were continually accessing support (via the internet, etc), whereas the Intervention Group, who had demonstrated a significant increase in Efficacy during the intervention period, had ceased to receive structured support and might have scored their final questionnaires in a more negative way in response to this. Also, as noted previously, it is possible that those parents completing the follow-up questionnaire some months post the intervention might be those with the greatest needs (therefore providing lower scores), as those with fewer needs (who might have scored higher) might have dropped-out by this stage.

In summary, Competency for the combined group data (both Intervention and Control) significantly improved over the study period, partly down to the significant improvement in Intervention Group Efficacy over the intervention period, but also due to a general improvement of both group's scores, as there were no other significant effects identified.

The qualitative data obtained from interviews was consistent with the quantitative results and was positive about the intervention's impact on the parents' self-efficacy. This finding was consistent with parents' comments made in a study by Cutress and Muncer (2014) which mentioned that parental self-efficacy had increased following attendance on a parent intervention programme. Parents who were interviewed in the current study also spoke of the intervention giving them confidence to cope with the daily challenges that daily life presents.

The parents interviewed in this study said that the Cygnet intervention provided them with knowledge about autism and information about strategies they could use with their child. This is consistent with evidence found in the study by Clubb (2012) which reported that parents particularly mentioned the benefits of receiving information about problem-solving skills and specific strategies that they could use with their child. Some of the parents in the current study also

identified specific strategies which were relevant to their child, such as the 'Iceberg principle', 'social stories', or the 'sessions on sensory issues'.

The knowledge received was seen by the parents in the current study as helping them to go 'back to basics' and, once they realised that there was a 'reason for the behaviour' of their child, they began to engage in a 'different way of parenting.' This enabled them to feel more confident, as they now had the background knowledge to 'adapt situations' and 'handle things differently.' Parents commented that, by changing certain things, especially at home, certain behaviours, such as meltdowns, became less challenging to manage.

They commented that their confidence improved even further when they observed their child responding positively to a strategy that they had used. This finding was consistent with findings from a study by (Preece, 2014) in which parents reported that, by learning specific techniques, it gave them a better understanding of what they were doing and, as a result, their confidence improved. One parent in the current study commented in their interview that by doing 'a good job' they felt happier and more confident in themselves. However, it is important to note that the confidence they commented on was their perception of how they felt, as there was no independent measure of confidence.

Parents in the study described this new approach to managing their child as 'parenting in a different way', which empowered them, as they felt more confident. This confidence resulted from the knowledge they had acquired from the programme which enabled them to 'adapt situations' and therefore 'handle things differently.' One parent said that the intervention provided them with 'tools, knowledge and information' which they thought had helped them become a 'better parent.'

This concept of being a 'better parent' empowered the parents in this study to have increased self-efficacy, as they had a better understanding about autism. A study by Grahame et al. (2015) reported that improved parental self-efficacy was linked with attendance on an intervention programme where they had received information about strategies they could use to support their child. The knowledge

the parents in this current Cygnet study acquired, not only gave the parents a better understanding of why their child behaved in a particular way, but also what was 'acceptable behaviour' and what was not, and also how they could manage these behaviours differently.

Overall the qualitative data appears to confirm the quantitative data for the Intervention Group of an improvement in their knowledge and resulting self-efficacy over the period of the study. Unexpectedly, the Control Group mean competency scores also made significant improvement over the period of the study. It was subsequently found that the Control Group were accessing various forms of unstructured support, such as websites and online forums, during the timeframe of the study, which might have led to this result.

5.2   Research Question 2: Does attendance on the Cygnet intervention have an impact on the parents' perceived wellbeing?

The improvement in wellbeing scores for the combined data (Intervention and Control Groups) was not statistically significant, and there was no statistically significant difference either within, or between, the Intervention and Control Groups.

However, the qualitative evidence provided some interesting views on the positive impact that the intervention had on their wellbeing. Some parents spoke of their feelings when they received the autism diagnosis for their child, of being 'over-whelmed, under-informed and lacking in confidence' and, to some, it felt like being at the 'end of the world'. They commented that the intervention had helped them re-shape their thoughts and they began to realise that it was not as bad as they initially thought. This often resulted in improvements to their mental health and wellbeing. Their positive comments on the impact of the intervention were consistent with those made in a study by Tonge et al. (2014) that the intervention, by providing them with information and strategies, helped them both understand and manage their child's challenging behaviour with the additional benefit of improvements to their own wellbeing.

Parents commented that, attendance on the programme provided an opportunity for them to talk with parents in a similar situation, with whom they were able to make comparisons to themselves. The intervention provided them with the opportunity to build a social network, evidence of which was also found in a study by Roberts et al. (2009). Comments were also made by parents in the interviews which were consistent with those reported in a study by Cutress and Muncer (2014). By sharing and listening to the views of other parents who were experiencing similar challenges to themselves, it was reassuring to them that they were not alone and, as a result, they experienced fewer feelings of social isolation, and felt better supported emotionally, as they were secure in the knowledge that help was to hand (DFE, 2012). In this way, they began to see their world in a more positive way and realise that others may be in a worse position than themselves, which led to improvements in their wellbeing.

Some parents commented that it was very positive for them to be able to work with their partner to carry out similar strategies for specific behaviours. Collaboration between the parents and their close family, and the ability to make agreed changes to strategies that did not seem to be working, seemed to have a very positive impact on the parents' wellbeing. One parent said that it made family outings 'more pleasurable.' This improved sense of wellbeing arising from the parents building a trust in themselves, was also reported in a study by Roberts et al. (2009). Parallels could be drawn between this current study and Roberts', in that the improved wellbeing which was reported post attendance on an intervention programme enabled them to develop trust in others. Relationships between the parents also improved and the parents began to create links with a community of parents in a similar situation, which helped them develop a sense of belonging. This often resulted in them beginning to enjoy their children more and the experiences they had with them. Comments such as those made in this current study by a parent, that family life had become 'more pleasurable' echo the concept of being able to enjoy their child more.

One parent commented on the positive feelings that they had had after being given positive comments about their child during a parents' evening at school,

and they acknowledged that this was due to the collaboration between school and home and the use of similar strategies. This comment provided further evidence in support of the findings of Roberts et al. (2009) and showed how, through collaborative working, not only had the parent's wellbeing improved, but their child's behaviour had too.

For some parents, the intervention had empowered them to think about themselves more, and to have the confidence to take time out for themselves and to do something that they had chosen to do. Comparison could also be made with a study of parental attendance on a mindfulness programme to help reduce parental stress which showed that, by thinking about themselves, the parents' stress reduced and high levels of satisfaction were also reported (Ferraioli & Harris, 2013).

In addition to the positive comments that parents made regarding their attendance on the programme, during the interviews, they also raised some issues and concerns not directly related to the programme. These might have had an impact on their wellbeing scores at different time points.

The parents described the roller-coaster volatility of their daily lives, which meant there were significant 'ups and downs'. Several of the parents gave the timing of when they were given the questionnaire, i.e. how they were feeling at that time (and where they were on the roller-coaster) as the possible reason why the quantitative score for wellbeing differed from their interview comments. Despite these comments, the parents in this current study endorsed the comments made in a study by McAleese et al. (2014) which found that parents said they enjoyed the secure and nurturing environment provided by the intervention, which enabled everyone to feel relaxed.

In the period following the end of the Intervention, some parents realised that they were now on their own, as they no longer had the support of either the EPs or other parents, and the reality of living with a child with autism was going to be an ongoing challenge, rather than something that could be easily 'fixed'. One parent commented that there had been a 'void' when the intervention had ended, and

there was a concern from some parents that they might 'lose the knowledge they had gained', with a possible associated loss of confidence. Another realised that, whilst the Intervention would not solve everything, it could be 'a starting point for growth'. To help them overcome this 'void' many of the parents expressed a need for some ongoing support.

These concerns might have had an impact of how the parents responded to the questionnaires at different time points within the study. This might provide a reason for the lack of statistically significant differences in the wellbeing quantitative data for the Intervention Group.

There was no statistically significant difference in the mean score for Wellbeing over time for the Control Group. However, the Control Group were subsequently found to be accessing unstructured support which also might have had an impact of how they responded to the questionnaires.

5.3 Research Question 3: Do the parents' views of their child's behaviour change post attendance on the intervention?

From the quantitative data there was a significant main effect of time when looking at the data for the Intervention and Control groups combined over the study period (T1-T3) however, there was no significant effect of group, or interaction between group and time over the study period. Further analysis was unable to identify any significant effects, either by time period (T1-T2 or T2-T3), or within group that might have driven this.

In summary, whilst the scores for the combined data improved over time, there was no statistically significant difference either within, or between, the Intervention and Control Groups, or by time period. The small sample sizes in the individual groups might mean that the sample is underpowered.

Although not statistically significant, evidence from the questionnaires showed some improvement in the Intervention Group scores of the parents' perception of

their child's behaviour over the course of the study, which was consistent with the findings in a previous study of the Cygnet intervention (Stuttard et al., 2016) which found similar evidence, though also not statistically significant. It should be noted that the Stuttard study used the Eyberg Child Behaviour Inventory (1999) as a measure for perceived child behaviour.

The qualitative data collected from the parents in the interviews was however very positive. The parents reported that, due to their attendance on the Intervention, their child's behaviour had changed over the period of the study, which had resulted in an easier life at home. The parents commented that, by changing certain things, they observed that their child's behaviour was not as 'bad' as they had originally thought. Some parents spoke about trying out specific strategies, such as the 'Iceberg' principle, and how they had noticed that this had resulted in an improvement in their child's behaviour.

The parents also said that, by being more able to pre-empt possible difficult times, they were able to plan for and effectively manage the behaviour before it became too challenging, which is consistent with evidence found in Cutress and Muncer's (2014). The study found that the intervention helped the parents feel more able to manage or even prevent the occurrence of challenging behaviours. By avoiding potential challenging behaviours, with a possible reduction in the number of 'meltdowns' occurring, their child's behaviour could be said to have improved, although during the interviews this was not commented on directly by the parents in this current study.

Qualitative evidence in this study appeared to support the findings from Radley et al., (2014) that perceived improvements were reported by the parents of their child's behaviour post attendance on an intervention. Furthermore, this current study found qualitative evidence that was consistent with evidence found in other studies (Preece, 2014; Schultz et al., 2012). These studies found that, if parents were provided with the appropriate skills and strategies, some parents were able to continue to apply the knowledge long after the intervention, by generalising and adapting the strategies to new situations without the ongoing support from the course leaders.

Although parents in this study might not have been able to recognise specific improvements in their child's behaviour, in the interviews, they commented that the intervention had made them more aware of the triggers for certain behaviours, and to also find other ways of resolving them. Therefore, as Pillay et al (2011) suggested in their study, by acquiring knowledge about triggers to behaviours and strategies to manage them, the parents' perceptions may have changed with regard to the way they feel about such behaviours, as they have acquired the skills to be able to manage their child more effectively.   In this way, by reducing the impact of their child's challenging behaviours this could be seen as an improvement in the child's behaviour.

Due to a possible change in perception of their child's behaviour, resulting from their more effective management, pre-emption and avoidance of challenging situations, the parents in this current study might have altered their expectations of what represented 'challenging behaviour' during the period of the study. This re-baselining could then mean that they were assessing their child against a higher standard of what represents challenging behaviour than at the start of the study. They might also be understating the improvement in their child's behaviour by failing to register a problem which would otherwise have occurred, being avoided, or substantially reduced in severity, as an improvement. However, as this current study did not include a direct measure of the child's behaviour this was not able to be confirmed. This might provide a possible reason for the lack of statistically significant differences in the perceived child behaviour quantitative data for the Intervention Group.

There was no statistically significant difference in the mean score for Child Behaviour over time for the Control Group. It was found that the Control Group were subsequently found to be accessing unstructured support which might have influenced the way they responded to the questionnaires.

5.4 Research Question 4: Are there any correlations between the parents' perceived views of self-efficacy, wellbeing and their child's behaviour?

5.4.1 Intervention Group

The literature review highlighted several studies, such as Ferraioli & Harris (2013), that found, or hypothesised, associations between the parents' perceived self-efficacy, wellbeing and child behaviour. The current study found a statistically significant (at .05 level) positive correlation in the Intervention Group scores between perceived competency and wellbeing and perceived wellbeing and child behaviour. There was no significant correlation for the Intervention Group between scores for perceived competency and child behaviour.

5.4.1.1 Self-efficacy and Wellbeing

The parent interviews provided supporting evidence for the positive correlation between perceived competency and wellbeing when parents mentioned the positive experience of being able to attend the intervention on a weekly basis and talking and sharing information with other parents. They commented that, by talking with other parents they were able to gain knowledge of strategies and approaches that had worked for others and they also felt empowered and their confidence had increased.

Other parents spoke about specific sessions they enjoyed which provided them with information which was particularly relevant to their child. Cutress and Muncer (2014) found evidence that by attending an intervention the parents' self-efficacy improved which enabled them to improve the quality of family life in general, which is consistent with the findings in the current study. In this study the parents commented that, the knowledge acquired from the intervention had had a positive effect on them. It gave them the confidence to know that they could manage the 'daily challenges', resulting in them feeling happier and making family life 'easier.'

Another study (McAleese et al., 2014) also hypothesised that, by increasing parental self-efficacy, this could have an impact on reducing parental stress.

Similar reflections were made in a study (Sharp et al., 2014) exploring the effectiveness of a social competency programme found evidence that increased self-efficacy empowered parents to manage their difficulties with a possible reduction in their stress levels. This current study found qualitative evidence to support Sharp's study and the current study's hypothesis that, by increasing parental self-efficacy, this could have an impact on reducing parental stress and increasing wellbeing.

5.4.1.2 Wellbeing and Child Behaviour

The qualitative data collected from the interviews provided supporting evidence for a correlation between perceived wellbeing and child behaviour. Comments made by the interviewees identified that parental wellbeing was dependent on the type of day they were having, as there were a lot of ups and downs and, if they were going through a 'tricky period' with their child, this would have a negative impact on their wellbeing.

Hastings' (2002) model, discussed earlier, suggested that parental stress and challenging child behaviour are connected where one can feed from the other. As one parent stated, if they were having a 'bad day', this could escalate a situation into a 'messy' downward spiral. However, there could also be an inverse to the situation in which the opposite could happen and one parent commented that their bad times could quickly become good times when they observed improvements in their child's behaviour, which was consistent with Hastings' model of the two-way process of parental stress and child behaviour.

Parents also talked about preparing their child for changes in routine, as this not only made the child feel more secure, as they already knew what was expected of them, which made it easier for them, as well as making it easier for the parent and the rest of the family. One parent commented how family outings had become 'more pleasurable' as their child's behaviour had improved. This had particularly helped improve their husband's wellbeing, as he was not the primary carer and he was not as used to certain behaviours,

5.4.1.3 Self-efficacy and Child Behaviour

The quantitative data in this study did not find a statistically significant correlation between perceived competency and perceived child behaviour data. However, themes from the parents' interviews clearly connected the two factors. The parents commented that, by understanding their child's behaviours, they not only knew the reasons why, but how to manage them in a 'different way'. Whilst this knowledge did not necessarily improve the behaviour of the child, and therefore create a connection, the parents now felt more confident to carry out their role and reduce the impact of their child's behaviour. Similar evidence was found in a previous study (Pillay et al., 2011) which reported that there were indications of associations between parents' knowledge of how to manage their child's behaviour and their perceived improvements in that behaviour, but this was based on a small sample and parental perceptions, rather than hard evidence, and thus must be interpreted with caution.

Although few specific references were made to improved behaviour of the child, parents in this current study commented that, by changing their strategies (i.e. using the increased knowledge and self-efficacy that they had acquired from the programme), 'meltdowns' at home were 'not as bad 'and were less frequent. These comments are consistent with those suggested in a study by Clubb (2012). Clubb suggested that attendance on a parent intervention gave parents both knowledge about autism and a skill set which helped them communicate with their child which resulted in possible improvements to behaviour. Similar comments were made by the parents in this study, that the child had become calmer and 'more settled' in their behaviour since they had begun to use a different set of strategies, which could be interpreted as possible improvements in child behaviour.

Evidence was found in this study of the parents making use of their knowledge of strategies to explain to their child about changes, or future events that they were going to attend, which helped the child feel 'more secure.' Similar evidence was found in a study (Stuttard et al., 2014) which showed associations between the parents' self-efficacy and improved child behaviour.

There were also comments made by the parents in the current study that, by having a better understanding of potential causes of the behaviours, as well as the strategies that they could use to manage them, parental self-efficacy had improved. Although there were no specific comments stating that their child's behaviour had improved, parents commented that the use of the acquired knowledge and strategies had helped them to either avoid or modify their child's challenging behaviour. This was supportive of evidence found in a study (Grahame et al., 2015) of associations between parents acquiring knowledge about how to manage restricted repetitive behaviours in children with autism and parental self-efficacy and improved child behaviour. Attendance on the intervention had equipped them with a better understanding of autism and specific strategies which they could use helped improve their self-efficacy. Preece (2014) also reported in a previous study that acquiring greater self-efficacy through knowledge of a range of strategies enabled parents to continue to manage their child's behaviour 12 weeks post course completion, indications of which were also found in the current study.

5.5 Control Group

There was no significant correlation in the Control Group of scores between any of the three questionnaire types. Whilst the mean scores for each questionnaire type improved over the period of the study, potentially as a result of the parents accessing support to help them understand and manage their child in an unstructured way (websites, online discussion groups, etc), the absence of similar correlations to the Intervention Group would suggest that the acquisition of knowledge in this unstructured way does not lead to any consistent and linked improvement across the three areas of the study for the parents.

5.6 Summary

The discussion above has shown that the Cygnet Intervention is beneficial for parents of a child with autism. This was seen from the qualitative data collected from the interviews about the Cygnet programme itself. All the parents interviewed were extremely positive about the programme, not just for the

knowledge they acquired and subsequently able to utilise, but for the contact they had with parents in a similar situation.

It has also showed that there was evidence to suggest that there were statistically significant associations between perceived self-efficacy (competence) and wellbeing and perceived wellbeing and child behaviour for the Intervention Group, which partially supports the hypothesis for the current study. These associations were not however replicated in the Control Group. This suggested that the structured support of the Cygnet programme was potentially a reason why these associations had been found, particularly as it had been subsequently found that the Control Group had also received support during the course of the study. Although associations between all three areas had been suggested, they had not been looked at together in the same study in the literature reviewed.

In addition, the qualitative evidence collected in this study has highlighted the challenges of obtaining reliable quantitative data in studies of this nature where the quantitative data was based on individual's self-report at a point in time and not hard, measurable facts. This was particularly an issue with wellbeing and child behaviour.

Chapter 6: Conclusions

6.1 Limitations

As this was a small-scale research study, it is important to recognise the limitations this presents. Many of these had been acknowledged prior to the start of the study, and were not able to be realistically addressed, primarily due to time constraints and because this study was being carried out by only one researcher.

The researcher's Yr 1 project on the Cygnet programme had produced positive findings in relation to this intervention which were welcomed by the LA. Although the LA had not requested that the researcher carry out a follow-on project, when she approached the Senior EPs to request their permission to carry out a follow-on study this was positively received. In this way, the study could be open to researcher bias in seeking to provide positive results for the EPS and demonstrate support for the team, as this study was carried out by one researcher in an LA where they were currently working.

There was potential for researcher bias to seek to find support for the intervention through the way that the semi-structured interviews were conducted, which may have influenced the interviewees' responses (Vivash, 2015), or selectivity in the analysis of the qualitative data. In order to mitigate this potential researcher bias, independently standardised and validated quantitative measures, completed anonymously, were used to collect objective data for comparison with the qualitative data obtained.

One of the key limitations was the small sample size, which may not therefore be representative of the wider population of parents of a child with autism. The samples were also drawn from a tight geographical area (a single local authority) and consequently also will not reflect the wider demographic of the population.

As well as being a small sample, it was also a self-selecting one. All the parents had chosen to attend the Cygnet intervention and were currently either, attending the sessions, or were waiting to attend. It could be suggested that such a sample

may not represent the wider population of parents of a child with autism, as some parents may not want to attend such a group intervention, either from a practical perspective, in that they could not attend the programme at that time, or they did not think it would be beneficial to them. The participants in this study may not therefore be said to be a random sample and, potentially, therefore not representative of the population of parents of a child with autism. In addition, as no personal data was collected, such as parental age, gender, ethnicity, employment and educational status, it was not possible to analyse and compare it to wider population norms.

This study did not collect data about the cultural and home backgrounds of the parents attending the programme, their fluency in English, or information on the parents' initial understanding of autism. A small number of the participants were of an ethnicity that might have different cultural norms, particularly in relation to 'disability'. Such differences and any issues with their knowledge of the English language might have affected how those participants responded to the intervention and influenced their completion of the questionnaires. It is important that future studies attempt to address this issue to increase the generalisability of the findings.

Although the study did include the collection of data post completion of the course, it would have been beneficial to have a further data collection at, for example, a 6-month time frame as well. This might have identified if there were similar variations seen in the parents' ability to maintain the improvements to the child's behaviour as were found in the study by Stuttard et al. (2014), i.e. how well could the parents adapt and generalise the strategies to new and different situations. This information could have provided more information about the specific needs and/ or the type of ongoing support the parents might need in the future.

Another limitation was that this study was based solely on the parents' perceptions at specific points in time, and therefore only reflected an individual's immediate thoughts and current emotional state. When interviewed, the parents

spoke of living very volatile and stressful lives. As a result, this might account for unexpected or inconsistent variations in their responses to the questionnaires, which were influenced by how they were feeling on the day. Without a clear measure of 'underlying wellbeing' it was difficult to confirm the accuracy of the quantitative data obtained for wellbeing particularly but, potentially, also for the other questionnaires. This difficulty in obtaining an accurate measure for wellbeing was consistent with the comments made by Roberts, et al. (2009) in their review.

Another limitation relating to the parental perception of their child's behaviour was that it was possible that the absence of a correlation between competency and child behaviour could be the result of the parents 'rebalancing' their baseline of acceptable behaviour for their child over time. Potentially, as their child's behaviour improved, their expectations were also raised. The child may thus have been scored against a higher standard over time, as parental expectations of acceptable behaviour had been raised by a general improvement in behaviour over the period of the study.

During the interviews one of the parents mentioned that it should be recognised that some of the parents of the children may also be on the autistic spectrum, as they themselves were, and this could not only have an impact on the way that they manage and respond to their child but could also have an impact on the way that the parents responded to the questionnaires.

A further challenge to the reliability of the findings from this study was that, the majority of the Control Group who completed questionnaires at all three time points, and who had previously confirmed that they were not receiving any form of structured support, were in fact found to be receiving outside support, albeit in an unstructured form, This, potentially, affected their scores as a result, and consequently the comparison of data between the Intervention Group and Control Group.

6.2 Strengths

The current study contributed to research into the value of parent interventions. and, more specifically, the importance of interventions to parents of a child with autism. It also helped fill the gap in research exploring the impact of interventions which support these families identified by Karst and Van Hecke (2012). Despite there being documented evidence of the high levels of need of parents of children with autism and the number and range of interventions available relatively few studies of such interventions have been carried out to date. This study also addressed the comment made by Stuttard et al. (2016), that few studies have focused solely on the Cygnet intervention.

Most of the studies examined in the literature review focused on just one or two areas, or just examined the overall impact of the intervention on the parents and/ or the child, from which the researchers drew possible hypotheses. This study responded to this gap in research by including the three separate areas of self-efficacy (competence), wellbeing and child behaviour and exploring evidence of possible associations between the areas. The area of wellbeing and the impact of it on both the parent and child, had been specifically suggested by Stuttard et al. (2016) as an area for future research in relation to the Cygnet programme.

Another strength of this study was that it used a mixed methods design, which facilitated a richer, broader data set, and helped provide some possible suggestions to explain the results from the questionnaires. As noted above, the quantitative data has potential limitations to their reliability. It also examined not just the means for each group as other studies have, but also looked for associations which may exist between the three areas under scrutiny.

This study found evidence that there were associations between perceived self-efficacy and wellbeing and perceived wellbeing and child behaviour for the Intervention Group which were not found in the Control Group. This suggested that the parents may have benefited from the structured programme, delivered by professionals, creating a more 'joined up' framework for them to work within.

6.3 Implications for future research

As this study was confined to a small sample from a single geographic area, it would be beneficial to extend it further, with a larger sample and to include a comparison with other LAs with different demographics and a broader ethnicity.

It would also be beneficial if a future study included a wider age range of children, i.e. to include more parents of young people of a secondary (11+) age range. As the children were all attending a mainstream school, another area for future research would be to include some parents of children currently in a specialist setting, to add further diversity. Future studies could also explore the impact that the Cygnet programme had on members of school staff who had attended the sessions alongside the parents. It would also be interesting to make a comparison between instances of the intervention being delivered by specialist teachers or EPs.

As this study's sample only consisted of four fathers, one of which was in the Control Group, it was not possible to make comparisons between the impact that the programme had on the fathers and the mothers as had been reported by Hastings & Brown (2002) in their study. Future studies, with a larger sample, could examine the impact that the Cygnet programme had on both parents/ carers which might highlight that mothers could have different needs from fathers, which could depend on which of the parents/ carers spends the most time with the child and is the primary carer.

It would be beneficial if further studies could seek to identify those key factors, such as current level of wellbeing at the time of completing the questionnaires, that might have an impact on the reliability of the parental responses to the questionnaires, either through further longitudinal studies, or experimental designs which aim to manipulate those factors which may impact parental bias, including current family situation, financial status and general mental health (Jones & Prinz, 2005).

This issue of current level of wellbeing could be addressed to a certain extent if an additional question had been added at the end of each set of quantitative data

questionnaires asking the participants to rate their current state of wellbeing, with an explanation as to the reasons why they were rating themselves with that score at that time.

Future areas of research could also explore further the associations between the three areas (self-efficacy, wellbeing and child behaviour) that were scrutinised in this study to identify the validity of these associations.

To address the issue found within this study of the control group accessing unstructured support during the period of the study, further studies could potentially include a placebo control group, where parents meet up with each other, with the same level of contact time as the intervention, to further explore if and why the structured support of the Cygnet programme might be more beneficial. However, Kowalkowski (2013) found that this approach was not successful, as the control group participants abandoned the study after only one or two sessions, mentioning a need for more formal guidance from a trained professional.

6.4 Implications for the practice of Educational Psychologists

This study of a psycho-educational intervention for parents of children with autism and delivered by EPs has shown that the programme has met its aims. Clubb, (2012) in their study noted that EPs, were not only able to provide a valuable contribution to managing group dynamics, but also, able to support the specific needs of individual parents, as their knowledge was able to provide additional insights for the parents as to what it is like to be a child with autism.

Brown et al's. (2012) comments provide further evidence for EPs being the most appropriate professionals to deliver such interventions when they reported that, for an intervention to be effective, it must be delivered by practitioners who are both highly skilled and who have the knowledge to deliver the programme in a therapeutic and empathic way, whilst using their communication skills to engage and facilitate group interactions. EPs also seem to be well-placed to provide the ongoing support that most parents were keen to receive, and to support the development of collaborative team work with schools, to help them in contributing

towards providing consistent strategies and continual support for both the parent and child.

In summary, EPs have the psychological skills which equip them with the ability to engage with children, young people and adults and to support them in developing positive relationships. They also have the psychological knowledge which they can use to gain a better understanding of a situation and the processes to effect appropriate change (Beaver, 2011).

In addition, this study found evidence to show that, although parents thought the Cygnet programme was very beneficial to them, they would also like to be able to access ongoing support from professionals, such as EPs, as well as have a more collaborative and joined-up approach with their child's school. The importance of ongoing support for these parents is consistent with National the Autism Plan for Children (Le Couteur, 2003). Weiss (2002) commented that the knowledge of the availability of support for the parents was as important as the support itself with more emphasis being placed on supporting all the members of the child's 'family' unit as they were reported to provide the greatest benefits to the parents.

6.5 Conclusions

This study has provided additional evidence of the importance of interventions for parents of a child with autism, to support and guide them through their journey which, for these parents, can be a challenging and lifelong experience. The study has shown that the intervention was able to meet its aims (see 1.1 above), as evidenced by the data collected which for the quantitative data was 'to some extent', but not statistically significant for wellbeing and child behaviour. However, there was strong evidence obtained from the qualitative data.

The benefits of the intervention were strongly endorsed through the parents' interviews. The parents commented that attendance on the intervention had been an extremely valuable experience. They spoke of how they had benefited from the structured support of the intervention, as the consistency of the sessions provided them with background information about autism. This enabled them to

build on their knowledge and identify strategies to help them manage their child's behaviour.

This study also highlighted the request that parents made for ongoing support after the end of the programme. The need for continued support was also highlighted in studies such as Weiss (2002), although it must be recognised that there are both practical and financial implications for ongoing support to take place.

Finally, this study provided further evidence of the importance of therapeutic interventions to parents of children with autism, which was consistent with the suggestion made in a narrative review (Da Paz & Wallander, 2017) that, as these parents experienced high levels of stress, they might benefit from targeted support for their own needs, in addition to support for their child. The high levels of stress experienced by the parents, which became apparent during the study, and the impact that this had on their wellbeing, also raised questions about the reliability of the questionnaire scores for this sample of parents.

Future studies of interventions for such parents could support a better understanding of the current symptoms of stress. They could also consider any future mental health costs that might ensue if these signs of stress are not addressed early. as raised in the report by Brown et al. (2012), which commented on the benefits of such interventions, not just for the wellbeing of the parents, but for the possible long-term financial benefits to society as a whole. This has implications for the Cygnet intervention, which currently does not have any specific focus on parental wellbeing, to consider the inclusion of additional time and emphasis on this area.

Perhaps then, more parents would be able to say as a parent in this study said:

'M*aybe it's [the situation] not as bad as I think it is.'*

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Appendix A: Systematic literature review

The following systematic search was conducted in the University College of London Library Services Explore, British Education Index, ERIC, PsycINFO and SCOPUS. Science Elsevier

Abstracts and articles were initially searched for parent intervention programmes. This was then narrowed to parental group intervention programmes* and then group intervention programmes for parents of children with autism*. The search was narrowed further to include one of the terms, competency*, wellbeing*, or benefits to the child*. The more detailed search, following the acquisition of sufficient background information on the development of parent intervention programmes in general over time, was carried out between December 2016 and February 2017, and was confined to studies which focused on parents of children with autism and the children's behaviours.

This search initially focused on articles dated from 2012 to coincide with the DFE (2012), which formed the basis of this study. The search was later extended to include studies of interventions for parents of children with autism carried out pre-2012 in order to broaden and develop the evidence base for this study.

Institute of Education

UCL

Appendix B: Application for Ethical Approval

Ethics Application Form: Student Research

Anyone conducting research under the auspices of the Institute (staff, students or visitors) where the research involves human participants or the use of data collected from human participants, is required to gain ethical approval before starting. This includes preliminary and pilot studies. Please answer all relevant questions in terms that can be understood by a lay person and note that your form may be returned if incomplete.

For further support and guidance please see accompanying guidelines and the Ethics Review Procedures for Student Research http://www.ioe.ac.uk/studentethics/ or contact your supervisor or researchethics@ioe.ac.uk.

Before completing this form you will need to discuss your proposal fully with your supervisor(s).

Please attach all supporting documents and letters.

For all Psychology students, this form should be completed with reference to the British Psychological Society (BPS) Code of Human Research Ethics and Code of Ethics and Conduct.

Section 1 Project details				
a.	Project title		A study exploring the wellbeing and experiences of parents attending the Cygnet Parent Intervention Programme	
b.	Student name		Alison Bates	
c.	Supervisor/Personal Tutor		Anna Remington/ Karen Majors	
d.	Department		Centre for Doctoral Education	
e.	Course category (Tick one)	PhD/MPhil ☐	EdD ☐	
		MRes ☐	DEdPsy X	

		MTeach ☐	MA/MSc ☐
		ITE ☐	
		Diploma (state which) ☐	
		Other (state which) ☐	

f.	Course/module title	Doctoral Thesis
g.	**If applicable,** state who the funder is and if funding has been confirmed.	N/A
h.	Intended research start date	10/16
i.	Intended research end date	5/18
j.	Country fieldwork will be conducted in *If research to be conducted abroad please check www.fco.gov.uk and submit a completed travel insurance form to Serena Ezra (s.ezra@ucl.ac.uk) in UCL Finance (see guidelines). This form can be found here (you will need your UCL login details available): https://www.ucl.ac.uk/finance/secure/fin_acc/insurance.htm*	UK

k.	Has this project been considered by another (external) Research Ethics Committee?	
	Yes ☐	External Committee Name:
	No X ⇨ *go to Section 2*	Date of Approval:

If yes:
  − Submit a copy of the approval letter with this application.
  − Proceed to Section 10 Attachments**.**

Note: Ensure that you check the guidelines carefully as research with some participants will require ethical approval from a different ethics committee such as the National Research Ethics Service (NRES) or Social Care Research Ethics Committee (SCREC). In addition, if your research is based in another institution then you may be required to apply to their research ethics committee.

Section 2 Project summary

Research methods (tick all that apply)

Please attach questionnaires, visual methods and schedules for interviews (even in draft form).

	☐ Controlled trial/other intervention study

X Interviews	☐ Use of personal records
☐ Focus groups	☐ Systematic review ⇨ *if only method used go to Section 5.*
X Questionnaires	☐ Secondary data analysis ⇨ *if secondary analysis used go to Section 6.*
☐ Action research	
☐ Observation	☐ Advisory/consultation/collaborative groups
☐ Literature review	☐ Other, give details:

Please provide an overview of your research. *This should include some or all of the following: purpose of the research, aims, main research questions, research design, participants, sampling, your method of data collection (e.g., observations, interviews, questionnaires, etc.) and kind of questions that will be asked, reporting and dissemination (typically 300-500 words).*

This study will be a follow-on from my Yr 1 Project on the effectiveness of the Cygnet psycho-educational intervention programme for parents of children with an autistic condition. One of the main themes that was identified in this project by the participants was interaction and the importance of meeting others who were also parents of children on the autistic spectrum (ASC). The interaction with like-minded parents was highly valued by the participants and they identified that there was a need for ongoing going support provision beyond the end of the programme.

The Cygnet programme was highly valued by the participants in my previous project because of the programme content and the contact they had with other parents, to follow on, this study will aim to explore in greater depth the effect that the intervention programme had on the parent's wellbeing immediately post completion of the intervention and then 12 weeks later.

 This was an area of future research specifically mentioned by Stuttard, Beresford, Clarke, Beecham & Morris (2016) in their recent quantitative study evaluating the Cygnet Programme

As a follow on from the Yr 1 Research Project which evaluated the strategies that the programme provided to support the parents manage their child's behaviour, this study will also explore whether parental competence had changed as a result of the programme.

The study will also explore the parents' views of the impact that the programme had on their child's challenging behaviour. A recent DFE report (2015) commented that where parents/ carers are provided with support to manage their child's challenging behaviour there is a greater chance of the child's behaviour improving. This finding was also supported by evidence in the report A Chance to Change, commissioned by the Centre for Mental Health (Brown, Kahn & Parsonage, 2012) which suggested that family-based programmes are beneficial, both in improving a child's behaviour and also in providing long-term benefits.

The study will also explore whether there was any connection between the parents' views of their child's behaviour and their wellbeing and seek to identify the medium-term effects of the programme.

I propose using a mixed methods design using three short (i.e. 10 mins to complete) questionnaires, The questionnaires used in the DFE (2012) study of a range of parent intervention programmes will provide one source for such questionnaires I will follow-up the

questionnaires with a semi-structured interview of a sample of the participants, three months after completion of the programme.

Questionnaires

- A Wellbeing questionnaire which will be completed pre and post the Cygnet Programme and again 12 weeks later. The questionnaire asks questions about their current feelings, level of confidence, interest in the world around them and social/ emotional situation whilst bringing up an ASC child.
- A Parental Competency questionnaire which will be completed pre and post the Cygnet Programme and again 12 weeks later. The questionnaire asks for the parents' views on whether they believe they currently possess the appropriate skills, and an assessment of their personal effectiveness, for living with and bringing up an ASC child.
- A child's challenging behaviour questionnaire which will be completed at the start of the programme and 12 weeks after the end of the programme. The questionnaire asks for the parents' current views on the ASC child's behaviour, across a range of challenging behaviour types, and the parent's ability to manage such behaviour.

The size of my sample will be determined by the numbers of parents attending the programmes run in the Local Authority who are willing to participate. This is expected to be between 30- 35 participants including a control group. A pilot study will be carried out with some of the members of the first cohort of the programme which is running this year. The control group will consist of parents of an ASC child who have not attended the programme and who are not receiving any other kind of structured support. They will be asked to fill in the wellbeing and parental competency questionnaires and then this will be repeated, with the addition of the child's challenging behaviour questionnaire, 18 weeks later (to replicate the time-frame from the start of the programme and the12 week post-programme review).

Suggested research questions:

1. Does attendance on the Cygnet programme have an impact on the parents' wellbeing and in what way?
2. Does the Cygnet programme have an impact on the parents' competency to manage their child's behaviour and in what way?
3. Do the parents' views of their child's challenging behaviour change post attendance on the programme, and is this correlated with the parents' wellbeing?

References:

Brown, E.R., Khan, L., & Parsonage, M. (2012). *A Chance to Change. Delivering effective parenting programmes to transform lives.* London: Centre for Mental Health.

Department for Education (DFE). (2015). *Mental Health and Behaviour in schools: Departmental advice for schools staff.* London: Author.

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Section 3 Participants

Please answer the following questions giving full details where necessary. Text boxes will expand for your responses.

a.	Will your research involve human participants?	Yes X	No ☐ ⇨ *go to Section 4*

b.	Who are the participants (i.e. what sorts of people will be involved)? Tick all that apply.		

	☐ Early years/pre-school ☐ Ages 5-11 ☐ Ages 12-16 ☐ Young people aged 17-18	☐ Unknown – specify below X Adults *please specify below* ☐ Other – specify below

	NB: Ensure that you check the **guidelines** (Section 1) carefully as research with some participants will require ethical approval from a different ethics committee such as the National Research Ethics Service (NRES). Parents attending the Cygnet programme and the control group of parents with children recently diagnosed with ASC who have not, as yet, attended the programme (on the waiting list) and are not receiving any other structured support.

c.	If participants are under the responsibility of others (such as parents, teachers or medical staff) how do you intend to obtain permission to approach the participants to take part in the study? **(Please attach approach letters or details of permission procedures – see Section 9 Attachments.)** N/A

d.	How will participants be recruited (identified and approached)? Programme attendees - from the attendees of the individual programmes via the programme leader running the programme.

	For the control group, the Cygnet programme is co-ordinated across XXX by the XXX ASC Outreach Centre (not connected to the EPS) who also maintain the waiting list for the programme. They have details of all children known to the LA diagnosed with ASC and I will ask them to contact potential participants who meet the control group criteria on my behalf seeking volunteers. I will then either work through XXX Outreach Centre (if they are willing) or contact the volunteers directly to send them the Consent Form and questionnaires.	
e.	Describe the process you will use to inform participants about what you are doing.	
	Information letter, Letter of Consent, face to face briefing to all participants	
f.	How will you obtain the consent of participants? Will this be written? How will it be made clear to participants that they may withdraw consent to participate at any time?	
	See the guidelines for information on opt-in and opt-out procedures. Please note that the method of consent should be appropriate to the research and fully explained.	
	Signed Letter of Consent in line with UCL standards for such letters	
g.	**Studies involving questionnaires:** Will participants be given the option of omitting questions they do not wish to answer?	
	Yes X No ☐	
	If **NO** please explain why below and ensure that you cover any ethical issues arising from this in section 8.	
h.	**Studies involving observation:** Confirm whether participants will be asked for their informed consent to be observed.	
	Yes ☐ No ☐ N/A	
	If **NO** read the guidelines (Ethical Issues section) and explain why below and ensure that you cover any ethical issues arising from this in section 8.	
i.	Might participants experience anxiety, discomfort or embarrassment as a result of your study?	
	Yes ☐ No X	
	If **yes** what steps will you take to explain and minimise this? If **not**, explain how you can be sure that no discomfort or embarrassment will arise?	

	Personal observations on the effectiveness of the programme that they have attended, no personal data/ questions involved
j.	Will your project involve deliberately misleading participants (deception) in any way? Yes ☐ No X
	If **YES** please provide further details below and ensure that you cover any ethical issues arising from this in section 8.
k.	Will you debrief participants at the end of their participation (i.e. give them a brief explanation of the study)? Yes X No ☐
	If **NO** please explain why below and ensure that you cover any ethical issues arising from this in section 8.
l.	Will participants be given information about the findings of your study? (This could be a brief summary of your findings in general; it is not the same as an individual debriefing.) Yes X No ☐
	If **no**, why not?

Section 4 Security-sensitive material

Only complete if applicable

Security sensitive research includes: commissioned by the military; commissioned under an EU security call;   involves the acquisition of security clearances; concerns terrorist or extreme groups.

a.	Will your project consider or encounter security-sensitive material?	Yes ☐ *	No X
b.	Will you be visiting websites associated with extreme or terrorist organisations?	Yes ☐ *	No X
c.	Will you be storing or transmitting any materials that could be interpreted as promoting or endorsing terrorist acts?	Yes ☐ *	No X

* *Give further details in **Section 8 Ethical Issues***

Section 5 Systematic review of research

Only complete if applicable

a.	Will you be collecting any new data from participants?	Yes ☐ *	No ☐
b.	Will you be analysing any secondary data?	Yes ☐ *	No X

* *Give further details in **Section 8 Ethical Issues***

*If your methods do not involve engagement with participants (e.g. systematic review, literature review) **and** if you have answered **No** to both questions, please go to **Section 10 Attachments.***

Section 6 Secondary data analysis Complete for all secondary analysis

a.	Name of dataset/s	N/A			
b.	Owner of dataset/s				
c.	Are the data in the public domain?	Yes ☐	No ☐		
			If no, do you have the owner's permission/license? Yes X No* ☐		
d.	Are the data anonymised?	Yes ☐	No ☐		
		Do you plan to anonymise the data?	Yes ☐	No* ☐	
		Do you plan to use individual level data? Yes* ☐	No ☐		
		Will you be linking data to individuals? Yes* ☐	No ☐		
e.	Are the data sensitive (DPA 1998 definition)?	Yes* ☐	No ☐		
f.	Will you be conducting analysis within the remit it was originally collected for?	Yes ☐	No* ☐		
g.	**If no,** was consent gained from participants for subsequent/future analysis?	Yes ☐	No* ☐		
h.	**If no,** was data collected prior to ethics approval process?	Yes ☐	No* ☐		

* *Give further details in **Section 8 Ethical Issues***

*If secondary analysis is only method used **and** no answers with asterisks are ticked, go to **Section 9 Attachments.***

Section 7 Data Storage and Security

Please ensure that you include all hard and electronic data when completing this section.

a.	Confirm that all personal data will be stored and processed in compliance with the Data Protection Act 1998 (DPA 1998). *(See the Guidelines and the Institute's Data Protection & Records Management Policy for more detail.)*	Yes X
b.	Will personal data be processed or be sent outside the European Economic Area? Yes ☐ *	No X

* If yes, please confirm that there are adequate levels of protections in compliance with the DPA 1998

 and state what these arrangements are below.

c.	Who will have access to the data and personal information, including advisory/consultation groups and during transcription? For interviews, no-one other than myself and my thesis supervisors.

During the research

d.	Where will the data be stored? On audio disk and personal PC
e.	Will mobile devices such as USB storage and laptops be used? Yes X * No ☐ *** If yes,** state what mobile devices: Hand held Dictaphone device and personal laptop *** If yes,** will they be encrypted?: No

After the research

f.	Where will the data be stored? Personal PC
g.	How long will the data and records be kept for and in what format? Five years on a secure laptop
h.	Will data be archived for use by other researchers? Yes ☐ * No X *** If yes,** please provide details.

Section 8 Ethical issues

Are there particular features of the proposed work which may raise ethical concerns or add to the complexity of ethical decision making? If so, please outline how you will deal with these.

It is important that you demonstrate your awareness of potential risks or harm that may arise as a result of your research. You should then demonstrate that you have considered ways to minimise the likelihood and impact of each potential harm that you have identified.

Please be as specific as possible in describing the ethical issues you will have to address. Please consider / address ALL issues that may apply.

Ethical concerns may include, but not be limited to, the following areas:

− Methods − Sampling − Recruitment − Gatekeepers − Informed consent − Potentially vulnerable participants − Safeguarding/child protection − Sensitive topics	− International research − Risks to participants and/or researchers − Confidentiality/Anonymity − Disclosures/limits to confidentiality − Data storage and security both during and after the research (including transfer, sharing, encryption, protection) − Reporting − Dissemination and use of findings

Informed Consent

All participants must sign the attached Consent Form to take part in the study. The participants will be informed of their ability to withdraw from the study at any time, and this will be stated on the letter of consent and repeated verbally both at the beginning and end of the interview.

Confidentiality

Confidentiality and anonymity of all the participants will be adhered to at all times and each participant will be given a unique personal identifier that is not traceable back to them as an individual. The data collected will only be used for the purposes of this study and not shared with any other party except in anonymised form i.e. not traceable back to any identifiable individual

Debriefing

At the end of the study the participants will be given a debrief of the research and an opportunity to discuss the study further, either then, or at a later date if they prefer e.g. via email to the researcher. My contact details are provided on the Information Sheet and available via the programme leader.

Section 9 Further information

Outline any other information you feel relevant to this submission, using a separate sheet or attachments if necessary.

Section 10 Attachments Please attach the following items to this form, or explain if not attached

a.	Information sheets and other materials to be used to inform potential participants about the research, including approach letters	Yes X	No ☐
b.	Consent form	Yes X	No ☐
	If applicable:		
c.	The proposal for the project	Yes ☐	No X
d.	Approval letter from external Research Ethics Committee	Yes ☐	No X
e.	Full risk assessment	Yes ☐	No X

Section 11 Declaration

	Yes No
I have read, understood and will abide by the following set of guidelines. ☐	X

BPS X	BERA ☐	BSA ☐ Other (please state) ☐

I have discussed the ethical issues relating to my research with my supervisor. ☐	X
I have attended the appropriate ethics training provided by my course. ☐	X

I confirm that to the best of my knowledge:

The above information is correct and that this is a full description of the ethics issues that may arise in the course of this project.

Name	Alison Bates
Date	22/10/16

Please submit your completed ethics forms to your supervisor.

Notes and references

Professional code of ethics

You should read and understand relevant ethics guidelines, for example:

British Psychological Society (2009) *Code of Ethics and Conduct*, and (2014) *Code of Human Research Ethics*

or

British Educational Research Association (2011) *Ethical Guidelines*

or

British Sociological Association (2002) *Statement of Ethical Practice*

Please see the respective websites for these or later versions; direct links to the latest versions are available on the Institute of Education http://www.ioe.ac.uk/ethics/.

Disclosure and Barring Service checks

If you are planning to carry out research in regulated Education environments such as Schools, or if your research will bring you into contact with children and young people (under the age of 18), you will need to have a Disclosure and Barring Service (DBS) CHECK, before you start. The DBS was previously known as the Criminal Records Bureau (CRB)). If you do not already hold a current DBS check, and have not registered with the DBS update service, you will need to obtain one through at IOE. Further information can be found at http://www.ioe.ac.uk/studentInformation/documents/DBS_Guidance_1415.pdf

Ensure that you apply for the DBS check in plenty of time as will take around 4 weeks, though can take longer depending on the circumstances.

Further references

The www.ethicsguidebook.ac.uk website is very useful for assisting you to think through the ethical issues arising from your project.

Robson, Colin (2011). *Real world research: a resource for social scientists and practitioner researchers* (3rd edition). Oxford: Blackwell.

This text has a helpful section on ethical considerations.

Alderson, P. and Morrow, V. (2011) *The Ethics of Research with Children and Young People: A Practical Handbook.* London: Sage.

This text has useful suggestions if you are conducting research with children and young people.

Wiles, R. (2013) What are Qualitative Research Ethics? Bloomsbury.

A useful and short text covering areas including informed consent, approaches to research ethics including examples of ethical dilemmas.

Departmental use

If a project raises particularly challenging ethics issues, or a more detailed review would be appropriate, you may refer the application to the Research Ethics and Governance Administrator (via researchethics@ioe.ac.uk) so that it can be submitted to the Research Ethics Committee for consideration. A Research Ethics Committee Chair, ethics representatives in your department and the research ethics coordinator can advise you, either to support your review process, or help decide whether an application should be referred to the Research Ethics Committee.

Also see' when to pass a student ethics review up to the Research Ethics Committee':

http://www.ioe.ac.uk/about/policiesProcedures/42253.html

Reviewer 1	
Supervisor name	Anna Remington
Supervisor comments	I confirm that there are no problematic ethical issues associated with this project.
Supervisor signature	
Reviewer 2	
Advisory committee/course team member name	Karen Majors – by email
Advisory committee/course team member comments	
Advisory committee/course team member signature	
Decision	
Date decision was made	1.11.2016 – by email from Karen Majors
Decision	Approved ☒
	Referred back to applicant and supervisor ☐
	Referred to REC for review ☐
Recording	Recorded in the student information system ☐

Once completed and approved, please send this form and associated documents to the relevant programme administrator to record on the student information system and to securely store.

Further guidance on ethical issues can be found on the IOE website at
http://www.ioe.ac.uk/ethics/ and www.ethicsguidebook.ac.uk

Appendix C: Content of the Cygnet sessions

Session 1: Autism and diagnosis

    Introduction to the group

    Aims

    Content

    Introduction to Children with autism

    What is it like to autistic?

    Experience of diagnosis

Session 2: Communication

    Understanding communication

    Building blocks of communication

    What is different in ASCs?

        Understanding communication

        Using communication

    Strategies & resources

Session 3: Sensory issues

    What are the senses?

    Types of sensory issues seen in children with autism

    Associated behaviours

    Strategies to help

Session 4: Understanding behaviour

    Types and functions of all behaviour

    Behaviour and autism

    Underlying difficulties behind the behaviour (Iceberg principle)

Session 5: Managing behaviour

    Using the information (Iceberg principle)

    Analysing and managing the behaviour (STAR analysis)

    Key strategies

    Management strategies

Session 6: Parents' (group) choice

Appendix D: The Parenting Sense of Competency Scale (PSOC)

Parenting Competence Questionnaire

Location:

Unique Personal Identifier:

Time:

For each of the 16 statements below, please consider how it applies to you with respect to your child with ASC.

For each statement please tick one box only from A to F to indicate how much you agree or disagree at the present time.

Please answer each question based on your initial feeling, rather than spending a long time over each.

	A Strongly agree	B Agree	C Slightly agree	D Slightly disagree	E Disagree	F Strongly disagree
1. The problems of taking care of a child are easy to solve once you know how your actions affect your child. I have acquired this understanding						
2. Even though being a parent could be rewarding, I am frustrated now while my child is at his/her present age						
3. I go to bed the same way I wake up in the morning, feeling I have not accomplished much						
4. I do now know why it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated						
5. My mother/father was better prepared to be a good mother/father than I am						

	A **Strongly agree**	B **Agree**	C **Slightly agree**	D **Slightly disagree**	E **Disagree**	F **Strongly disagree**
6. I would make a fine model for the mother/father of another child to follow so that she/he could learn to be a good parent						
7. Being a good parent is manageable, and any problems are easily solved						
8. A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one						
9. Sometimes I feel like I'm not getting anything done as a parent						
10. I meet my own personal expectations in my ability to care for my child						
11. If anyone can find the answer to what is troubling my child, I am the one						
12. My talents and interests are in other areas, not in being a parent						
13. Considering how long I've been a mother/father, I feel thoroughly familiar with this role						
14. If being a mother/father were only more interesting, I would try harder to do a good job as a parent						

	A **Strongly agree**	B **Agree**	C **Slightly agree**	D **Slightly disagree**	E **Disagree**	F **Strongly disagree**
15. I honestly believe that I have all the skills necessary to be a good mother/father to my child						
16. Being a parent makes me tense and anxious						

Appendix E: The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)

Wellbeing Questionnaire

Location:

Unique Personal Identifier:

Time:

Please answer the following questions with respect to your child with ASC.

Please answer each question based on your initial feeling, rather than spending a long time over each.

	None of the time	Rarely	Some of the time	Often	All of the time
1. I've been feeling optimistic about the future					
2. I've been feeling useful					
3. I've been feeling relaxed					
4. I've been feeling interested in other people					
5. I've had energy to spare					
6. I've been dealing with problems well					
7. I've been thinking clearly					
8. I've been feeling good about myself					
9. I've been feeling close to other people					
10. I've been feeling confident					
11. I've been able to make up my own mind about things					
12. I've been feeling loved					
13. I've been interested in new things					
14. I've been feeling cheerful					

Appendix F: The Child's Challenging Behaviour Scale (CCBS)

Child's Challenging Behaviour Questionnaire

Location:

Unique Personal Identifier:

Time:

Please describe your ASC child's current behaviour.

Please answer each question based on your initial feeling, rather than spending a long time over each.

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. My child **never** has tantrums.				
2. My child aggravates others.				
3. My child is **never** aggressive and violent toward others.				
4. My child does not mind when I leave them at home with another adult while I go out.				
5. My child can be stubborn and uncooperative.				
6. I am able to manage the most challenging and difficult behaviours effectively on my own at home.				
7. My child is happy and content at home most of the time.				
8. My child follows the family routine easily.				
9. My child copes well with disruptions to the family routine.				

Appendix G: Semi-structured interview questions

Cygnet psycho-educational intervention programme for parents of children on the autistic spectrum: A study exploring changes in the parents' perceived self-efficacy, wellbeing and their children's behaviour

Interview Questions for Participants

Firstly, can I thank you again for taking part in this Cygnet Programme study, and remind you that I will be recording it for transcription purposes. The interview will last around 30 minutes. I would also like to remind you that your responses will remain confidential and, if at any time during the interview you need further clarification on the question, or feel uncomfortable about responding to any question, please do not hesitate to tell me.

Before I start recording, are there any questions that you would like to ask me?

1. **Overall Programme:**
   a. What did you find the most useful topics of the whole programme and why?
   b. What did you find the least useful topics of the whole programme and why?

2. **Perceived Competence**
   a. How did you feel the programme affected your overall sense of competence in being able to manage your child and why?
   b. Based on your specific responses to the questionnaire, why do you think …………..? (*based on individual's actual responses*)

3. **Perceived Wellbeing**
   a. How did you feel the programme affected your overall sense of wellbeing and why?
   b. Based on your specific responses to the questionnaire, why do you think …………..? (*based on individual's actual responses*)

Pause *I am going to pause for a moment to check that you are happy for me to continue with the interview?*

4. **Perceived Child's Behaviour**
   a. How did you feel the programme affected your child's behaviour specifically, or your view of your child's behaviour, and why?
   b. Based on your specific responses to the questionnaire, why do you think …………..? (*based on individual's actual responses*)

5. Anything else

Is there anything else you would like to share regarding **the programme** itself, how **the programme** affected you or your child's behaviour.

Many thanks for taking part in my project - I have now turned the recorder off and you are welcome to ask me any questions about the project as part of the debriefing session.

Appendix H: Parent Information Sheet

Project Title: Cygnet psycho-educational intervention programme for parents of children on the autistic spectrum: A study exploring changes in the parents' perceived self-efficacy, wellbeing and their children's behaviour

October 2016 – May 2018

Information sheet

Dear Parent

My name is Alison Bates and I am inviting you to take part in my research project. I am a Year 2 Trainee Educational Psychology student at the Institute of Education and, as part of the programme, we are required to undertake a Doctoral Thesis project.

The aim of this project is to explore the experiences of people attending the Cygnet Parent Intervention programme. I am hoping to find out more about the impact that attending the programme has on the wellbeing of the participants and how well participants feel they can manage their child's behaviour. I plan to take this information back to the authority to help them in developing the programme for parents in the future.

You have been invited to take a part as you are just starting the programme and your observations and evaluations would be valuable to this study.

What would I need to do if I took part?

Part 1: Information gathering will initially be three short questionnaires (around 10 mins each) which you will be asked to complete at the start of the programme, at the end of the programme and, finally, at the 12 week follow–up session.

Part 2: At this final session, you may also be invited to take part in a semi-structured interview with myself at a time and location convenient to you. The interview will consist of 8-9 questions seeking your views on the effect that the programme has had on your well–being and competency to manage your child's behaviour. There are no wrong or right answers to these questions, as they are just a reflection of your own thoughts and opinions. The interview will take around 30 minutes and will be voice recorded so it is easier for me to take notes afterwards. The recording will then be destroyed. All your responses will be kept confidential. The two parts of the study are separate, so you can decide whether you want to take part in the interview at a later point. Agreeing to fill in the questionnaires does not mean you have to also do the interview.

Confidentiality

To preserve your anonymity, I will be allocating you a unique person identifier, which I will let you know prior to completing the questionnaires. If you subsequently, at any stage, decide that you would rather not participate, your data will be withdrawn if requested at any time up to 14 days after completion of the final questionnaires, or of your interview whichever is the later. After this point all data will be included, but only in anonymous form.

All data will be stored on a password protected university computer which only myself and the marker have access to. It will not be shared with anyone else other than the Institute of Education and, in a more generic sense, with XXX Educational Psychology Service. All data will be deleted once the work has been graded and I would just like to reiterate that confidentiality will be maintained at all times.

It is of course, entirely up to you whether or not you choose to take part, and I will respect your wishes if you decide to decline and there will be no negative consequences of so doing.

I very much hope that you would like to take part and take this opportunity to share your views and feelings. This information sheet has tried to answer any questions you might have about the project, but please don't hesitate to contact me if there is anything else you would like to know.

Thank you very much for taking the time to read this information sheet.

Kind regards

Alison Bates

If you would like to be involved, please complete the Consent Form and return it with your completed questionnaires.

If you have any further questions before you decide whether to take part, you can reach me at: email address

This project has been reviewed and approved by the UCL IOE Research Ethics Committee.

Appendix I: Parent Consent Form

Project Title: Cygnet psycho-educational intervention programme for parents of children on the autistic spectrum: A study exploring changes in the parents' perceived self-efficacy, wellbeing and their children's behaviour

If you are happy to participate, please complete this consent form and return it with the
completed questionnaires.   **Yes   No**

I've read and understood the information sheet about the research   ☐   ☐

I understand that I can withdraw from the project at any time, and that if I choose to do   ☐   ☐
this within 14 days of the submission of the final set of questionnaires, any data I have
contributed will not be used

I understand that I can contact Alison Bates at any time if I   ☐   ☐
have questions or concerns about the study

I understand that the anonymised results will be shared with   ☐   ☐
XXX Educational Psychology Service and my tutors at the
UCL Institute of Education.

Name and initials _____

Signed _____   Date _____

Subsequent Research

                                                                                                          Yes   No

I am happy for the researcher to contact me with information   ☐   ☐
about the interview phase of the project

Appendix J: Interview Consent Form

Project Title: Cygnet psycho-educational intervention programme for parents of children on the autistic spectrum: A study exploring changes in the parents' perceived self-efficacy, wellbeing and their children's behaviour

If you are happy to participate in an interview, please complete this consent form and return it with the completed questionnaires.

	Yes	No
I've read and understood the information sheet about the research	☐	☐
I am happy for my interview to be audio recorded	☐	☐
I understand that if any of my words are used in reports or presentations they will not be attributed to me	☐	☐
I understand that I can withdraw from the project at any time, and that if I choose to do this within 14 days of the interview, any data I have contributed will not be used	☐	☐
I understand that I can contact Alison Bates at any time if I have questions or concerns about the study	☐	☐
I understand that the anonymised results will be shared with XXX Educational Psychology Service and my tutors at the UCL Institute of Education	☐	☐

Name and initials _____

Signed _____   Date _____

Contact details: email/ phone: _____

Researcher's name: Name and email address

Appendix K: Email inviting parents to participate in the Control Group

Dear Parents

Understanding the experiences of parents of children on the autism spectrum is very important. In particular, understanding the challenges being faced day-to-day helps us provide the best support that we can.

With that in mind, trainee Educational Psychologist and Doctoral student, Alison Bates, is carrying out some important research in connection with the Cygnet Parent Intervention Programme.

She would very much like to hear your views and experiences, as parents who are yet to take part in the Intervention. You would have the opportunity to fill out a few short questionnaires (15 minutes on three occasions). All your answers will be anonymised, so they are not traceable back to you.

If you would like to know more about the study, or to arrange to take part, please email Alison Bates (email address) and she will send you further information.

Your participation in this important research would be greatly appreciated and will not require a significant time commitment.

Very many thanks

Kind regards

Appendix L: De-brief Sheet

Project Title: Cygnet psycho-educational intervention programme for parents of children on the autistic spectrum: A study exploring changes in the parents' perceived self-efficacy, wellbeing and their children's behaviour

October 2016 – May 2018

De-brief

Dear Parent

Thank you for taking part in my research project, your contribution is greatly appreciated.

As you are aware, the aim of this project is to explore the experiences of people attending the Cygnet Parent Intervention programme. When the data is analysed I am hoping to find out more about the impact that attending the programme has on the competency and wellbeing of the participants and how well participants feel they can manage their child's behaviour. I plan to take this information back to the local authority to help them in developing the programme for parents in the future.

Confidentiality and right to withdraw

To preserve your anonymity, you were allocated a unique personal identifier and all data is stored using this identifier. If you decide that you would rather not participate, your data will be withdrawn if requested at any time up to 14 days after completion of the final questionnaires, or of your interview whichever is the later. After this point all data will be included, but only in anonymous form.

All data is stored on a password protected university computer which only myself and the marker have access to. It will not be shared with anyone else other than the Institute of Education and, in a more generic sense, with XXX Educational Psychology Service. All data will be deleted once the work has been assessed and graded and I would just like to reiterate that confidentiality will be maintained at all times.

Results of the research

If you would like to receive a summary of the results obtained from this research project please let me know and I will send you a copy, though please note that this is unlikely to be available until late 2018.

This De-brief note has tried to answer any questions you might have about the project, but please don't hesitate to contact me if there is anything else you would like to know.

Thank you very much for taking the time to read this information.

Kind regards

Alison Bates

If you have any further questions, or would like to receive a summary of the research findings you can email me at: email address

This project has been reviewed and approved by the UCL IOE Research Ethics Committee.

Appendix M: Example extract from interview transcript with initial codes and subthemes

Speaker	Transcript	Initial codes	Subthemes
Int:	I would now like to hear more about your child's behaviour. So how did you feel the programme affected your child's behaviour specifically, or your view of your child's behaviour, and why?		
Parent K:	Well I think it helped me to identify where behaviours were coming from, because we basically said that all behaviours are trying to communicate something so they're behaving in that way because they are unsettled, so what's unsettling them. You know it gives you an opportunity to look for the underlying issue. Um, so I would say, as a result, we're handling specific situations differently, so we're coming up to a holiday, or someone is visiting, or we're going to have a different kind of outing, or whatever. And I'm talking to my husband about this and saying how are we going to handle this? Do you think we should and do you think we should do this or should we take them there as they are going to be unsettled this is going to be different this is gonna bother them, so we're trying to see in advance what things are which would then improve their behaviour when we actually do whatever it is. But also it's I was saying this a couple of days ago it's that kind of mental agility cos we are thinking fast all the time to recognise there's a bit of behaviour that is saying something and to think fast enough like what that is and to be addressing it and to be able to already have the strategy that you see the problem coming and they are going to react badly to that so I'm already	Identifying the triggers behaviours Looking for the cause Solving things together Planning how to manage the behaviour	Understanding the reasons for the behaviour Working together Parenting in a different way

	thinking that if you say something there will be a battle so I'm thinking that if I say something now that will mitigate it, kind of hard work. But I think that I think we've probably ==avoided some messy situations as a result== you don't know because you don't get to do it twice and try it both ways. But certainly, ==some events like Christmas were much more peaceful== than the previous year because we thought about it in that light and I'm trying to ==reduce that stress== so it's that thing of ==they're behaving that way, that's because they're stressed about something, and we want to bring that down, we want to stop that, so we are addressing that.== So, we do still have bad behaviour but and some of it is just bad behaviour as they are still young children ==because we are reading into it why, where's it coming from all the time== I think that we are ahead of it more when we are thinking fast enough. But it's practice isn't it?	Avoiding messy situations Reducing the stress Reading into/ pre-empting possible difficulties	Understanding and planning for the behaviour Parenting differently Understanding the reasons for the behaviour
Int:	So, I'm getting a sense that the programme is probably giving you some insight into some prevention type strategies, and perhaps being able to pre-empt things like Christmas as you say and those other 'hot' times, but also times when you are in a situation where you think actually I think that might trigger something and you think that what can I do to alleviate that or distract the child away from that tricky situation. So, do you think there is quite a lot of prevention that you are doing?		
Parent K:	There is, and it is quite a difficult balance, because what I was thinking there was, if we are in something like the toddler group or something and he's playing with a particular toy truck, whatever, and you can see another child coming and he's got his eyes on that truck it's going to cause a problem and it's going to cause a problem to any child, but that's going to cause a big		

	problem to mine, but if I see that child start to head across the room, maybe I can say that if another child wants to play with it, to share it, or you'll have another time when the sand's gone or something, there's a lot of things, <mark>where if we just say something, if it's a bigger event if you say something the day before so they know what's coming, even if I can say something five seconds before sometimes you can calm it before it happens</mark> .	Planning and/ or pre-empting stressful times	Parenting differently
Int:	It's linked a little bit to your wellbeing and also your child's behaviour. ….. There may be a similar number of difficulties happening but, because you've got this empowerment, knowledge and experience and wellbeing, you are actually able to manage them better. Would you be able to say that there might be an element of that?		
Parent K:	Yeah, and I think that the thing <mark>if I'm feeling overall more confident or that I've got the ideas</mark> in my head then as soon as I see something happening I can go into it like with like <mark>we are going to do this</mark> or if that doesn't work I'm going to do this, <mark>and with a patient voice and a calm attitude maybe rather than just kind of panicking.</mark> Like I can see it starting but I don't know how to handle it and then it's gone too far before you can start. And I think handling them with the patient voice is so hard but it's so hard to maintain but I think that makes a big difference. So, they start screaming over who's going to ride on the buggy when I leave the shop, and you're trying to talk to them calmly and ignore that lady just gave me a really nasty look. <mark>So, it's but it's knowing the quickest way to not let this turn into a massive tantrum</mark> on the floor is to handle it this way now so however much other people may think that <mark>this is the better way.</mark>	Feeling confident and knowing what to do

Having knowledge and confidence | Increased confidence

Parenting differently |

Int:	So, unpicking it a little further. Would you say that perhaps his behaviours have improved as a result of the programme, or do you think it is just your perceptions of being able to handle them better?		
Parent K:	I think there's both so, we think we handle better what doesn't happen most of the time, but I also think about <mark>pre-empting stuff well in advance.</mark> Like we're not even going to take them to that wedding, because that's going to cause problems or, at the time, trying to deflect as it happens means that <mark>some of the stuff doesn't escalate as far as it would have done,</mark> you cut it off sooner, or come up with a different solution to it, and I think we are doing that a lot, all day long.	Pre-empting difficult times and avoidance of them	Understanding behaviour
	We are trying another difficult one like, sometimes, when the kids have gone to bed, and we are having dinner or something, to say when we were in town this morning that really didn't go too well but here's how I saw it, here's how you saw it. <mark>What could we have done differently, we try and take it apart a bit</mark> and say yeah maybe we shouldn't have gone to town on a Saturday morning or maybe if you had paid more attention to the kids that wouldn't have happened <mark>but not to make it into an argument</mark> ideally but where we can both learn and do it differently next time.	Thinking about how to avoid difficult situations	Working together
	We know it's positive, but it doesn't always happen. That's why it generally needs to be after the kids are in bed. You've got to have the day over and you can stop.		
Int:	Thank you, based on your specific responses to the Child Behaviour		

Parent K:	Questionnaire, why do you think your scores between the post programme questionnaire and the 12 week one decreased? Can you think of anything that you are happy to share with me that might have happened during that time that might have influenced your scoring? I am trying to think. I don't know. Do you think that there could anything in my expectation that on just finishing the course – we're going, yes, this is going to solve everything and, actually, you've ==got to settle into reality a bit and go, OK, it's not going to solve everything, but it can be a starting point for growth,== but there might just be a slightly more realistic look at it. I can't think of anything that might have happened. I was on the course for P, but it was becoming increasingly clear that M is also autistic, but completely different so there's a bit of which child I have in mind or a combination of the two. So, we've certainly been developing the fact that there's two of them and so ==we've been throwing strategies at them, but does it need to be different, or what, and trying to work out what things affect M, why he is being stressed,== which might be different from P's things, or they might be the same, or what. So, I think that and then the combination of them when they're together it complicates it a bit. .... But it may be just sibling stuff and they are just siblings as well. They deliberately wind each other up constantly they know each other's weaknesses and the parents' as well.	Being realistic about what you can achieve. Identifying strategies that work best for their child.	Understanding reasons for the behaviour Parenting in a different way.

Appendix N: Additional question for Control Group

Dear Parent

You very kindly participated in my Cygnet research as one of the Control Group and I have just started the final analysis of the data.

I wondered if you could spare me a few minutes of your time to answer the following question, which would help in clarifying a particular point:

Between completing the first and last set of questionnaires, did you access any support relating to working with, or being the parent of, a child with autism?

Yes/No

If your answer was 'Yes', please indicate what type of support it was. (Please indicate as many as you wish/ are relevant.)

a. Informal chat with other parents
b. Facebook group
c. Online forum for parents of children with autism
d. Information from website(s), e.g. National Autistic Society
e. Other - please specify

Many thanks once again for your contributions.

Best wishes

Alison