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DOCTOR OF PHILOSOPHY

Parent-mediated interventions for children with social-communication difficulties

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Parent-mediated Interventions for Children with Social-
communication Difficulties

Bangor University

2015

Emily Bloxham

Table of Contents

Table of Contents

	Page
Thesis Abstract	I
Declaration	II
Acknowledgements	III
Word Count	IV
Paper 1 Literature Review:	1
Parent-mediated early intervention for children at risk for or diagnosed with ASD and the social-communicative parent-child relationship; a narrative review of the literature	
Title Page	2
Journal Submission Guidelines	3
Abstract	14
Introduction	15
<i>Aims</i>	19
Methods	20
Results	21
<i>Study Characteristics</i>	21
<i>Intervention Characteristics</i>	22
<i>Theoretical approaches</i>	22
<i>Intervention approaches</i>	23
<i>Treatment delivery and intensity</i>	23
<i>Child Outcomes</i>	24
<i>Child outcomes in children at risk for ASD</i>	25
<i>Child outcomes in children diagnosed with ASD</i>	26
<i>Parent Outcomes</i>	27
<i>Responsive strategies taught to parents of children at risk for ASD</i>	28
<i>Responsive strategies taught to parents of children diagnosed with ASD</i>	29
<i>Outcomes Related to Parent Satisfaction and Parent Feedback</i>	30
Discussion	31
<i>Strengths and Methodological Limitations</i>	34
Conclusion	36
References	37
Figure Caption Sheet	44
Figures	45
Figure 1: Flowchart of literature search strategy	45
Tables	46
Table 1: Summary of study and intervention characteristics	46
Table 2: Summary of targeted child behaviours and associated outcomes	49
Table 3: Summary of responsive behaviours taught to parents and associated outcomes	51
Appendices	52
Appendix 1a: Author Note	52

Table of Contents

	Page
Paper 2 Empirical Study:	53
Parental Sense and Sensibility: An IPA study of parental experiences of a parent-mediated intervention	
Title Page	54
Journal Submission Guidelines	55
Abstract	66
Introduction	67
<i>Aims</i>	68
Methods	69
<i>Participants</i>	69
<i>Design</i>	70
<i>Procedure</i>	70
<i>Data collection</i>	71
<i>Data analysis</i>	71
<i>Ethical considerations</i>	72
Results	72
<i>Theme 1 The Parent-Child Relationship</i>	73
1.1 <i>Sense of Separateness and Guessing Games</i>	73
1.2 <i>Awareness of Intentional Communication</i>	74
1.3 <i>A Closer Bond</i>	76
<i>Theme 2 Expectations and Processes</i>	77
2.1 <i>The Camera as the Third Eye</i>	77
2.2 <i>You Need to Do It In Order to Know It</i>	78
2.3 <i>PACT as Special Time</i>	80
2.4 <i>Oh, This Is About Me!?</i>	80
<i>Theme 3 Heartbreak, Failure, and Guilt</i>	81
<i>Theme 4 Growth of Understanding</i>	82
4.1 <i>Empowerment</i>	83
4.2 <i>Holding Back and Doing Less</i>	84
4.3 <i>A New Understanding</i>	85
Discussion	86
<i>Clinical Implications</i>	89
<i>Limitations and Future Research</i>	90
References	92
Tables	95
Table 1: Participant characteristics	95
Table 2: Summary and description of themes	96
Appendices	97
Appendix 2a: Author Note	97

Table of Contents

	Page
Paper 3 Contributions to Theory and Clinical Practice:	98
Contributions to Theory	99
Implications for Clinical Practice	102
<i>Improvements to Service Delivery</i>	102
<i>Parental Wellbeing During Intervention</i>	104
<i>The Importance of Fit</i>	105
<i>The Influence of Other Interventions</i>	106
<i>The Role of Diagnosis in Offering Intervention</i>	107
Implications for Future Research	108
Personal Reflections	109
References	113
Ethics Submission:	115
1. IRAS Form	116
2. Study Invitation Letter	147
3. Participant Information Sheet	150
4. Consent Form	155
5. Semi-structured Interview Schedule	156
6. Correspondences Regarding Ethics Submission	162
a. REC approval email and letter	169
7. R&D Response to submission	171
8. Response Letter to R&D	173
9. R&D Approval Letter	175
General Thesis Appendices:	177
Appendix 3a: Semi-structured Interview Schedule	178
Appendix 3b: Example of data analysis based on transcript excerpt	180

Parent-mediated Interventions for Children with Social-communication Difficulties

Thesis Abstract

This thesis examines parent-mediated interventions for children at risk for and diagnosed with autism spectrum disorder (ASD) across three papers. The first paper is a narrative literature review, evaluating parent-mediated early interventions (PMEI) for children up to the age of three years in terms of behaviours related to synchrony. The review identifies specific parent and child behaviours that are targets in diverse interventions. It integrates quantitative and qualitative evidence, and summarises evidence suggesting that PMEIs increase synchrony in parent-child dyads with children at risk for and children diagnosed with ASD. The second paper is a qualitative empirical study, examining parents' experiences of participating in a parent-mediated intervention, using an interpretative phenomenological analysis (IPA) methodology. Seven mothers and one father of children with social-communication impairments were interviewed using semi-structured interviews. Four interrelated themes were identified: *The Parent-Child Relationship* theme described parents' experience of relational and affective changes in the parent-child relationship over time. The impact of experiencing specific aspects of the process of participating in PACT emerged as the theme *Expectations and Processes*. Parents' described participating in PACT evoked significant negative feelings as a result of knowledge gained through PACT (*Heartbreak, Failure, and Guilt*). *Growth of Understanding* captured parents' experience of learning and a sense of empowerment. By taking a qualitative approach this study focused on the process issues rather than the outcomes of the intervention. The third paper integrates findings from the literature review and the empirical study, and discusses implications for theory, future research and clinical practice. This paper also includes personal reflections on the research process.

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Acknowledgements

I would like to thank a number of people who have supported and guided me through the process of completing this thesis. First, I am thankful to my supervisors, Dr Helen Delargy and Dr Helen Healy, for providing the opportunity to embark on this research, and for their encouragement and support throughout. I also wish to thank Dr Gemma Griffith for reading drafts of my work.

To the parents who so generously gave their time and so willingly shared their stories; meeting each of you was an inspiring and enjoyable experience. I have learned so much – thank you.

A very special thank you to my awesome family and friends – my brilliant parents, Anna, Rhi, Theresa, and Jude – all of whom have been so supportive throughout training, and particularly the last few months. As ever, I am so very grateful for your encouragement and support.

Word Count

Paper 1: Literature Review

Parent-mediated early interventions for children at risk for or diagnosed with ASD and the social-communicative parent-child relationship; a narrative review of the literature

Word count without references:	6223
Tables, Figures, References, and Appendices:	3983

Paper 2: Empirical Paper

Parental Sense and Sensibility: An IPA study of parental experiences of a parent-mediated intervention

Word count without references:	6994
Tables, Figures, References, and Appendices:	946

Paper 3: Contributions to Theory and Clinical Practice

Word count without references:	4263
Tables, Figures, References, and Appendices:	364

General Thesis Appendices	1300
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Overall thesis word count:

Total (without references):	17,480
Total of Tables, Figures, References, and Appendices:	6593

Paper 1: Literature Review

Parent-mediated early interventions for children at risk for or diagnosed with ASD and the social-communicative parent-child relationship; a narrative review of the literature

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Abstract

Early diagnosis and intervention in autism spectrum disorder (ASD) is a growing area of research, with more studies focused on children at risk for ASD and young children diagnosed with ASD. Many parents of children with ASD report difficulties communicating with their child. A transactional model suggests that a mismatch between the parent's and the child's communication behaviours may contribute to an increasingly atypical developmental trajectory. The present review examined which specific behaviours within the parent-child social-communicative relationship were targeted by interventions for children at risk for and diagnosed with ASD, and how these behaviours changed following intervention. Fourteen studies were identified for inclusion in the review. Several specific parent and child behaviours pertinent to increasing synchrony within the parent-child interaction were identified. The findings suggest that parent-mediated early interventions for children at risk for and diagnosed with ASD impact on specific parent and child behaviours within the parent-child relationship; it is possible these changes may increase synchrony within the parent-child interaction. Methodological limitations are discussed.

Keywords: ASD, Communication, Synchrony, Parent-mediated intervention, Review

Parent-mediated early interventions for children at risk for or diagnosed with ASD and the social-communicative parent-child relationship; a narrative review of the literature.

Autism Spectrum Disorder (ASD) is a developmental disorder characterised by difficulties with social communication and social interaction alongside restrictive interests and repetitive and rigid behaviours. (DSM 5; American Psychiatric Association 2013; NICE 2011). The estimated prevalence for ASD is approximately 1% (Baird et al. 2006), and the behavioural, social and communicative difficulties associated with ASD have a significant impact on children's social development into adulthood (Howlin Goode Hutton and Rutter 2004). Caring for a child diagnosed with ASD places an emotional and financial burden on families (Falk Norris and Quinn 2014; Vernon Koegel Dauterman and Stolen 2012), and this financial burden increases with increasing symptom severity and increasing child age (Barrett et al. 2012).

Early diagnosis and intervention for ASD is now the expected norm (Department of Health 2004). Consequently, there has been a recent emphasis on identifying early markers of autism and developing effective early interventions for children and their families that may mitigate or prevent the symptoms and severity of disability associated with ASD (Wallace and Rogers 2010; Webb Jones Kelly and Dawson 2014). Social and communication deficits are not only core difficulties in children diagnosed with ASD (Morgan et al. 2014), they are also among the first symptoms observed (Zwaigenbaum et al. 2009). Reduced neural response to eye gaze (Elsabbagh et al. 2012), reduced behavioural attention to social scenes (Chawarska Macari and Shic 2013), and changes in attention disengagement (Elsabbagh et al. 2013) are behavioural characteristics that are observable in infancy and which are predictive of ASD. This focus on early intervention has led to an increase in research with children characterised as being at-risk for ASD. The term 'at risk for ASD' has been operationally defined in numerous ways: having an older sibling with an ASD diagnosis (Green et al. 2015;

Steiner et al. 2013), showing symptoms of ASD (Rogers et al. 2014), or parental concern coupled with scores on risk measures (Kasari et al. 2014). For the purpose of this review, ‘at-risk for ASD’ refers to children that may have an older sibling diagnosed with ASD, and/or may be showing symptoms of ASD as observed by parents or as measured on ASD risk measures, but who did not have a diagnosis at entry into the study. The term ‘diagnosed with ASD’ refers to children meeting criteria for ASD diagnosis on standardised assessment measures such as the Autism Diagnostic Observation Schedule (ADOS; Lord Rutter DiLavore Risi 1999).

Children with social communication difficulties show atypical patterns of interpersonal responsiveness, making it likely that their communication behaviours are difficult for parents to understand (Busch 2009; unpublished dissertation), and therefore difficult to respond to effectively. Indeed, some parents of children with ASD reported feeling unable to form productive two-way relationships with their children (Busch 2009), as well as experiencing a sense of limited personal connectedness with their child (Vernon et al. 2012). Furthermore, evidence suggests that the quality of the interaction between parents and children at risk for ASD differs from that within dyads with typically developing children (Wan et al. 2012). Wan et al. (2012) found that children at risk for ASD were significantly less lively than typically developing controls, while parents were more directive and responded less sensitively in interactions with their child (once the analysis was adjusted for child age and non-verbal developmental level the difference in sensitive responding reached only a non-significant trend). In particular, dyadic mutuality¹, attentiveness to parent and child positive affect at 12 months were predictive of three-year ASD outcomes, while the child’s ASD-related atypical behaviour was not (Wan et al. 2013). Thus it appears that a

¹ Dyadic mutuality is the degree of reciprocity of experience and shared interaction between the parent and child (Elsabbagh et al. 2014).

mismatched or asynchronous interaction style between parent and child may play a significant role in maintaining difficulties within the parent-child communicative relationship.

The present review examined which specific behaviours within the parent-child social-communicative relationship were targeted by parent-mediated early interventions (PMEIs) for children at risk for and diagnosed with ASD. It further examined how these behaviours changed following intervention.

A transactional model provides a framework for how this mismatch may play out over time: the child's intrinsic risk vulnerabilities may impact on the quality of the parent-child interaction, which may increase the child's difficulties, thus contributing to an increasingly atypical developmental trajectory over time (Sameroff 2009; Wan et al. 2013). Importantly, Wan et al. (2013) highlight that this is not a conceptualisation where the parents are seen as responsible for having caused ASD, but rather it emphasises the complexity of interactions between the children's vulnerabilities and their environments. This model also points to the potential of the parent, as the primary care giver², having a significant role in influencing the parent-child interaction by changing their own responses to the child's communication behaviours, and therefore changing the child's environment.

Parental synchrony is a term used to describe a close match between the parent's and the child's affective behaviour, and is built on the parent's moment-to-moment attention, sensitivity and responsiveness to the child's behavioural patterns (Feldman and Eidelman 2004). Thus it can be said that interventions aimed at reducing a mismatch between parent and child communicative styles are in fact increasing synchrony. According to Feldman (2003; 2007), synchrony plays a critical role in development, as the child's positive affect is

² The term parent is used throughout this review to refer to the child's primary care-giver, although it is acknowledged that for some children the primary care-giver may not be a parent.

hypothesised to increase during synchronous exchanges, which is thought to accelerate learning related to relational, self-regulatory, and emotional skills. Furthermore, it is suggested that synchronous exchanges facilitate these behavioural patterns to be internalised, and to subsequently shape the child's development (Feldman 2003; 2007). In line with these hypotheses, Wan et al. (2012) found that child attentiveness to the parent was positively correlated with positive affect in children at risk for ASD, while Siller and Sigman (2002) found that higher levels of parental synchrony were associated with increased joint attention in the short-term, and better language skills in the long-term.

Sensitivity is commonly viewed as the context within which secure attachments are developed (Siller Swanson Gerber Hutman and Sigman 2014). Despite core social deficits in autism, children with ASD can develop secure attachment relationships (Rutgers Bakermans-Kranenburg van IJzendoorn and Berckelaer-Onnes 2004). It has been suggested that it may take children with ASD more time to develop coherent internal working models of the parent and self, possibly due to difficulties with interpreting emotional cues and intentional states (Siller Swanson Gerber Hutman and Sigman 2014). An intervention for children with ASD, which focused on increasing parental responsiveness, resulted in increased parental perception of child attachment in the children randomised to the experimental condition, compared to those randomised to a control condition (Siller Swanson Gerber Hutman and Sigman 2014). Furthermore, it has been suggested that a relationship between early attachment relationships and children's long-term outcomes may be at least in part mediated by children's early joint attention milestones (Claussen Mundy Mallik and Willoughby 2002). While there is emerging evidence for links between the concepts of parent-child synchrony and attachment, these relationships are as yet poorly understood, and a full discussion of these associations is beyond the scope of the present review.

Current recommendations for interventions for children at risk for or diagnosed with ASD should involve the parents, begin as early as possible, and be individualised to the child's particular needs and developmental profile (NICE 2013; Wallace and Rogers 2010). Indeed many early interventions for children at risk for or diagnosed with ASD are parent-mediated, and have been found to play a valuable role in improving early social engagement and interpersonal synchrony by targeting behaviours such as imitation, joint attention, and social reciprocity (Bradshaw et al. 2015; Morgan et al. 2014; Schertz Reichow Tan Vaiouli and Yildirim 2012). Given the importance of social engagement and interpersonal synchrony in facilitating social and language development (Vernon et al. 2012 Koegel et al. 2014), a closer examination of the specific behaviours targeted in PMEIs and pertinent to synchrony within the parent-child social-communicative relationship is warranted.

Aims

Despite the growing interest in PMEIs for children at risk for or diagnosed with ASD, and the hypothesised bidirectional relationship between child risk vulnerabilities and parental synchrony, there is as yet little understanding of how early interventions aimed at supporting families affect the relationship between children and their care givers. In the context of parent-mediated interventions that aim to support the capacity of families to meet the needs of young children with ASD, relationship related outcomes seem particularly relevant (Siller Swanson Gerber Hutman and Sigman 2014). Further research is required to investigate how interventions impact on the parent-child social-communicative relationship, and thus potentially mediate intervention effects (Landa et al. 2010). The present review seeks to address these issues.

First, it focuses on early intervention, thus it considers two groups for whom such early interventions have been developed: children aged three years or less, who are at risk for or have been diagnosed with ASD. Both groups will be discussed in turn.

Second, the review identifies and categorises the parent and child behaviours targeted by PMEIs that are pertinent to synchrony, thus facilitating a better understanding of specific behaviours targeted by PMEIs. In doing so the review endeavours to bring parsimony to a field characterised by diverse interventions with similar features. A review of the outcomes related to language and ASD symptomatology lies outside of the scope of the present paper, and has recently been reviewed elsewhere (Bradshaw et al. 2015; Morgan et al. 2014).

Finally, the review examines the impact of PMEIs on these specific parent and child behaviours. Where reported, parent feedback data will be included in the review.

Methods

A systematic literature search was carried out between October 2014 and March 2015, using the following electronic databases: PsychINFO, Pubmed Central Open Access, and Web of Science. The search terms were used as follows: '*social communication difficulties*' OR 'ASD' OR '*autistic spectrum disorder*' OR '*Asperger's Syndrome*' OR '*autism*' AND '*attachment*' OR '*parental sensitivity*' OR '*child parent interaction*' OR '*child parent relationship*' AND '*intervention*'. Date restrictions were applied to data parameters (2010-2015) in order to reflect the most recent developments in the literature. After the initial search, titles and abstracts were reviewed and included according to more specific inclusion/exclusion criteria:

Inclusion criteria:

- Participants identified as being at-risk for autism due to having an older sibling diagnosed with ASD, meeting minimum criteria on standardised screening and diagnostic measures
- Parent-mediated interventions focusing on social and communication difficulties

Exclusion criteria:

- Studies involving children older than 36 months at entry to the study
- Children with additional diagnoses such as attention deficit/hyperactivity disorder

The review process is outlined in Figure 1, and details the number of papers retrieved and accepted/rejected at each stage. Fourteen suitable papers were identified.

[Insert Figure 1 here]

Fig. 1 Flowchart of literature search strategy

Results

Study Characteristics

Fourteen studies were identified for inclusion in the narrative review, the study characteristics are summarised in Table 1; results for both groups will be outlined in turn.

[Insert Table 1 here]

Nine studies were concerned with children at risk for ASD, and included a total of 318 children between 4 and 31 months of age (Baranek et al. 2015; Carter et al. 2011; Green et al. 2013; Green et al. 2015; Kasari et al. 2014; Koegel et al. 2014; Rogers et al. 2012; Rogers et al. 2014; Steiner et al. 2013). Five studies used a randomised controlled trial (RCT) design (Baranek et al. 2015; Carter et al. 2011; Green et al. 2015; Kasari et al. 2014; Rogers et al. 2012). Two studies used a multiple baseline assessments across participants design (Koegel et al. 2014; Steiner et al. 2013), one study used a case series design (Green et al. 2013), and another used a matched comparisons design (Rogers et al. 2014). The sample sizes of individual studies were small (median=18; range 3-98).

Five studies were concerned with children diagnosed with ASD, and included a total of 219 children, ranging in age from 16 to 36 months (Dawson et al. 2010; Kasari et al. 2010; Landa et al. 2011; Schertz et al. 2013; Wetherby et al. 2014). All five studies used an RCT design. The individual studies were characterised by small sample sizes (median=38; range 23-82).

Intervention Characteristics

Theoretical approaches

All interventions for children at risk of and diagnosed with ASD aimed to improve social communication in children; however, a variety of approaches were used to achieve this. Thirteen studies focused on increasing parental responsiveness and synchrony, and drew on developmental and behavioural theory. Of these, one study focussing on children at risk for ASD also drew on attachment theory (Green et al. 2013). For both the at risk group and the group diagnosed with ASD, the parent-child interaction was a key focus in the interventions.

The remaining study (Koegel et al. 2014) was focused on children at risk for ASD. It aimed at increasing child motivation for social engagement and drew on the social motivation hypothesis of ASD³.

Intervention approaches

The majority of studies for both the at risk group and for children diagnosed with ASD used a modelling and coaching approach for parents (see Table 1), whereby the parent was instructed in the target strategy through a combination of interventionist modelling, use of teaching materials, parent practice with the child, reflection, and feedback. Four interventions for children at risk for ASD (Carter et al. 2011; Green et al. 2015; Green et al. 2013; Kasari et al. 2014), and one intervention for children diagnosed with ASD (Schertz et al. 2013) augmented parent coaching with video-feedback. In all interventions parents were encouraged to complete home practice and/or integrate new behaviours into family routines between sessions.

Treatment delivery and intensity

Of the nine studies concerned with the at risk group, only Carter et al. (2011) used a combination of group education and individual home-based training sessions, the remaining interventions were delivered one-to-one. Of these, six interventions were delivered in the community, usually at home (Baranek et al. 2015; Green et al. 2015; Green et al. 2013;

³ The social motivation hypothesis of ASD seeks to explain the overall decrease in the attentional weight assigned to social information in ASD and suggests that the diminished social orienting, social reward and social maintaining present in ASD may account for a range of behaviours (Chevallier Kohls Troiani Brodtkin & Schultz 2012).

Kasari et al. 2014; Koegel et al. 2014; Rogers et al. 2012). One intervention was delivered in a clinic setting (Rogers et al. 2014), and one was delivered across both clinic and community settings (Steiner et al. 2013).

Of the five studies concerned with children diagnosed with ASD, two interventions used a combination of group education and individual home-based training sessions (Landa et al. 2011; Wetherby et al. 2014). One intervention was delivered in a research setting (Kasari et al. 2010), and one intervention was delivered across both clinic and community settings (Wetherby et al. 2014). Two interventions were individual and were delivered in the community (Dawson et al. 2010; Schertz et al. 2013).

For children at risk for ASD intervention intensity and duration ranged from 10 hours over 10 weeks (Koegel et al. 2014) to 30 sessions plus six phone contacts over six months (Baranek et al. 2015).

Intervention intensity and duration for children diagnosed with ASD ranged from 24 sessions over eight weeks (Kasari et al. 2010) to 20 hours per week over two years (Dawson et al. 2010).

Child Outcomes Pertinent to the Parent-child Communicative Relationship

A number of child behaviours targeted by interventions were identified in the present review as relevant to the parent-child communicative relationship, and were categorised according to the following headings: child engagement⁴, dyadic joint attention⁵, play, affect, eye contact and gesture; summarised in Table 2. The terms used to categorise the child

⁴ Child interacting with the parent.

⁵ Joint attention between the parent and child.

behaviours were developed by grouping together similar child behaviours targeted by the interventions included in this review.

[Insert Table 2 here]

Child outcomes in children at risk for ASD

In the at risk group dyadic joint attention was an intervention target in seven studies (Baranek et al. 2015; Carter et al. 2011; Green et al. 2015; Kasari et al. 2014; Rogers et al. 2012; Rogers et al. 2014; Steiner et al. 2013). Five interventions targeted child engagement (Baranek et al. 2015; Koegel et al. 2014; Rogers et al. 2012; Rogers et al. 2014; Steiner et al. 2013). Three studies targeted child play (Baranek et al. 2015; Kasari et al. 2014; Rogers et al. 2014) and eye contact (Koegel et al. 2014; Rogers et al. 2014; Steiner et al. 2013). Two studies targeted affect (Baranek et al. 2015; Koegel et al. 2014), and one study targeted child gesture (Steiner et al. 2013).

A statistically significant effect size was reported for increased child initiation of joint attention, which ranged from small (Carter et al. 2011), to medium (Green et al. 2015). Increases in eye contact were maintained at follow-up (Koegel et al. 2014). Two studies found increases in child positive affect, which demonstrated a small intervention effect (Green et al. 2015) and were maintained at follow-up (Koegel et al. 2014). Carter et al. (2011) found a small effect on increased child initiation of behaviour requests and frequency of child intentional communication. An increase in child responding to his/her name was found by Koegel et al. (2014), which was maintained at follow-up.

Although the interventions included differed in terms of duration and intensity, and were developed by different research teams, there was overlap of many of the child behaviours targeted in the at risk group. Dyadic joint attention and child engagement were the most common targets for interventions. While effect sizes varied, the evidence suggests that interventions do indeed increase child behaviours that are important for increasing synchrony within the parent-child social-communicative relationship, and that these changes are largely maintained over time.

Child outcomes in children diagnosed with ASD

In terms of interventions targeting children diagnosed with ASD all five studies targeted child engagement (Dawson et al. 2010; Kasari et al. 2010; Landa et al. 2011; Schertz et al. 2013; Wetherby et al. 2014), three targeted dyadic joint attention (Kasari et al. 2010; Landa et al. 2011; Schertz et al. 2013), and one targeted child play (Kasari et al. 2010), while another targeted child affect (Landa et al. 2011). Child eye contact and gesture were not among reported outcome measures for interventions aimed at children diagnosed with ASD (it is of note that these were intervention targets in the at risk group).

Schertz et al. (2013) found a significant medium intervention effect for increased child initiation of joint attention (IJA), which was maintained at follow-up. Landa et al. (2011) found a trend toward significance for a large effect on increased IJA. Effect sizes for child responding to joint attention ranged from medium (Kasari et al. 2010) to large (Kasari et al. 2010; Schertz et al. 2013), and were maintained at follow up (Schertz et al. 2013).

Large effect sizes were found for focusing on faces (Schertz et al. 2013), and socially engaged imitation (Landa et al. 2011). A medium effect at post-test was found for turn taking (Schertz et al. 2013), which continued to increase to a large effect at follow-up. Large

intervention effects were also found for increased functional play (Kasari et al. 2010) and reduced object focus (Kasari et al. 2010).

As was the case for the at risk group, PMEIs for young children diagnosed with ASD varied in terms of duration and length, but there was overlap regarding the child outcomes targeted. Child engagement and dyadic attention were the most common intervention targets. Effect sizes indicated that these behaviours were increased significantly as a result of the intervention. While there was a lack of long-term outcomes, those reported suggested that intervention gains were maintained at follow-up.

Summarising the outcomes for both the at risk and the group diagnosed with ASD, child engagement and dyadic mutuality were the most common child behaviours targeted by PMEIs in both groups. Effect sizes in the at risk group were smaller than those in the group diagnosed with ASD.

Parent Outcomes Pertinent to the Parent-child Communicative Relationship

A number of parent behaviours targeted by interventions were identified as relevant to the parent-child communicative relationship, and were categorised according to the following headings: following the child's lead, imitating the child, responding sensitively to the child's communication, turn taking, reciprocity, contingency, modelling, and positive affect; these are summarised in Table 3. These categories were developed by grouping together similar responsive parent behaviours taught in the interventions included in this review.

[Insert Table 3 here]

Responsive strategies taught to parents of children at risk for ASD

In the at risk group, five interventions targeted the parent following the child's lead during interactions (Baranek et al. 2015; Carter et al. 2011; Kasari et al. 2014; Rogers et al. 2014; Steiner et al. 2013), responding sensitively to the child's communication (Carter et al. 2011; Green et al. 2013; Green et al. 2015; Kasari et al. 2014; Steiner et al. 2013), and contingency (Baranek et al. 2015; Carter et al. 2011; Rogers et al. 2012; Roger et al. 2014; Steiner et al. 2013). Positive affect was an intervention target in four studies (Baranek et al. 2015; Green et al. 2013; Green et al. 2015; Rogers et al. 2014). Imitating the child (Baranek et al. 2015; Rogers et al. 2012; Rogers et al. 2014), taking turns (Baranek et al. 2015; Carter et al. 2011; Roger et al. 2014), and reciprocity (Baranek et al. 2015; Green et al. 2013; Green et al. 2015) were intervention targets in three studies respectively. Modelling was not an intervention target in any of the interventions for children at risk for ASD (it is of note that this was an intervention target in PMEIs for children diagnosed with ASD).

Green et al. (2013) found their intervention increased parental sensitive responding and non-directiveness towards the child for some participants compared to matched controls. Effect sizes for sensitive responding ranged from small (Green et al. 2015), to large (Carter et al. 2011; Kasari et al. 2014) at post-intervention, and were maintained at follow-up (Carter et al. 2011). The effect sizes for non-directiveness ranged from large at post-intervention (Baranek et al. 2015; Green et al. 2015; Kasari et al. 2014), to medium at follow-up (Baranek et al. 2015). Additional reported outcomes were for dyadic mutuality (Green et al. 2015), which showed a small intervention effect, increasing dyadic mutuality. Effect sizes for other reported variables such as percentage of play act ignored by parent (Kasari et al. 2014) did not reach significance.

Although interventions were diverse, there was overlap in terms of the responsive behaviours taught to parents; following the child's lead, responding sensitively and providing contingency were the most common strategies taught by PMEIs. Effect sizes ranged from small to large, and where reported were maintained at follow-up. This suggests that PMEIs were effective in increasing parental behaviours thought to contribute to increased synchrony with in the parent-child social-communicative relationship.

Responsive strategies taught to parents of children diagnosed with ASD

Three interventions for children diagnosed with ASD targeted responding sensitively to the child's communication (Dawson et al. 2010; Landa et al. 2011; Wetherby et al. 2014). Two studies targeted turn taking (Dawson et al. 2010; Schertz et al. 2013), and a further two targeted imitation (Kasari et al. 2010; Landa et al. 2011). Only one study targeted following the child's lead during interactions (Kasari et al. 2010), modelling (Landa et al. 2011), and positive affect (Dawson et al. 2010) respectively. Reciprocity and contingency were not included as intervention targets in any of the studies of children diagnosed with ASD (it is of note that these were strategies taught to parents in the at risk for ASD group). None of the studies of interventions for children diagnosed with ASD reported effect sizes for parental behaviours.

In terms of strategies taught to parents, there was greater heterogeneity between the at risk and the group diagnosed with ASD. Overall, the most common responsive strategies taught in both groups was sensitive responding. Effect sizes reported in the at risk group suggest that PMEIs are effective in increasing responsive behaviours in parents, and that these gains are maintained in at follow-up. No such effect sizes were reported for PMEIs for

children diagnosed with ASD, thus it is unclear to what extent these interventions impacted on parent responsiveness.

Outcomes Related to Parent Satisfaction and Parent Feedback

Three studies of interventions for the at risk group (Green et al. 2013; Rogers et al. 2014; Steiner et al. 2013) and one study focusing on children diagnosed with ASD (Schertz et al. 2013) reported outcomes for parent satisfaction. These indicated that parents were generally satisfied with the intervention they had received, giving ratings of four or above on a 5-point Likert scale self-report measure. Green et al. (2013) reported data from post-intervention interviews carried out to explore intervention acceptability. This highlighted parents' learning: all parents reported increased awareness of their child's communication with them and of the interaction: "It makes you look really closely at what your interaction with your child is and there is much more in it than you really thought"; and "It's amazing watching back how much she understands and how much she's taking in and communicating with you and you just don't notice" (Green et al. 2013 p. 2508). It further identified increased recognition of the child's emotionality and intentionality as additional benefits of participating in the intervention: "I was like – maybe he hasn't yet developed emotions...But through the sessions I found out that actually, no it was just the way that you do things and now he's full of energy" and "It made me aware he does have feelings and he gets them across. Before I ignored it and thought it's just baby grunting" (Green et al. 2013 p. 2508). Furthermore it highlighted aspects of the intervention that parents found the most helpful, such as reviewing video content, while also identifying aspects of the intervention parents found difficult, such as initially feeling awkward being video recorded (Green et al. 2013).

Discussion

The present review sought to identify the parent and child behaviours targeted by PMEIs for children at risk for or diagnosed with ASD, and to examine the effect of such interventions on these specific parent and child behaviours that are pertinent to synchrony within the parent-child social-communicative relationship.

A small number of studies that investigated PMEIs for children at risk for ASD and for those diagnosed with ASD was identified. These were characterised by small sample sizes and, reflecting that research of early intervention in ASD, whether for children thought to be at increased risk or those already diagnosed, is an emergent field of study. Although interventions were developed by different research teams, and were different in terms of the duration, intensity and the settings in which they were delivered, there was some similarity in terms of both the parent and the child behaviours that were targeted by the interventions. In terms of child behaviours, child engagement and dyadic mutuality emerged as the most commonly targeted behaviours for both children at risk for and children diagnosed with ASD, and effect sizes suggested that interventions were effective in increasing these. In terms of responsive parenting strategies, greater heterogeneity was identified; however, the most common strategy taught in both groups was sensitive responding. Effect sizes indicated that PMEIs were effective in increasing parental sensitive responding in parents of children at risk for ASD. No such data was available for children diagnosed with ASD, precluding any conclusion about the effectiveness of PMEIs in changing parents' behaviour in this group, and also pointing to a significant gap in the literature.

The majority of studies for both participant groups aimed to increase parental synchrony through interventions informed by behavioural and developmental theory and employed a coaching and mentoring approach with parents. A relatively recent development

appears to be the increasing use of video feedback to supplement parent coaching, all aimed at increasing parents' understanding of their child's patterns of communication and interaction. Thus these studies reflect current recommendations for clinical interventions (NICE 2013).

From the description of each intervention a number of parent and child behaviours were identified as being intervention targets and as also being pertinent to the concept of synchrony, i.e. facilitating a close match between the parent's and the child's affective behaviour. These behaviours were grouped together according to similarity and yielded the following categories for children: engagement, dyadic joint attention, play, affect, eye contact and gesture. The same approach was taken for parent behaviours and yielded the following categories: following the child's lead, imitating the child, responding sensitively to the child's communication, turn taking, reciprocity, contingency, modelling, and positive affect. It is acknowledged that this method of grouping may be somewhat arbitrary, and that there may be considerable overlap between the specific strategies used: for example, following the child's lead, imitation, turn taking, providing contingency, reciprocity, and positive affect may all be considered as ways of responding sensitively to a child's communication attempts. Similarly, engagement and dyadic joint attention may be comprised of play, affect, eye contact, and gesture. Nevertheless, parent and child behaviours were categorised to facilitate an overview of similarities and differences in these behaviours targeted by diverse interventions with common goals.

The most frequently targeted child behaviour for the at risk for ASD group was dyadic joint attention, while child engagement was the most frequently targeted child behaviour for the group of participants diagnosed with ASD. However, overall there was considerable similarity among the child behaviours targeted by interventions for both groups of children. Effect sizes were reported for only a small number of dependent variables (such

as joint attention; Carter et al. 2011; Green et al. 2015), and ranged from small to large, with some effects being maintained at follow-up. While the paucity of effect sizes reflects the nascent nature of the evidence base, the direction and maintenance of gains suggests that PMEIs for children at risk for and diagnosed with ASD may impact on child behaviours pertinent to synchrony and contribute to an increase in synchrony within the parent-child social-communicative relationship.

In terms of parental behaviours, the most frequently targeted behaviours within the at risk group were following the child's lead, responding sensitively, and providing contingency, while sensitive responding, turn taking and imitation were the most frequently targeted parent behaviours for the group of participants diagnosed with ASD. Effect sizes were only reported in studies of the at risk group; none of the interventions for children diagnosed with ASD reported effect sizes. This may reflect a focus on child outcomes rather than parent outcomes in the literature of early intervention in ASD. The effect sizes that were reported ranged from small to large, with some maintenance at follow-up for sensitive responding and non-directiveness (Carter et al. 2011; Baranek et al. 2015). This provides evidence that PMEIs for children at risk for and diagnosed with ASD may increase parental synchrony and contribute to an increase in synchrony within the parent-child social-communicative relationship.

Other outcomes of interest in the context of this review were parent satisfaction data, which were only reported by a minority of studies. Those that did report such data provided evidence to suggest that participants were generally highly satisfied with PMEIs. Given the suggestion that children with social communication difficulties may be difficult to understand (Busch 2009), the qualitative data included in the present review are of interest, as they highlight changes in parental perception of their child's understanding and ability to communicate (Green et al. 2013). This suggests early interventions aimed at improving social

communication difficulties may indeed result in altering parental perception of their child's communication, and thus result in increased mutual understanding and increased synchrony. Further research examining parental perception of children's social communication difficulties may serve to inform this hypothesis.

The outcomes of this review suggest that PMEIs impact on several specific parent and child behaviours pertinent to synchrony, although effect sizes varied. However, taken together with the high level of satisfaction reported by participants, these findings point to important clinical implications for service delivery. In particular services may want to consider interventions that target the parent-child interaction. Furthermore, such interventions may be helpfully offered to families in the absence of a diagnosis or while waiting for an assessment, and as such may provide families with access to support at what is likely to be difficult time.

Strengths and Methodological Limitations

This review was based on a systematic search strategy with a focus on recent literature to capture the most recent developments in the field. It brought together data regarding two distinct groups to whom early interventions in ASD are offered: children thought to be at increased risk for ASD and very young children diagnosed with ASD. Furthermore, it brought together data from a variety of sources such as controlled trials, pilot designs, case series and qualitative interviews. In doing so the review identified areas where there is currently a lack of research, such as studies based on larger samples with longer follow-up periods, and studies with comparisons against other interventions rather than treatment as usual or wait list control groups. Furthermore there is currently a lack of data

regarding the effectiveness of PMEIs in increasing synchronous parent behaviours in intervention studies of children diagnosed with ASD.

This review sought to examine the effect of parent-mediated interventions on specific parent and child behaviours pertinent to synchrony, and in so doing summarised and categorised diverse intervention targets. Each study included in this review may differ in their operational definition of these intervention targets, thus it is acknowledged that there may be some overlap between the categories identified. This was a pragmatic decision made to facilitate comparison of specific aspects of diverse interventions with similar goals. Consequently it is not possible to draw any firm conclusion regarding the frequency with which specific strategies are used across the studies reviewed.

Although not the focus of the present review, it was noted that reported child outcomes for language and developmental outcomes varied greatly. It is possible that this heterogeneity reflects not only the diverse sample (some participants were diagnosed with ASD, while others were deemed to be at risk as defined by a variety of measures), different study designs (some were randomised trials, some used small samples and pilot/case study designs), varied interventions (e.g. some interventions had a group element, some were solely individual, and treatment length varied). Future research should aim to replicate and extend findings regarding language, developmental, and parent-child synchrony outcomes.

Given that this review took a narrative approach, it has some limitations which are inherent in the narrative review design, such as risk of author bias (Green Johnson and Adams 2006). As a result the author took care to follow a systematic search protocol, and to write in an unbiased manner, which may have been helped by the fact that the author was new to this field of research. Further limitations of the design are that it does not allow for

conclusions of relative effectiveness between studies, nor for conclusions regarding the relationship between variables of interest.

Conclusion

The aim of the present review was to examine the literature on PMEIs for children at risk for or diagnosed with ASD with particular reference to parent and child behaviours relevant to increasing synchrony within the parent-child social-communicative relationship. Despite the heterogeneity of the studies included, similarities in terms of study aims, particular parent and child behaviours targeted by interventions, theoretical models informing intervention design, and coaching approaches used with parents were noted. Based on an examination of recent literature it can be said that PMEIs appear to impact on specific parent and child behaviours within the parent-child relationship. This may be due to increased sensitive responding in the parent, and increases in engagement in the child. These changes would be hypothesised to increase synchrony in the parent-child interaction. However, further research is required to address the gaps in the current literature.

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Note. Studies reviewed in this paper are indicated by an asterisk.

Figure Caption Sheet

Figure 1.

Fig. 1 Flowchart of literature search strategy

Figure 1 top

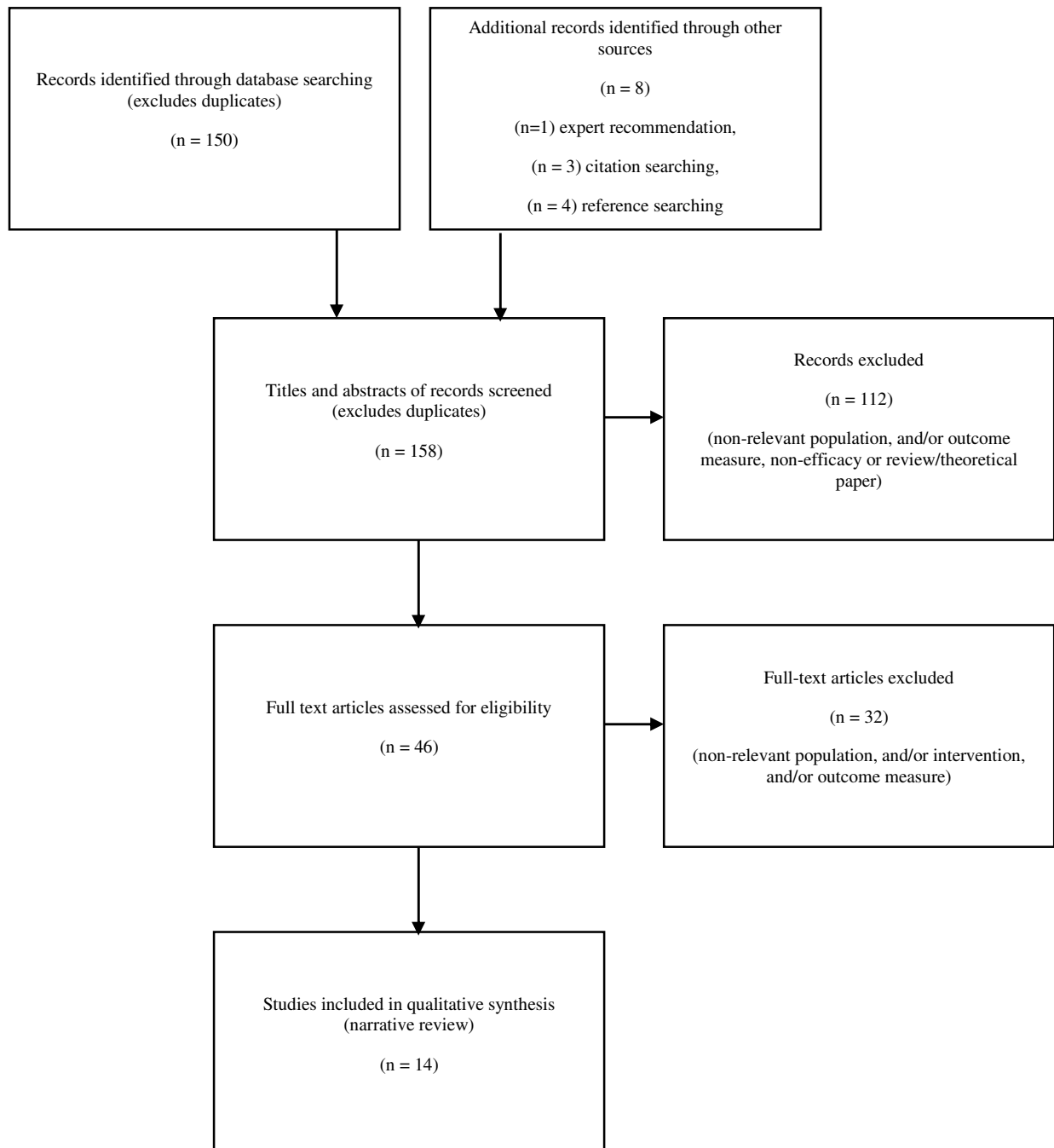


Table 1 Summary of study and intervention characteristics

Study	Country	N	Design	ASD risk/diagnosis	Intervention approach	Intervention length
Baranek et al. (2015)	USA	18	Randomised controlled trial with treatment as usual group	Infants at risk for ASD, based on screening measure, parental concern and family history	Adapted Responsive Training (ART) <i>Theoretical model:</i> not stated <i>Aims:</i> improving parental responsiveness and child development outcomes <i>Approach:</i> individual, home-based modelling & coaching, parent-mediated, routine-based	30 sessions, plus 6 phone contacts, over 6 months
Carter et al. (2011)	USA	62	Randomised controlled trial, with no treatment control group	Met symptom criteria for ASD on screening tool	Hanen's More Thank Words (HMTW) <i>Theoretical model:</i> developmental and behavioural theory <i>Aims:</i> teach parents strategies aimed at improving two-way communication <i>Approach:</i> group and individual home-based sessions (incorporating video-feedback), parent-mediated	8 group sessions plus 3 individual session, over 3 months
Green et al. (2013)	UK	7	Case Series, n=7 at risk group compared to n=37 high risk group (HR), and n=33 low risk group (LR)	At-risk: Older sibling diagnosed with ASD and use of screening measures	Intervention in BASIS (iBASIS; based on Video Interaction for Promoting Positive Parenting and elements of Preschool Autism Communication Therapy, PACT) <i>Theoretical model:</i> developmental theory <i>Aims:</i> increase parental synchrony <i>Approach:</i> individual home-based learning through observation of video feedback, parent-mediated, routine-based, includes daily structured 30 minute home practice	12 sessions over 5 months, initially weekly sessions, then reduced in frequency
Green et al. (2015)	UK	54	Randomised controlled trial, with no treatment control group	Older sibling with a diagnosis of autism	Modified Video Interaction for Promoting Positive Parenting (iBASIS VIPPP) <i>Theoretical model:</i> developmental theory <i>Aims:</i> Increase parents' understanding of infant's communication style, increase parental responsiveness, improve infants' social & communication outcomes <i>Approach:</i> Individual, home-based, use of video to aid parental learning, parent-mediated	6 sessions plus 6 planned booster sessions over 12 weeks
Kasari et al. (2014)	USA	66	RCT: FPI vs monitoring group	Parental concern and use of screening measures	Focused Playtime Intervention (FPI): <i>Theoretical model:</i> not stated <i>Aims:</i> understanding child's communication skills, increase responsiveness <i>Approach:</i> coaching, modelling, practice and feedback (including video feedback), individual, home-based, parent-mediated	12 x 90 minute session weekly over 12 weeks

Koegel et al. (2013)	USA	3	Multiple baseline assessment across participants, staggered over 3, 5, & 7 weeks for each participant Included 2 month, 6 month follow-up	Parental concern (n=2), older sibling with diagnosis of ASD (n=1) Paediatrician confirmed parental concern, plus intake screening at the start of the study	Modified Pivotal Response Training: <i>Theoretical model:</i> developmental and behavioural theory, social interactionist theory <i>Aims:</i> increasing infant motivation for social interaction based on classical conditioning principles <i>Approach:</i> individual, home-based coaching, including practice with feedback, routine-based	1 hour/week, between 10 and 17 sessions were delivered
Rogers et al. (2012)	USA	98	Randomised controlled trial with treatment as usual group	Meet cut off criteria on measures, judgement by two independent clinicians	<i>Theoretical model:</i> developmental theory <i>Aims:</i> teach responsive strategies and promote dyadic engagement <i>Approach:</i> individual home-based coaching and modelling (including practice with feedback), routine-based	12 x 1 hour sessions over 12 weeks
Rogers et al. (2014)	USA	7	Pilot matched comparisons study (matched on gender, AOSI and MSEL scores), HR, LR and Autism Outcome (AO) comparison groups	Symptomatic of ASD and familial risk (older sibling with ASD diagnosis)	Parent-implemented ESDM (P-ESDM): <i>Theoretical model:</i> developmental theory <i>Aims:</i> teach responsive strategies <i>Approach:</i> delivered in clinic, individual coaching and modelling (including practice with feedback)	12 x 1 hours weekly sessions
Steiner et al. (2013)	USA	3	Pilot study, multiple baseline assessment across participants	Older sibling diagnosed with ASD	Pivotal Response Treatment (PRT): <i>Theoretical model:</i> behavioural theory <i>Aims:</i> teach responsive strategies to improve social communication by targeting pivotal areas of motivation <i>Approach:</i> Individual, modelling and coaching (including practice with feedback), delivered in clinic and at home	10 x 1 hour weekly sessions over 3 months
Study	Country	N	Design	ASD risk/diagnosis	Intervention approach	Intervention length
Dawson et al. (2010)	USA	48	Randomised controlled trial with treatment as usual group	ASD or PDDNOS – meeting criteria for ASD on ADOS & clinical diagnosis based on DSM IV	Early Start Denver Model (ESDM) <i>Theoretical model:</i> developmental and behavioural theory <i>Aims:</i> address the needs of infants at risk for/diagnosed with ASD <i>Approach:</i> individual, home-based, therapist and parent delivered, relationship – based, routine-based	20 hours/week, over 2 years
Kasari et al. (2010)	USA	38	Randomised controlled trial, with waitlist control group	Met criteria for clinical diagnosis of ASD structured and observational measures	Joint Attention Intervention: <i>Theoretical model:</i> developmental and behavioural theory <i>Aims:</i> Increase responsive skills and facilitative interaction <i>Approach:</i> individual, modelling, guided practice and feedback, delivered in research setting	24 sessions, three sessions per week over 8 weeks

Landa et al. (2011)	USA	28	Randomised controlled trial, individual augmented intervention compared with basic group intervention	ASD diagnosis – meet criteria on ADOS & diagnosed with ASD by expert clinician	<i>Theoretical model:</i> developmental theory, <i>Aims:</i> teach responsive strategies, increase interpersonal synchrony <i>Approach:</i> group plus individual sessions, parent-mediated	38 hours parent-education classes, 1.5 hours per month home-based training for 6 months, over 6 months
Schertz et al. (2013)	USA	23	Randomised controlled trial with treatment as usual group	Scores above cut off on assessment measure	Joint Attention Mediated Learning (JAML): <i>Theoretical model:</i> developmental theory and mediated learning <i>Aims:</i> increase understanding of function of child communication, focus on parent-child interactions <i>Approach:</i> individual home-based coaching (including practice, video feedback, guided reflection), parent-mediated, relationship-based	Weekly sessions over seven months
Wetherby et al. (2014)	USA	82	Randomised controlled trial comparing individual treatment to group treatment	ASD diagnosis given between the age of 16 and 20 months	Manualised Social Communication, Emotion Regulation and Transactional Supports (SCERTS) curriculum: <i>Theoretical model:</i> developmental theory <i>Aims:</i> Increase joint attention/responsivity Teaching parents how to support active engagement in natural environments <i>Approach:</i> individual and group delivered, coaching and modelling (including), practice and feedback, skills-based, relationship based, routine-based	Individual treatment condition: 24 sessions over 9 months Group treatment condition: 1 session/week over 9 months

Table 2 Summary of targeted child behaviours and associated outcomes

Study	Intervention Targets						Associated Outcomes*
	Child engagement	Dyadic joint attention	Child play	Child affect	Child eye contact	Child gesture	
Baranek et al. 2015	X	X	X	X			MSEL ^a Receptive Language 0.704 L + non-significant decrease at f/u VABS ^b Expressive Communication 0.940 L; non-significant reduct at f/u VABS Receptive Communication 1.514 L; 0.650 at time 3 VABS socialisation 1.852 L, non-significant reduction at time 3
Carter et al. 2011							Frequency of initiating joint attention: T1 to T2 .00 95% CI (-.58, .58), T1 to T3 .12 95% CI (-.46, .70) Frequency of initiating behaviour requests: T1 to T2 .00 95% CI (-.58, .58), T1 to T3 .16 95% CI (-.42, .74) Frequency of intentional communication: T1 to T2 .00 95% CI (-.80, .80), T1 to T3 .16 95% CI (-.57, .88) PIA ^c -CV non-verbal communication: T1 to T2 .00 95% CI (-.64, .64), T1 to T3 -.19 95% CI (-.81, .43)
Green et al. 2013							AOSI ^d : 2 cases showed $\geq 1.5SD$ compared to high risk group MSEL expressive language: 1 case showed $\geq 1.5SD$ compared to high risk group, 1 case showed $\geq 1.5SD$ compared to low risk group
Green et al. 2015		X					Infant attentiveness 0.29 (-0.24, 0.86) Infant affect 0.19 (-0.42, 0.82) AOSI Total Score 0.50 (-0.15, 1.08) MSEL receptive language -0.42 (-0.99, 0.07) MSEL expressive language -0.24 (-0.90, 0.28) MCDI ^e receptive language -0.17 (-0.79, 0.42) MCDI expressive language -0.21 (-1.00, 0.46) MCDI gestures -0.01 (-0.52, 0.5) VABS communication -0.36 (-1.04, 0.31) VABS socialisation 0.42 (-0.07, 0.98)
Kasari et al. 2014		X	X				Outcomes did not reach statistical significance
Koegel et al. 2013	X			X	X		(Observational data) Baseline: little to no positive affect, increase in positive affect during intervention, & maintained 6 months and 2 month follow-up for all participants Baseline: active avoidance/some avoidance of eye contact, to reduced avoidance of eye contact during intervention, & maintained at 6 and 2 month follow-up for all participants Response to name increased during intervention and maintained at follow up (percentage of time responding to name: from 10% to 70%; 0-29% to 50%; 6 to 48/50% respectively per participant)
Rogers et al. 2012	X	X					Effect sizes ranging from small to large on various measures (MSEL, VABS, MCDI), but significance is not reported
Rogers et al. 2014	X	X	X		X		ASD risk group (intervention group) compared to matched ASD diagnosis (AO) group, High Risk (HR) group, Low Risk (LR) group, and Declined Referral (DR) group Intervention group had significantly more symptoms than all comparison groups, except DR, at 36 month follow-up Intervention group had significantly lower ADOS severity scores than AO or DR groups MSEL visual receptive: at 36 month follow-up IV group had significantly higher scores than DR group MSEL language development: at 36 month follow-up Intervention group had higher scores than DR

Steiner et al. 2013	X	X			X	X	Percentage of intervals with child functional communication: Case 1: 0.8 (baseline) to 21.9 (intervention) to 11.6 (post-intervention) Case 2: 4.4 (baseline) to 16.1 (intervention) to 43.3 (post-intervention) Case 3: 5.6 (baseline) to 31.9 (intervention) to 36.6 (post-intervention) MSEL report t scores, at 36 months, majority of subscale scores fell within 1 SD of the mean, 1 participants diagnosed with ASD
	Intervention Targets						
Study	Child engagement	Dyadic joint attention	Child play	Child affect	Child eye contact	Child gesture	Associated Outcomes*
Dawson et al. 2010	X						(Comparison of mean change points from baseline) MSEL Early Learning Composite: 1Y; 4.4. v 15.4; 2Y 7.0 vs 17.6 MSEL Visual Reception: 1Y; -1.7 v 5.6 VABS Communication: 2Y -0.7 vs 13.7 VABS Daily Living: 2Y -14.5 vs -6.2 VABS Motor Skills: non-significant 1Y, 2Y -23.1 vs -9.9
Kasari et al. 2010	X	X	X				Percentage of time in object engagement: ES 1.09 post-intervention Percentage of time in time joint engagement: ES 0.87 post-intervention Frequency of child's response to joint attention; ES 0.74 post-intervention Frequency of functional child play acts: 0.88 post-intervention
Landa et al. 2011	X	X		X			Socially engaged imitations (SEI, proportions of imitations paired with eye contact): ES 0.86, at follow-up
Schertz et al. 2013	X	X					(Observations) Focusing on faces: ES 1.24 post-intervention, ES .84 at follow-up Turn taking: ES .55 post-intervention, ES .10 at follow-up Responding to joint attention: ES 1.36 post-intervention, ES 1.18 at follow-up Initiating joint attention: ES .70 post-intervention, ES .58 at follow-up VABS communication: ES .59 MSEL receptive language: ES .34
Wetherby et al. 2014	X						Significant greater improvement in individual intervention condition on (Common Language Effect Size; CLES): CSBS ^f social composite (0.63) VABS communication (0.69) VABS daily living (0.66) VABS socialisation (0.68) MSEL receptive language (0.66)

^aMullen Scales of Early Learning (MSEL; Mullen 1995; standardised developmental assessment measuring early motor, language and cognitive development in children aged 0 to 68 months)

^bVineland Adaptive Behaviour Scales (VABS; Sparrow Cicchetti & Balla 2005; parent-reported measure of adaptive behaviour on domains of motor skills, communication, socialisation, and daily living skills, yielding age-normed competency levels)

^cParent Interview for Autism – Clinical Version (PIC-CV; Stone Coonrod Pozdol & Turner 2003; parent interview report measure of autism symptom severity for children between 20 months and 5 years 11 months old)

^dAutism Observation Scale for Infants (AOSI; Bryson Zwaigenbaum McDermott Rombough & Brian 2008; semi-structured observational assessment of behavioural risk markers for children with ASD, and assesses attention, sensory behaviours and motor skills)

^eMacArthur-Bates Communicative Development Inventory (MCDI; Fenson Bates Dale Marchman Reznick & Thal 2007; parent-reported measure of vocabulary and gesture)

^fCommunication and Symbolic Behaviour Scales (CSBS; Wetherby & Prizant 2002; standardised, norm-referenced assessment, examiner administered relying on systematic naturalistic sampling to encourage spontaneous social communication)

*Only those effect sizes that reached significance are reported here.

Table 3 Summary of responsive behaviours taught to parents and associated outcomes

Study	Responsive strategies taught to parent								Associated Outcomes
	Follow child's lead	Imitate child	Sensitive responding to child's communication	Turn taking	Reciprocity	Contingency	Modelling	Positive affect	
Baranek et al. 2015	X	X		X	X	X		X	Reduced directiveness: ES -1.379 at post-intervention, ES -0.356 at follow-up
Carter et al. 2011	X		X	X		X			Increased parental responsivity: ES .71 95% CI (-.01, 1.44) at post-intervention, ES .50 at follow-up 95% CI (-.18, 1.18)
Green et al. 2013			X		X			X	Sensitive responding 3 cases showed Z scores $\geq 1.5SD$ compared to high risk group, 2 cases $\geq 1.5SD$ compared to low risk group Non-directiveness: 2 showed Z scores $\geq 1.5SD$ compared to low risk group
Green et al. 2015			X		X			X	Increased non-directiveness 0.81 95% CI (0.28, 1.52) Increased dyadic mutuality 0.05 95% CI (-0.54, 0.63) Increased caregiver sensitive responding -0.06 (-0.63, 0.51)
Kasari et al. 2014	X		X						Percentage of time in responsive mode: 1.81 post-intervention, 0.98 at follow-up Percentage of parent directed play acts: 0.99 post-intervention
Koegel et al. 2013									None reported
Rogers et al. 2012		X				X			None reported
Rogers et al. 2014	X	X		X		X		X	None reported
Steiner et al. 2013	X		X			X			None reported
Dawson et al. 2010			X	X				X	None reported
Kasari et al. 2010	X	X							None reported
Landa et al. 2011		X	X				X		None reported
Schertz et al. 2013				X					None reported
Wetherby et al. 2014			X						None reported

Appendix 1a: Author Note

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Compliance with Ethical Standards

Conflicting Interests: The authors declare that they have no conflict of interest.

Paper 2: Empirical Study

Parental Sense and Sensibility: An IPA study of parental experiences of a parent-mediated intervention

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INSTRUCTIONS FOR AUTHORS

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- Appendix
- Figure Caption Sheet
- Figures
- Tables
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Abstract

There is a paucity of qualitative studies of parents' experiences of parent-mediated interventions for children with social communication difficulties. The present study is the first to explore parents' understanding of their experiences of participating in Pre-School Autism Communication Therapy (PACT). Semi-structured interviews were used with eight parents who had received at least four sessions of PACT. Data were analysed using Interpretative Phenomenological Analysis (IPA). Four interrelated subordinate themes were identified: (i) *The Parent-Child Relationship*, (ii) *Expectations and Processes*, (iii) *Affective Responses*, and (iv) *Growth of Understanding*. Results are discussed in context with extant research of PACT. Clinical implications and study limitations are outlined.

Keywords: parent-mediated intervention, autism, parenting, synchrony, qualitative

Parental Sense and Sensibility: An IPA study of parental experiences of a parent-mediated intervention.

Pre-School Autism Communication Therapy (PACT) is an intervention aimed at improving social communication abilities in children with autistic spectrum disorders (ASD) and related social communication impairments, at either pre-verbal or early stages of language development (Aldred et al. 2011). Its principles are derived from research on pre-linguistic, pragmatic and language development and draws on Fey, Catts and Larivee's (1995) interventions for children with developmental language delays. The rationale for PACT is based on research evidence suggesting that children with ASD require an interactive style that is specifically matched to their individual level of social communication (Yoder and Warren 2001), therefore the focus of the intervention is on changing the interaction of the parent-child dyad, in order to improve child communication.

While there is evidence to support the effectiveness of PACT and similar interventions (Bradshaw Steiner Gengoux and Koegel 2014; Green et al. 2010; Morgan et al. 2014), there is a paucity of research concerned with parents' views and experiences of engaging in these interventions. Only two qualitative studies of parent-mediated interventions were identified, one focused on Hanen's More Than Words (MTW; Patterson and Smith 2011) and the other focused on adapted responsive teaching, a parent-child relationship-focused intervention (Freuler et al. 2014). A third study reported qualitative data collected from parents as part of an effectiveness study of a joint attention intervention (Schertz and Odom 2007). No qualitative studies of PACT have been carried out to date, although Green et al. (2013) reported post-intervention comments from parents regarding their experiences of an intervention similar to PACT. These comments suggested that parents noted an increased awareness of interaction with their child, and also of their child's communication with them (Green et al. 2013).

Green et al. (2010) hypothesised that PACT may improve parents' perception of, and sensitivity to, their child's communication needs. Additionally, it was suggested that the effect on parent behaviour may generalise to the wider family environment, and thus may result in increased effects on the child's development over time. A qualitative study may increase knowledge concerning the processes of change involved in PACT.

The present study aimed at exploring parents' understanding of their experiences of participating in a modified form of PACT. With the agreement of the Manchester-based PACT team (authors of the original randomised controlled trial, Green et al. 2010; personal communication), PACT was rolled out as a new intervention within a local NHS trust. PACT sessions were based on the intervention manual (Aldred et al. 2011); however, given the constraints on resources in local health services, the duration of the intervention offered in routine clinical practice was significantly less than what was provided as part of the PACT protocol (biweekly two hour sessions over six months, with additional monthly booster sessions for a further six months, Green et al. 2010).

Aims

The aim of the present study was to gain an in-depth understanding of parents' experiences of receiving a modified form of PACT, delivered as an early intervention in routine clinical practice by a local child intellectual disability service. Whilst the original study of PACT (Green et al. 2010) focused on children diagnosed with ASD, the present study extends current knowledge by including parents whose children had not been diagnosed with ASD, but presented with broader social communication difficulties. The main research question was thus:

What are the experiences of parents who have received PACT as a therapeutic intervention?

Method

Participants

Seven participants were mothers, one was a father. Ages ranged from 20 to 50 years, and participants had received between four and ten PACT sessions. Children's ages ranged from two years to six years. All children presented with significant social communication impairments, and five children had received a diagnosis of neurodevelopmental disorder by the time of the interviews. All participants and their children were assigned pseudonyms to ensure anonymity. Participant characteristics are summarised in Table 1.

Specific inclusion and exclusion criteria were used to facilitate a homogeneous sample of participants.

Inclusion:

- Parents of children who were referred to a specialist child intellectual disability service due to concerns regarding the child's social communication development
- Parents who had completed a minimum of four PACT sessions
- Parents to have completed the intervention between one and six months ago

Exclusion:

- Parents not fluent in English
- Parents with significant mental health problems
- Parents with a significant communication or intellectual disability

[Insert Table 1 here]

Design

A qualitative research design was employed. In keeping with Interpretative Phenomenological Analysis (IPA), a purposive sample was recruited based on inclusion and exclusion criteria that would yield a homogenous sample. Semi-structured interviews were audio-recorded, transcribed verbatim and analysed using IPA (Smith Flowers and Larkin 2009).

Procedure

Participants were recruited from two tier three services for children with intellectual disabilities within North Wales. Clinicians working with families who had participated in PACT approached families with an initial invitation letter to inform them about the study. A verbal overview of the study aims and procedures was provided by clinicians, and supplemented by an information pack containing a detailed information sheet and an opt-in sheet. Participants interested in participating in the study gave verbal permission to the clinician for their contact details to be passed on to the lead researcher. The lead researcher telephoned participants and gave detailed information about the study aims and procedures over the phone, and answered any questions participants had. Mutually convenient times were arranged for participants to be interviewed in a location of their choice. Informed consent was obtained from all individual participants included in the study.

Data collection

Single semi-structured interviews were carried out with each participant, guided by an interview schedule. The interview schedule was developed with clinicians working in services offering the intervention, and focused on parents' views of various aspects related to participating in PACT. Participants were encouraged to explore their experiences freely, and the interview schedule was used flexibly in order to reflect the idiographic approach of IPA. All participants were interviewed in their own homes. The length of interviews ranged from 21 minutes to 63 minutes.

Data analysis

IPA is an inductive approach, and focuses on the personal meaning and sense-making of individuals who share a particular experience. It is committed to examining how people make sense of major life experiences, with the aim of "understanding how particular experiential phenomena (an event, process or relationship) have been understood from the perspective of particular people" (Smith Flowers and Larkin 2009 p. 29). Thus the focus is on the particular rather than the general, and as such it requires samples to be small and homogenous (Smith Flowers and Larkin 2009). Given the study's concern with developing a greater understanding of the experiences of the participants, IPA was the preferred method of analysis. In giving parents a voice to express their experiences of PACT, the study intended to highlight the nature of participants' experiences and how they made sense of them, and did not intend to produce an absolute description of what it means to participate in PACT.

IPA recognises that data are not analysed in a contextual vacuum. Indeed, the researcher is making sense of the participant's sense making of his or her own experience. This relationship is described as the "hermeneutic circle", whereby the analysis is a dynamic

process, which takes place in the context of the researcher's own experiences (Smith Flowers and Larkin 2009 p. 35).

Data were analysed according to guidelines provided by Smith, Flowers, and Larkin (2009). Transcripts were read several times, and notes were made. Emergent themes were developed from the initial notes, and were discussed with colleagues experienced in IPA, who also examined a selection of transcripts as a credibility check, and to ensure the quality of the analysis. Core themes were identified, and organised as subordinate and superordinate themes according to their relationship with each other. These are outlined in a narrative form to convey parents' subjective understanding of their experience.

Ethical considerations

Ethical approval was granted by NISCHR Research Ethics Committee Wales REC 7 (Reference: 14/WA/1041) and the study was subject to NHS R&D approval following full review.

Results

Four interrelated themes were identified, which conveyed to me a sense that participating in PACT had been a profound experience for parents. The first was the theme of *The Parent-Child Relationship*, which described the nature of the parent-child relationship before and after PACT, as well as capturing associated relational and affective changes. The second theme of *Expectations and Processes* addresses the impact of specific aspects of the process of participating in PACT, and highlighted the specific mechanisms through which parents gained new knowledge about their child's difficulties, illustrating the experiential

nature of PACT. The third theme, *Heartbreak, Failure, and Guilt*, described how participating in PACT evoked significant negative feelings as a result of knowledge gained through PACT. *Growth of Understanding*, conveys the parent's learning as a result of participating in PACT and relates to a sense of empowerment, increased knowledge and a new understanding of the child's difficulties. See Table 2 for a description and summary of themes.

[Insert Table 2 here]

Theme 1 The Parent-Child Relationship

This theme relates to the relationship between the parent and their child, and how the parents perceived their relationship over the course of participating in PACT.

1.1 Sense of Separateness and Guessing Games

The parents' experience of their relationship with their child before PACT was characterised by a sense of separation and lack of connection, which was seen as a contributory factor in finding it difficult to communicate with the child.

Karen described how her daughter "just went into a bubble [...], she'd never laugh, [...], she'd hardly, like, smile, she'd hardly look at you". Similarly, other parents described their children as being "distant" and "in [their] own world" or "zone". The term "bubble" suggested a sense of feeling cut off from the child, and the child being isolated. Karen's repeated use of the negative illustrated the lack of interaction demonstrated by her daughter, a focus on all the things she did not do.

Rebecca described the difficulty of making sense of her daughter's communication, given that Chelsea did not engage in typical communication behaviours, such as bringing objects of interest to the parent "Chelsea didn't do that. If Chelsea was upset and she wanted something, she would cry, and then for us it's a guessing game, why is she crying?". Therefore parents were actively trying to interpret and make sense of their child's behaviours, having to rely on guesses to inform their responses to the child.

Thus, in addition to the difficulty in interpreting their child's behaviour, parents experienced a sense of separation from their child, which had a significant impact on their experience of interacting with their child. Abbey described how a lack of interactive responses from her daughter impacted on her feelings of closeness:

"I don't get anything from Julie, you see, so, my relationship, my bond with Julie was very difficult, because I was doing everything for her, and, you know, but getting nothing back, [...] and, obviously having her, no eye contact from Julie, it was, I used to say, 'God, does she even know who I am?' 'Does she know what I look like?'"

Abbey's questions about her daughter's awareness of her as a parent illustrated a parent's need for recognition or acceptance of themselves by the child. This may also speak to a need for mutual engagement and a sense of reciprocity within parent-child relationships to foster emotional bonds.

1.2 Awareness of Intentional Communication

Three parents stated explicitly that the process of participating in PACT made them realise that their child had been communicating with intention all along, but that they may not have been aware of this. Indeed, Michael described how subtle such communication might be:

“Even at, at this young age there are a lot of subtle little looks aren’t there, and little, you know, things, and that’s the thing that we really did explore, [...] she was trying to tell you, she *was* communicating with you, but you can’t always, sort of, catch it.”

It appeared that becoming aware of their child’s intentional communication changed the parent’s perception of the child. Although the child appeared to be isolating itself, as captured in the previous theme, there were subtle hints that the child was wanting to and actively seeking to engage with his/her environment and his/her parent. Karen described how her daughter “understands a lot of things, [...], I’ve noticed *now*”, suggesting that once she realised that her daughter understood and wanted to interact, she was able to recognise this behaviour in her daughter on other occasions also.

Therefore realising that their child was communicating with intention, perhaps that their child *had the ability* to communicate with intention, prompted parents to look out for occasions when their child demonstrated such behaviour. Michael reflected on how this increased awareness of his daughter’s communication prompted him to change his own behaviours, and how this gave way to increased mutual engagement:

“She engages more now because I think I engage more with her than I did [...] you know there were just certain little things that I now, um, um, I can now sort of see, that at the time I didn’t see, and that’s part of the thing, isn’t it, it’s knowing, um, is taking the hint maybe, maybe that was something that I wasn’t good at doing.”

Thus realising their child’s intentional communication may have contributed to parents changing their own behaviour which resulted in increased engagement.

1.3 A Closer Bond

Emerging out of the increased mutual engagement described in the previous theme is a sense of feeling closer: “I think we’ve become closer to, to be honest, in the last couple of months, um, I have no doubt that that is as a result of, um, the various sessions that we’ve had” (Michael). More specifically it was the ability to engage with their child, knowing what to do to engage the child, which appears to have facilitated the sense of increased closeness. Abbey described:

“Since going to PACT, I’ve...me and Julie, our bond together now is very, is a lot stronger than what it was, you know, um, because I know now what to do with Julie.... my bond with Julie now is really, really good actually”.

Madeleine echoed: “We have a really good bond now, it didn’t feel the same then, you know, I didn’t have any tricks or anything I could play, you know, to get their attention”. Both Abbey and Madeleine’s comments illustrate parents’ experience of not being able to engage their child due to a perceived lack of skills, however through PACT parents came to realise what they needed to do, and were thus able to effectively increase engagement with their child. This appears to have resulted in a sense of a stronger bond with their child: “I used to enjoy going there, you know, it helps you build that bond”.

Thus for four parents there appeared to be a sense that doing PACT with their child altered the bond they had with the child; the four remaining parents did not discuss this explicitly.

Theme 2 Expectations and Processes

This theme relates to the actual experience of participating in the PACT sessions, and addresses parents' understanding of the most salient aspects of receiving PACT.

2.1 The Camera as the Third Eye

Viewing the video (and discussing this with the therapist) was described by all parents as a central part of PACT; some parents described it as the most helpful aspect of the intervention. Annabelle described: "after watching the video back, I could see things that he liked doing, and there were times when he'd instigate it and maybe I was trying to get him to do something else when he wanted to do that". For Michael:

"The analysis [of the video] was quite interesting um, because [...] you don't really notice a lot or maybe at the time I didn't sort of take enough notice of, you know, the body language and various looks and stuff like that, and that was I guess the thing I really valued the most".

Thus the video acted like a third eye, capturing aspects of the child's behaviour that would have otherwise gone unnoticed, such as responses from or initiations made by the child. As Karen described "you'd notice things and you'd be like 'I never knew she did that'". Additionally, watching the video gave parents the opportunity to identify aspects of their own behaviour within the interaction that had worked well, and those that were not effective in engaging the child. This was described by Annabelle above and also by Lilly, who spoke of it as helpful "to see back on video and for [clinician] to say 'look you're doing it then', and not actually realise I was doing it but, yeah, it was helpful".

Furthermore, being able to watch the video gave parents the opportunity to ‘reality check’ how their interaction with the child had gone. Madeleine described “I think we distort things and I think we make them feel worse than they actually, you know, but when you watch it back, you think oh no it wasn’t that bad”.

Through the process of watching the video parents seemed to gain new knowledge and insight regarding aspects of the parent-child interaction they had previously not been aware of. Interestingly, even those parents who had described PACT sessions as feeling uncomfortable, reported the video recording as helpful. Thus it appears that parents felt that the discomfort of being filmed and having to watch oneself on videos was outweighed by the benefits of doing so.

2.2 You Need to Do It In Order to Know It

All parents described not knowing what to expect of PACT, as illustrated by Rebecca’s description:

“It didn’t matter how much [clinician] had explained to us what was going to happen, you’re not prepared for how you feel when you actually have that first session.”

Although an explanation was provided of what would happen in the session, this appeared not to prepare parents adequately for the emotional aspect of taking part in PACT. In anticipating the first session, parents described feeling “nervous”, and worried about being “scrutinised” and judged.

A dichotomy emerged when parents spoke of their experience of participating in PACT sessions. For Lilly “it was so natural, cos it’s such a natural thing to play with your child anyway, you don’t actually realise you’re actually doing it”, and Michael also felt “it

was perfectly natural, um, for both of us, so I thought um, you know this doesn't feel like therapy or anything, it doesn't feel like anything out of the ordinary really". Both of these comments suggest that some parents found it natural and easy to play with their child in the session, so much so that it did not feel like there was any intervention happening, as described by not being aware of doing it and the session not feeling like therapy.

In contrast, two parents found having to play in session with their child as "a bit forced and awkward". This dichotomy may also reflect differences in parents' expectations. Annabelle, who described her experience of PACT sessions as "forced and awkward", also described that on reflection:

"Maybe I had the wrong perception of it. I thought I'd go there, and we'd be shown ways of, [...] doing things with him, and...and we were a bit, but it felt like it was mostly all based on play".

Thus parents' understanding of their experiences of PACT were characterised by initially not knowing what to expect from PACT. Although there was a difference in terms of how parents experienced the PACT sessions, on reflection all parents described PACT as helpful.

Parents also expressed being pleased about having taken the opportunity to do PACT, Karen stated "I'm quite glad I did now" and Serena felt the same "I was glad that I hadn't turned her down, really glad that I'd said 'yeah, I'll do that'". Karen's use of "now" and Serena's description of being glad about not having turned the opportunity down, may suggest they had considered not to do PACT, but that on reflection they were pleased they had.

Thus this change in parents' perception of PACT as initially being something unknown, and of not knowing what to expect, to a perception of PACT as having been

helpful, suggests an altered perception of PACT *after having completed* the intervention. This speaks to a significant experiential aspect of PACT. Madeleine's suggestion that "maybe a parent could explain" about PACT to another parent being offered the approach appears to emphasise the perception of needing to experience PACT to fully understand it.

2.3 PACT as Special Time

When parents described their PACT sessions, there was a sense that these had been experienced as special time. Madeleine described "we sometimes don't get that chance to have that, you know, undivided time together, so even though it's only for a limited amount of time, it's just me and him". Other parents also reflected that PACT sessions were "mum and daughter time [...] no distractions"(Karen), "it was sort of like very, sort of like, intimate, it was just me and Julie" (Abbey). The use of the word "just" emphasises the absence of others, which may have allowed the parent to focus all their attention on their child. This seemed to result in a sense of intimacy, which may have facilitated parents' increased awareness of how their child communicated. Thus PACT sessions were experienced as special time, not only because uninterrupted parent-child time did not occur often outside of the session (due to the parent's commitment to care for the family), but also due to the particular quality of the time spent together during PACT sessions. This was valued greatly by parents, as Abbey described: "the most thing I liked about it altogether is actually having time with Julie [...] our play sessions".

2.4 Oh, This Is About Me!?

Watching the videos facilitated an emerging awareness of who (the parent or the child) was the intended focus of the intervention. Michael described realising that:

“it was sort of more to do with sort of the parents than the child really [...] what we tend to forget is that you know um, it it’s um, you know, it’s a two-way thing isn’t it, you know, so I found that interesting because, um, you know I probably hadn’t thought about it much before [...] what did sort of surprise me, but in a nice way, was the fact that it seemed to me that the focus was more on the parent than on the child [...] and it’s never a bad thing to sort of just take a step back every now and then, and just have a look at yourself, and maybe you need to tweak a couple of things, and it’s not always someone else’s responsibility.”

Michael’s description suggests that parents may forget that interaction is a two-way process and that it was positive to be reminded of that. While watching the videos Serena also noticed: “it was more on my part really than his, that I was speaking too fast, and that I wasn’t saying maybe the right words for him to say that he wanted to carry on playing”. Serena’s repeated use of “I” statements illustrates how she focused on herself as the location for change within the parent-child relationship. Lilly’s description that “I’m doing a lot things that previously I wasn’t actually aware of that are actually [laughs] right for PACT” again emphasises the pivotal role of the parent in shaping the parent-child interaction.

Theme 3 Heartbreak, Failure, and Guilt

Parents described experiencing difficult emotions due to the quality of the parent-child relationship prior to PACT. Abbey described the lack of engagement between her and her daughter as “heart-breaking”.

Several parents also alluded to or spoke of experiencing difficult feelings while participating in PACT sessions, once they realised there had been a mismatch between their communication styles and their child’s communication needs. Serena described:

“I felt like, cos I didn’t understand how he communicated, I feel like he felt like he’d been ignored for a bit of his life, cos I didn’t understand [...] It’s not that I have ignored him, it’s just that I haven’t understood that he’s trying to tell me something”.

As described by Lilly: “I think you just want to help your child so much, and help them to communicate”, all parents did indeed describe wanting to help their child. In the context of wanting to help, the perception that their child may have felt ignored for a part of his/her life appears to have caused some parents significant feelings of guilt. Madeleine’s thoughts that “when there is stuff not quite right with your kids, you automatically think it’s you”, also suggest a sense of blame, of being responsible. Rebecca’s description of how it was “overwhelming to see, what I was doing as a parent wasn’t what she needed, and that’s typically what everybody thinks, ‘oh well, you need to explain to your child what you’re doing’, so, that was an eye opener” reflect the sense of “having failed”. Her description not only suggests feelings of guilt and disappointment, but also captures the poignancy of the realisation that caring behaviour motivated by wanting to help the child may have actually contributed to the child’s difficulties in communicating. Annabelle described the process of “picking out my own faults” while watching the video as “hard” because of the feelings it brought up for her: “I did feel like I hadn’t tried enough at home...It was horrible, I was upset with myself [...] it made we feel like I hadn’t done enough at home and maybe not persevered enough with him”.

Theme 4 Growth of Understanding

A theme touched on as part of earlier subordinate themes is that of parents having learned what to do, and having developed a new understanding of their child’s difficulties during the course of PACT.

4.1 Empowerment

Serena reflected during the interview that “you don’t know the information that you’re supposed to know, really, if your child is slower than other children, you just think automatically they’re going to come out and talk and walk”, which speaks to her sense of not feeling prepared, not knowing what she needed to know in order to help her child. This may suggest a sense of disempowerment due to a lack of knowledge.

Several parents described that they learned “what to do” through PACT, which is captured in greater detail in the following theme *Holding Back and Doing Less* below, and illustrates more specifically the understanding and skills developed through PACT. Lilly’s description that “it was just good to know that things that I was doing [...] , um, and told, oh try this and hold back, that they were helping Philip”, speaks to a sense of control and empowerment as a result of having learned to change the way she interacted with her child. This is further reflected in Michael’s comment:

“Then we can go off and do that kind of thing ourselves, so we, you know, we understood the lessons that were to be learned from the, the sessions that we had, so I’m not sure that more of that would have had any different, you know, would have benefitted us.”

This not only speaks to the parents’ perception of knowing what to do, and being able to take “what I’ve learned and carried on with it” (Serena) independently, it also suggests that parents had a clear idea of when they had received sufficient sessions. Annabelle described the sessions as being very similar, stating “I probably got as much from the first session as I did through the whole thing”. This could suggest that the greatest amount of benefit was perceived early on during the intervention, and that a limited number of sessions may be

beneficial to some parents. Thus parents may have felt further empowered by being able to learn quickly and not having to rely on the help of professionals in the long term.

4.2 Holding Back and Doing Less

Abbey described being taught to play with her daughter “in *her way*”, suggesting that there is a specific way her daughter likes to play. This reflects the idiosyncratic preferences the children had for playing and interacting with others, and which contributed to the difficulties parents had in interacting with their children prior to PACT.

Furthermore, there was a sense of having learned specifically “what to do” with the child “I’ve learned a lot, like what to do with Julie” (Abbey), as a result of which they made very specific changes to their behaviour. Lilly described “sometimes trying to hold back to encourage Philip’s communication”, and Karen developed a similar approach “I just like hold on a bit longer, [...] you’ve got more patience, and you know she can do it, so you hold on a bit longer”. For Rebecca it was also a case of slowing down what she did when playing with her daughter “the less I talked with her, the more she interacted with me, which...that’s nice, I didn’t always have that”. Madeleine described that “you realise that you don’t need to, you don’t have to be, be doing something all the time, you can slow it down and it’s so much more enjoyable rather than getting tense”. Therefore slowing down and not feeling under pressure to do something appeared to not only facilitate mutual engagement between parent and child, but also seemed to make the interaction with the child more enjoyable for the parent.

Lilly described how small changes in behaviour may have a significant impact “you don’t really realise [...] how much impact you’re having really, what, um, little things, just changing little things, and holding back, and not maybe doing what you want, you know,

straight away”. Her comment also speaks to the difficulties parents had implementing these seemingly simple steps of doing less and holding back, as they seemed to stand in direct contrast to parents’ urge to help their child and make the interaction or the communication easier for them. Karen described the same difficulty:

“It’s hard sometimes cos you feel like, as a mother, that you should, [...] when it comes to speech and things, instead of waiting for her to say something, and I just automatically, like, give a drink or something...it’s just like a mother...a motherly thing to do over them.”

Thus, although the changes parents made to their own behaviour were perceived as small, and the realisation that less is more freed parents from the pressure of having to always do something, this was not an easy change to make. However, this new way of interacting was perceived to get easier over time, as described by Serena when reflecting on what it is that she does differently now: “I just do it automatic now so it’s hard to think what I do [...] it was hard, in the start to always think ok, you’ve got to point at everything that you’re showing him, and really say it slow”.

4.3 A New Understanding

While participating in PACT parents developed a new understanding of their child’s difficulties. Prior to PACT parents had a sense of their child’s difficulties as “something” being “wrong”, but no explanation for the nature or cause; Abbey described her experience: “I couldn’t say what I thought was wrong with her then [...] I didn’t know what was wrong with her then, I didn’t have any explanation as to why she was the way she was”. The repeated use of “I didn’t” seems to emphasise her not knowing. Michael described how “that inability to communicate, that was the hard thing that made it just totally mysterious and

horrible all at once”. Michael’s description captures a sense of powerlessness over something strange described in abstract terms as “mysterious” and “horrible”.

As illustrated by the preceding themes *Awareness of Intentional Communication*, *The Camera as the Third Eye*, and *Oh, This is About Me!?* parents developed a new understanding of their child’s difficulties. Additionally, parents appeared to have developed a more hopeful view of their child’s future:

“He wasn’t talking, he didn’t have the eye contact, so I was just convinced that was it then, that’s how he’s going to be, this is his life, [...] and the biggest thing for me, I don’t care if he’s going to be intelligent, I want him to be happy, [...] but like I felt ‘oh, he’s not talking now, so he’s not going to socialise, he’s not going to have any friends’ [...] He should be doing what he’s doing anyway. He should have maybe been doing it two years ago, but it’s massive for him, the improvement is huge.”

Annabelle’s reflection illustrates not only the previous anguish about her child’s future, but importantly highlights the fact that he is continuing to develop, according to his own schedule. Similarly Karen commented that her daughter is “not, like, the same, like, on the same stage as other children, but she’s on her way there”. Realising that their child is continuing to develop, even after the intervention has been completed, seems to have given parents hope. Abbey spoke of “looking forward to Julie’s next chapter”.

Discussion

By giving parents the opportunity to give a personal account, this study aimed to gain a more in-depth understanding of their experiences of participating in PACT as a therapeutic intervention. The descriptions of the experience of receiving PACT presented here conveyed a sense that participating in PACT had been a profound experience for parents. Although

parents differed in their description of their experiences and in how they understood these, there was a sense of participating in PACT as facilitating changes in parents' perception of their relationship with their child, in their understanding of the intervention approach, in their affective responses and in terms of the growth of their own learning and understanding.

Although this is the first qualitative study of parents' experiences of participating in PACT, the themes here are reflective of those identified in Green et al.'s (2013) post-intervention interviews with parents regarding an intervention similar to PACT. In line with their data, parents in the present study also reported that the intervention had increased their awareness of interaction with their child, and of their child's communication with them. Similarly to Green et al. (2013), all participants in the present study identified reviewing the videos as the most helpful and essential aspect of PACT. Furthermore, the theme of increased recognition of the child's intentionality was also identified as salient to parents' understanding of their experience in the present study.

Other studies reporting qualitative data have focused on thematic analyses to complement quantitative outcome studies, and did not focus on parents' understanding of their experiences of participating in these interventions (Freuler et al. 2014; Schertz and Odom 2008). Patterson and Smith (2011) identified themes related to improving the specific intervention participants had received, and were also not focused on parents' understanding of their experiences of participating in a parent-mediated intervention. While extant research is limited, the fact that there is some overlap between the themes identified in the present study, and those reported by Green et al. (2013), lends credibility to the present findings.

In a randomised controlled trial of PACT (Green et al. 2010), it was hypothesised that PACT may be positive for parents themselves, and the results of the present study,

particularly with regard to the parent-child relationship and parental learning, provide some tentative evidence to support this idea.

A transactional model (Wan et al. 2013) has been suggested as a framework for understanding how the characteristics of the parent and the child interact with each other to result in asynchronous interaction and communication behaviours. It is suggested that the child's atypical pattern of communication may be difficult for the parent to interpret and respond to, and that a mismatch between the parent's communication style and the child's communication needs results in an increasingly atypical pattern of development over time. The themes identified in the present study appear to converge with this model. The parent-child relationship was central to parents' understanding of having participated in PACT. They described difficulties in interpreting their child's behaviour prior to having the intervention, which reflects previous findings (Busch 2009, unpublished dissertation). Through participating in PACT, that is, by watching video excerpts of their interaction with their child and honing their interactive style to facilitate their child's engagement (e.g. by slowing down, talking less), it appeared that parents had a sense of increased mutual understanding and a closer bond with their child. Similar findings were reported in a randomised clinical trial of an intervention increasing parental responsiveness, which found an increase in parents' perception of their child's attachment following the intervention (Siller Swanson Gerber Hutman and Sigman 2014). Essential to this process in the present study was the aspect of reviewing the videos, a procedure which expanded parents' awareness about their child's idiosyncratic communication behaviour repertoire (e.g. eye contact, increased vocalising), and increased their understanding of the meaning of these communication behaviours. Furthermore, the video procedure increased parents' awareness of the significant impact they could have on the parent-child interaction, as well as of their role in facilitating communication with their child and his/her wider environment. Thus the subordinate themes

related to the *Parent-Child Relationship* theme reflect the suggestions made within the transactional model (Wan et al. 2013), giving an account of parents' understanding of their experiences of this process.

Clinical Implications

The results of the present study point to several clinical implications. Of particular note was the theme *Heartbreak, Failure, and Guilt*, describing the difficult emotions evoked in parents during PACT. This may indicate that parents feel fragile while receiving PACT and therefore therapists might need to be particularly sensitive to parents at this time, taking care not to trigger negative cognitions and affect. Additionally, nurturing parents' confidence in their parenting skills may be especially important during this time.

In describing the growth of their understanding, parents reported that PACT was not only easy to do, but that they had a clear sense of when they had received sufficient sessions, and felt empowered to continue to independently apply the principles they had learned in their PACT sessions. Parents in the present study received between four and 10 PACT sessions, and described this as being helpful. This represents significantly less intervention than was delivered in a randomised controlled trial, which provided fortnightly two-hour sessions for six months, with additional monthly booster sessions over a further six months, as per the PACT protocol (Green et al. 2010). While measures regarding child social-communication and ASD outcomes were not collected in the present study, these results indicate that some parents may experience a benefit between four and 10 sessions of PACT. Future research is needed to evaluate the effectiveness of a modified version of PACT, similar to that delivered in routine clinical practice, to determine the optimal intensity and

duration of the PACT intervention, and thus to inform future service delivery in local health service trusts.

Limitations and Future Research

Parents' descriptions of their understanding of the changes that occurred in their relationship with their child hint at some tentative suggestions of the underlying psychological processes that may facilitate increased synchrony in the parent. It appears that parents' understanding of their child's intentional communication, that is, the realisation that the child's lack of engagement was based on an inability rather than a lack of desire to interact, may have increased parents' motivation to persevere in actively engaging their child. This may highlight the importance of the parents' needs for reciprocity within the parent-child relationship. It is possible that, once the child's engagement has increased, that this is reinforcing the parent's sensitive responding, thus the characteristics of the parent-child relationship mutually influence each other to increase synchrony, and over time contribute to improved developmental and social-communication outcomes for the child. Further research may elucidate the specific psychological processes that facilitate increased synchrony in parents.

Although efforts were made to check the credibility of the interpretation and analysis, the nature of IPA is interpretative, and as such requires the interpretative work by the researcher. This, however, means that the present analysis is simply one interpretation of parents' understanding of their experiences of PACT, and cannot provide a definitive account of these. Additionally, there is limited existing research with which the present findings may be triangulated.

Although some parents attributed observed changes in the parent-child relationship and their child's communication to PACT, other factors may have been relevant also (e.g. the child's schooling). Furthermore, parents' sense making is an ongoing process, which is also influenced by aspects of their own day-to-day lives. While the sample was in keeping with the requirements for IPA (it was small and homogenous), participants self-selected to take part in the study, thus these findings may not be generalised to other parents who have participated in PACT. Furthermore, all parents were still open to the services they were recruited from, and while efforts were made to design the study in such a way as to reduce any possible demand characteristics of being a participant, it is possible that some parents may have felt unable to report some aspects of their experiences.

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Table 1 Participant characteristics

Participant Pseudonym	Age	Child	Child Age (years)	Diagnosis	Number of PACT sessions	Time since last PACT session (months)
Lilly	33	Philip	6	ASD	6	6
Serena	32	Ollie	4	Assessment ongoing	4	3
Annabelle	25	Max	4	Assessment ongoing	4 or 5	5
Rebecca	29	Chelsea	2.5	ASD	4 or 5	1
Karen	20	Ruby	4.5	ASD	10	2
Abbey	26	Julie	2	ASD	6	1
Michael	50	Beth	2.5	None	5	2
Madeleine ⁶	41	Ben	4	Global Developmental Delay	Not sure	2

All parents were biological parents, none of the children had been in foster care, all parents were full-time carers for their children, apart from Michael and Karen (part-time employed), and Madeleine (full-time employed). Five were single parents, three were either married or cohabiting. Five parents had further children. Participants identified as Welsh, British, English and Indian, and five were first language English, while three were first language Welsh.

⁶ Although Madeleine had had PACT with two children, and referred to both experiences in the interview, only those data related to her son were considered, as her other child had had PACT more than six months ago, and so did not fit within the inclusion and exclusion criteria.

Table 2 Summary and description of themes

Superordinate Theme	Subordinate Theme	Descriptive Summary
The Parent-Child Relationship		Conveys the unfolding development of the parent-child relationship over the course of participating in PACT.
	Sense of Separateness and Guessing Games	Describes parents' perception of their child as being isolated, and the difficulties parents had in making sense of their child's behaviours.
	Awareness of Intentional Communication	Addresses parents' emerging awareness of their child's intent and desire to interact and communicate.
	A Closer Bond	Conveys the parents' perception of a greater mutual understanding and sense of closeness as a result of PACT.
Expectations and Processes		Reflects parents' understanding of the most salient aspects of participating in PACT.
	The Camera as The Third Eye	Describes how the camera brings new information into parents' awareness and thus shapes parents' perception of their interactions with their child.
	You Need to Do It In Order To Know It	Addresses the significance of the experiential aspect of PACT.
	PACT As Special Time	Conveys parents' perception of PACT sessions as valued, special time spent with their child.
	Oh, This Is About Me!?	Describes parents' realisation that they are the focus of change in PACT, rather than their child.
Heartbreak, Failure, and Guilt		Conveys parents' affective experiences regarding their relationship with their child, and as a result of gaining greater understanding of the role of their own behaviours within the parent-child interaction.
Growth of Understanding		Addresses how parents' understanding of their child's difficulties and their own learning has developed through participating in PACT.
	Empowerment	Conveys the new sense of knowledge, expertise and confidence parents appeared to experience following PACT.
	Holding Back and Doing Less	Describes specifically what parents learned to do differently when interacting with their child.
	A New Understanding	Addresses how parents' understanding of their child's difficulties changed during the course of their participation in PACT.

Appendix 2a: Author Note

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Compliance with Ethical Standards

Conflicting Interests: The authors declare that they have no conflict of interest.

Research involving Human Participants: All procedures performed in the study involving human participants were in accordance with the ethical standards of the institutional and/or research committee and with the 1962 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent: Informed consent was obtained from all individual participants included in the study.

Paper 3: Contributions to Theory and Clinical Practice

In this final paper the findings from the literature review and the empirical study are integrated to consider their combined impact. There are four sections to this paper: (i) Contributions to Theory, (ii) Implications for Clinical Practice, (iii) Implications for Future Research, and (iv) Personal Reflections regarding the research process.

Contributions to Theory

The parent-mediated interventions discussed in the literature review and the PACT intervention reported on by parents in the empirical paper all have the parent-child relationship as a proximal target for intervention. A framework for explaining how the child's social communication risk-vulnerabilities interact with the child's environment (which includes the parent-child relationship) has been suggested based on a transactional model (Sameroff, 2009). This view posits that the parent's and the child's characteristics may mutually influence each other and thus may contribute to an increasingly atypical developmental trajectory over time (Wan et al., 2013). Central to this theory is the *quality* of the parent-child relationship in terms of synchrony. Parental synchrony has been described as a close match between the parent's and the child's affective behaviour, based on attention, sensitivity and responsiveness of the parent to the child's behaviours (Feldman & Eidelman, 2004). The term synchrony is used here to describe the affective and behavioural match between the parent's and the child's interaction style. It has been found that synchrony partially mediated the treatment effect of a parent-mediated social communication intervention on autism spectrum disorder (ASD) outcomes (Aldred, Green, Emsley, & McConachie, 2012). Wan et al. (2013) found synchrony in parent-child interactions of 12 month old children with an older sibling diagnosed with ASD predicted ASD outcomes when the child was three years old.

Although Wan et al. (2013) formulated their transactional model based on data from children identified as at risk for ASD (due to having an older sibling diagnosed with ASD), this model also appears to fit with the experiences of parents reported in the research study of this thesis. In contrast, the children of parents interviewed constituted a more diverse sample in terms of age (which ranged from two to six years), and diagnosis: only one child, who received a diagnosis of Global Developmental Delay (GDD) had a sibling (twin) diagnosed with ASD, none of the other children had older siblings diagnosed with ASD. Of these seven children, four had received a diagnosis of ASD at the time their parents were interviewed. In the empirical study parents described interacting with their children prior to PACT as difficult, and reported that they would not persevere in trying to engage with their child. In particular, it appears that the child's response to the parent's attempt to interact was interpreted as a sign that the interaction was not welcomed by the child (for example, Madeleine spoke of the interaction feeling like trying to join a group she did not fit in with). Therefore parents were less likely to continue their efforts to engage their child. Previous research of interventions aimed at increasing parental synchrony found that parent-child dyads assigned to the control condition (treatment as usual) demonstrated a reduction in synchrony; that is, the level of synchrony within the parent-child interaction does not remain stable over time in the absence of intervention, it appears to deteriorate (Aldred, Green, & Adams, 2004; Green et al., 2010).

Parents' experiences outlined above may give some indication as to why synchrony declines: parents may become discouraged to persevere interacting with their child, given the perception that their attempts are unwelcome, and thus there is less interaction, and less opportunity for the quality of the interaction to be changed. Aldred, Green and Adams (2004) found that parents in the control condition demonstrated more intrusive language and increased demands. This contrasts with the kind of approach parents interviewed in the

present study reported as being helpful in engaging their child (which was doing less, and slowing down). Parent's responses to their child's perceived dislike of their communication attempts may therefore make it even more difficult for the child to engage with the parent. Thus the parent and child are stuck in a vicious cycle where their responses to each other mutually influence each other's behaviour, making it increasingly more difficult for them to be reciprocally engaged, as outlined by Wan et al.'s (2013) model. Therefore this model also appears to be pertinent to parent-child dyads of children of a broader age range, and those with more diverse clinical presentations, that is, both children diagnosed with ASD, and children that were not diagnosed by the time the parents were interviewed, but where there had been concerns about their social communication development. Furthermore, evidence from the research study may offer an explanation why parent-child dyads assigned to control conditions demonstrated decreased synchrony, and that it may still be of value to offer this intervention even if it has not been found to significantly impact on ASD symptomatology as measured by standardised diagnostic assessment measures (Green et al., 2010), to prevent potential deterioration or increased difficulties for families.

Although the present research is exploratory, it does hint at psychological processes that may be relevant to understanding the mechanisms that may play a role in increasing parental synchrony. Parents described that watching the videos in PACT sessions provided them with the opportunity to gain knowledge that had previously been outside of their awareness. In particular, parents became aware of their child's intentional communication and of communication behaviours (such as eye contact or vocalisations) that occurred in response to something the parent had done. From the data collected in the research study it appears that it was the parents' realisation that their child was indeed making attempts to communicate (suggesting a desire for interaction), but that his/her difficulties were related to a difficulty in *being able* to interact and communicate in a typical manner (rather than not

wanting to) that seemed to be a moment of significant learning. Once the parents understood what it was they needed to do in order to engage their child, and they were able to have a reciprocal interaction with their child, they were more likely to persevere in engaging their child. This suggests it may be the parents' attributions regarding their child's motives for interaction, coupled with the knowledge of how to elicit reciprocal interaction from their child, that may constitute important psychological processes within the parent that facilitate increases in parental synchrony. Once reciprocal interaction between parent and child is elicited and further developed, it is possible that this may be reinforcing for both the parent and the child, and contribute to maintaining increased synchrony within the parent-child interaction.

Implications for Clinical Practice

The results of both the literature review and the research study point to several clinical implications. These will be discussed in turn.

Improvements to Service Delivery

During data collection for the research study, parents offered some suggestions that are relevant in considering how the delivery of PACT may be improved in future. Of particular note was parents' perception that they had had sufficient PACT sessions, even though they each received only between four and ten sessions, on average almost six sessions each. Only one parent reported wanting to have more sessions. As was previously noted in the research paper, this is less than what is outlined in the original PACT protocol (Green et al., 2010). Given that the research paper was not an outcomes study, any conclusions regarding the effectiveness of the modified version of PACT in terms of increasing

synchrony or impacting on ASD symptomatology as measured by standardised assessment measures are precluded. However, parents' comments may suggest that a shorter version of PACT was perceived as beneficial.

Some parents spoke about the desire for contact with other parents who had received PACT. Abbey spoke of a desire to have contact with other parents who had completed PACT, and the idea of a peer group emerged during the interview. Michael had described an awareness of how lonely being a parent can be at times, suggesting that parents may find an opportunity to meet quite helpful. Services may wish to discuss this with families receiving PACT; for example, services could offer an opt-in to exchange contact details for those parents who are interested in meeting and supporting others.

Madeleine described how it would have been helpful to have had the opportunity to speak to a parent who had received PACT when she was considering taking up the intervention. She spoke of the difficulties of communicating with parents of typically developing children and feeling patronised by them, describing that it would be easier to relate to parents who had similar experiences in terms of parenting a child that was not developing as expected. Although she did not state this explicitly, it is also possible that Madeleine's comments may be applicable to her experiences of discussing PACT with the professionals of the service to which she was referred. Thus services may consider involving parents who have received PACT in explaining the approach to other parents who are considering this intervention. Additionally, an information leaflet developed by parents for parents may also serve to explain PACT in a manner that is more meaningful to parents of children referred to services offering PACT.

Two parents suggested that the service offer some form of distraction for the child during the section of the PACT session where the parent was occupied with watching the

video and discussing it with the therapist. It was felt that this was a significant part of the session, and parents described that it was difficult to give it their full attention when their child needed their attention also. Perhaps providing the child with some interactive toys that he or she could play with on his or her own may give the parent the space they need to focus on the video feedback. However, it is quite likely that effective strategies for distracting the child will depend on a range of factors (such as the child's preferences, age, mood state), and that it may be difficult for services to anticipate and cater for all such instances where a child may need to be distracted.

Overall, parents reported that they had enjoyed PACT. Apart from the points raised above, parents had no concerns about PACT itself, or how it was delivered by the service. Green et al., (2010) hypothesised that PACT may be beneficial to parents, and the high level of satisfaction reported during the research process may indeed reflect this.

Parental Wellbeing During Intervention

The research study indicated that participating in PACT evoked difficult feelings in some parents, such as feelings of failure and guilt. This suggests that parents may be quite vulnerable while receiving PACT. Certainly, Rebecca's comment that it was overwhelming to realise that what she had been offering her child was not what her child needed, indicates that parents may have a lot to process during this time. Thus it is important that therapists delivering PACT are sensitive to the parents' increased vulnerability while they are receiving PACT and making sense of their experiences. Given that parents had described that one way of dealing with difficulties in interactions with their child was to end them and to do something else, it is important to bear in mind that both parents and children may perceive that they do not have the option to leave the interaction during PACT sessions (since working

on the interaction is the aim of the session). Thus, it may be difficult for parents to tolerate sessions where they feel the interaction is not going well, but they are not able to escape from the situation. Great sensitivity is required by the therapist not to inadvertently trigger negative cognitions and affect during such sessions, and when reviewing the video feedback.

Emphasising those aspects that parents felt went well, or the therapist noted as going well, should be emphasised in order to strengthen the parent's sense of confidence and self-efficacy, which is consistent with the approach taken in PACT.

The Importance of Fit

Several parents commented on the importance of fit between the parent and PACT in order for the intervention to be successful. While some parents described this in terms of parental attitude, expressing that they felt parents needed to be open to critically evaluating and potentially changing their own behaviours, others described this in terms of the intervention not being suitable for everyone. It is possible that some parents were expecting a more didactic approach (Anabelle did indeed comment on this). Additionally, some parents reported that they felt they were already doing a lot of what was suggested during PACT sessions, and therefore did not describe it as being as helpful as some of the other parents (although they still described it as helpful). Thus there was a perception among some parents that the benefit of PACT was dependent on the extent of prior knowledge about engaging the child (such as coming down to the child's level). However, the philosophy of PACT is to coach the parent in observing their child and being curious about what their child is doing. To this end the therapy focuses on what the parent does well that works in engaging the child, and helps the parent to develop this, whilst at the same time ensuring the parent understands that the ideas for changing their own behaviour are based on their existing skills and their

own ideas. Therefore it is likely that parents may perceive that they already knew what to do when PACT is delivered well, and that this does not necessarily reflect negatively on the effectiveness of PACT.

Considering the potential increased emotional vulnerability of parents during PACT as discussed above, it is suggested that services consider carefully which families be offered PACT. It may be that PACT may be effective for parents who are 'robust' enough to tolerate critically evaluating their own behaviours, and that parents who are more sensitive or more inclined to feelings of shame or self-criticism be given additional support during this time. Additionally, it may be inappropriate to offer PACT to families who are under a lot of emotional stress, given that receiving PACT may add to this, and thus careful consideration should be given to the timing of offering PACT. It may be that a family who has received a diagnosis regarding their child's development may be overwhelmed by being offered PACT at the same time. It is suggested that clear and simple information be offered to parents about PACT, so that they know what to expect before agreeing to participate in it. Furthermore, the possibility of participating in PACT should be discussed on a case-by-case basis with each family, and under consideration of the parents' current circumstances, to ensure that the intervention does not unduly burden families.

The Influence of Other Interventions

All eight children of the parents interviewed for the research study had received Speech and Language Therapy (SaLT) and music therapy in addition to the PACT sessions. These sessions are unlikely to have been at the same time as PACT, though may have all been within the last six months. Several parents commented on similarities between PACT and these other interventions, and described that they felt these all converged on the same

goals. It thus appears that parents felt that the different interventions did not interfere with each other in an unhelpful way, rather they were perceived as mutually influencing each other in helping the child. It therefore seems plausible for families to continue to receive several interventions at the same time.

The Role of Diagnosis in Offering Intervention

Considering the findings of both the literature review and the research study, it appears that parent-mediated interventions are effective in increasing synchrony within parent-child interactions both for children at risk for ASD and those diagnosed with ASD. These findings are in line with current recommendations for clinical practice (NICE, 2013). Parents interviewed for the research study described the period of time waiting for intervention as challenging, as it was apparent that their child had difficulties, but parents described not knowing what to do. Given that there are interventions that are effective in increasing synchrony in parent-child dyads where children vary in ages from two to five years, and also in terms of being at risk for or having a diagnosis of ASD, (Aldred, Green, & Adams, 2004; Bradshaw, Steiner, Gengoux, & Koegel, 2014; Morgan et al., 2014), it appears that parent-mediated interventions could be offered flexibly in routine clinical practice. Parents interviewed in the present research study suggested that the intervention may be of benefit to other parents, and some stated they felt it may even benefit families of typically developing children. Thus it appears that parents perceive that making PACT available need not be contingent on having a specific diagnosis. Offering parent-mediated interventions flexibly may free services up to establish rolling programmes of a modified version of PACT (or similar short-term parent-mediated intervention aimed at increasing synchrony), which may be offered to families on referral to the service. Rather than having to wait for an

assessment to receive an intervention, a rolling programme would provide parents with the opportunity to learn how to engage their child and potentially ameliorate the child's difficulties. This may not only provide families with support sooner, but may also reduce the pressure on services in the long run, as parents are equipped to help their child as early as possible.

Implications for Future Research

The findings of the literature review identified a gap in the literature with regard to interventions increasing synchrony between parents and children diagnosed with ASD. While these interventions targeted specific parent behaviours that are pertinent to increasing synchrony, no effect sizes were reported for the intervention effect on parents' behaviours. Such data is available for children at risk for ASD. If increasing parental synchrony is the proximal intervention target to facilitate improvements in social communication in children with ASD, it is important to know to what extent interventions aimed at increasing parental synchrony change parents' behaviours. This is particularly relevant to research wishing to identify mediating factors of outcomes, therefore research studies should endeavour to measure and report intervention effect sizes on specific parent behaviours relevant to synchrony in studies with children diagnosed with ASD.

While there is increasing evidence suggesting synchrony has an important role within the parent-child relationship in terms of children's social-communication outcomes (Bradshaw, et al., 2014; Morgan et al., 2014), there is as yet little understanding of the mechanisms that facilitate increases in synchrony in parents and children. The present study hints at possible psychological processes that may be relevant in increasing parental synchrony, such as the changes in parent's attributions regarding the child's responses to

parental attempts to engage with the child. Thus more research regarding the role of parental attributions of their child's behaviour in relation to synchrony is needed.

Similarly, there is some evidence to suggest that interventions aimed at increasing responsiveness in parents of children at risk for ASD resulted in increased parental perception of child attachment (Siller, Swanson, Gerber, Hutman, & Sigman, 2014). There is at present no such research of parents of children diagnosed with ASD. Further research is needed to determine whether interventions increasing synchrony within the parent-child relationship impact on child attachment in both children at risk for and diagnosed with ASD, or whether they impact on parents' perception of child attachment, or both.

The parents included in the empirical study of this thesis had received a modified version of PACT. Parents reported finding the modified intervention helpful; however no outcome data is available for such a modified approach. Given that many of the early interventions aimed at young children at risk for ASD are briefer, yet demonstrate effectiveness in increasing synchrony (Bradshaw et al., 2014; Morgan et al., 2014), it is possible that a similarly modified version of PACT may be effective also. Longitudinal, randomised controlled trial design studies are required to determine the effectiveness of such a brief PACT intervention, and how this may compare to the original protocol of PACT as studied by Green et al., (2010).

Personal Reflections

Interpretative Phenomenological Analysis (IPA) emphasises the importance of personal reflection on the part of the researcher (Smith, Flowers, & Larkin, 2009). IPA involves the 'double hermeneutic' (Smith & Osborn, 2003), where the researcher is trying to make sense of the participant's sense making of a particular phenomenon. The researcher is

thus encouraged to acknowledge his or her own thoughts and feelings about the issue in question, in order to allow the data to ‘speak for itself’, and thus remain faithful to the inductive approach of IPA. This final section explores my own reflections on the research process.

In terms of my own background, I had no prior personal experience of knowing a child or adult diagnosed with, or identified as at risk for, ASD. I had some very limited clinical experience of working with children and adults diagnosed with ASD, which left me with a sense of how diverse (rather than similar) individuals diagnosed with ASD are, therefore I had no expectations of what parents might discuss about their child’s difficulties. I felt this relative lack of prior knowledge and experience made it relatively easy for me to bracket⁷ any preconceptions during the process of collecting and analysing data.

Central to the research was the experience of being a parent. I do not have children, and it is possible that this was an advantage in terms of bracketing personal preconceptions about parenting during the research process. It is also possible, however, that having experience of being a parent may have influenced the interview and the analysis in some way. During interviews I used skills developed during clinical training to build rapport with parents and foster a sense of connection despite the differences between the parents and myself, and I feel I was able to empathise with them.

Before the research began, I had observed one session of PACT, which gave me a feel for how the sessions are structured. This was helpful when parents were discussing specific aspects of the sessions, and I felt it was important to have had this experience, as parents’ reflections during the interview assumed prior knowledge of the intervention. It may have

⁷ Bracketing refers to the process of putting aside (bracketing) one’s own prior experiences, preconceptions and assumptions during the process of collecting and analysing the data to safeguard the fidelity of the results. It ensures that the themes are developed from the data rather than the data fitting into themes based on the researcher’s preconceived ideas (Smith, Flowers, & Larkin, 2009).

influenced parents' confidence in my role as researcher if they had felt that I was not familiar with the intervention I was asking them about, and this in turn may have influenced what they felt comfortable disclosing during the interview.

From the outset, it was clear that my role was as a researcher, and that the interviews were being carried out as part of the fulfilment of an educational qualification. Although I had the sense that parents felt reassured that I had some knowledge about PACT, and that I was familiar with some of the clinicians who had delivered the intervention, I had positioned myself as separate to the services delivering the PACT sessions. I felt this was important, as I wanted to gain an understanding of how parents had really experienced PACT. To this end, I wanted parents to feel able to speak freely and critically about PACT or about their experiences with services providing PACT, and I felt this would be easier for them to do if I were not affiliated with PACT (which I am not). Also, the study had been designed such that parents were only invited to participate once they had completed their PACT intervention. This was done in order to reduce any possible demand characteristics parents may have otherwise experienced. Indeed, during the interviews some parents were quite critical in their descriptions of some aspects of their experiences.

Carrying out the interviews was extremely enjoyable. As I was talking to parents I found myself feeling humbled and touched by the descriptions of their experiences. I also met several of the children that had been referred to the services providing PACT. While I was able to maintain appropriate boundaries during the interviews, I felt a sense of duty to parents to represent each of their experiences accurately in the empirical paper. This was further amplified during the transcription process, where repeated listening to the conversations impressed upon me the depth and complexity of each parent's experience. I felt that I wanted to give these parents a voice and to tell their stories. This desire to do justice to the parents' experiences made the process of the analysis feel tricky at times, in particular condensing and

streamlining themes. Discussions of themes with my supervisors helped me to overcome this difficulty.

This thesis aimed to explore parent-mediated interventions for children with social-communication difficulties. It considered the view of eight parents who had a child who was not developing as expected and who had received a modified version of PACT. It illustrated the parents' learning and new understanding of their children's difficulties, which facilitated the parents being able to increase engagement with their child after a relatively brief therapeutic intervention. While this is just one interpretation of the views of eight parents who had received PACT, it is hoped that the findings and discussions will contribute to the existing body of knowledge by contributing to theory, stimulating future research and highlighting implications for clinical practice.

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Ethics Submission

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IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)

Evaluation of parents' experiences of PACT Version 1

1. Is your project research?

Yes No

2. Select one category from the list below:

- Clinical trial of an investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an investigational medicinal product and an investigational medical device
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- Basic science study involving procedures with human participants
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- Study involving qualitative methods only
- Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- Study limited to working with data (specific project only)
- Research tissue bank
- Research database

If your work does not fit any of these categories, select the option below:

Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? Yes No
- b) Will you be taking new human tissue samples (or other human biological samples)? Yes No
- c) Will you be using existing human tissue samples (or other human biological samples)? Yes No

3. In which countries of the UK will the research sites be located? (Tick all that apply)

- England
- Scotland
- Wales
- Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- England
 Scotland
 Wales
 Northern Ireland
 This study does not involve the NHS

4. Which review bodies are you applying to?

- NHS/HSC Research and Development offices
 Social Care Research Ethics Committee
 Research Ethics Committee
 National Information Governance Board for Health and Social Care (NIGB)
 National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

- Yes No

6. Do you plan to include any participants who are children?

- Yes No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

- Yes No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

- Yes No

9. Is the study or any part of it being undertaken as an educational project?

- Yes No

Please describe briefly the involvement of the student(s):

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

- Yes No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

Yes No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

Yes No

Integrated Research Application System**Application Form for Research administering questionnaires/interviews for quantitative analysis or mixed methodology study****Application to NHS/HSC Research Ethics Committee**

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Evaluation of parents' experiences of PACT Version 1

Please complete these details after you have booked the REC application for review.

REC Name:

NRES Committee London - Fulham

REC Reference Number:

14/LO/1120

Submission date:

06/06/2014

PART A: Core study information**1. ADMINISTRATIVE DETAILS****A1. Full title of the research:**

Evaluation of parents' experiences of participating in Pre-School Autism Communication Therapy (PACT)

A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title	Forename/Initials	Surname
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Fax			

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:

Doctorate in Clinical Psychology

Name of educational establishment:

Bangor University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
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Academic supervisor 2

	Title	Forename/Initials	Surname
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Telephone	01286674686		
Fax	01286682539		

Please state which academic supervisor(s) has responsibility for which student(s):

Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Miss Emily Bloxham	<input checked="" type="checkbox"/> Dr Helen Healy <input checked="" type="checkbox"/> Dr Helen Delargy

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- Student
 Academic supervisor
 Other

A3-1. Chief Investigator:

	Title Forename/Initials Surname
	Miss Emily Bloxham
Post	Trainee Clinical Psychologist
Qualifications	Postgraduate Certificate in Psychological Therapies Higher Diploma in Psychology BA (Hons) European Business and German
Employer	Betsi Cadwaladr University Health Board
Work Address	North Wales Clinical Psychology Programme Brigantia Building, School of Psychology Bangor University, Bangor, Gwynedd
Post Code	LL57 2DG
Work E-mail	psp0c6@bangor.ac.uk
* Personal E-mail	emily.m.bloxham@gmail.com
Work Telephone	01248382205
* Personal Telephone/Mobile	447540181562
Fax	01248383718

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.*

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?

This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title Forename/Initials Surname
	Mr Hefin Frances
Address	School of Psychology Brigantia Building, Penrallt Road Bangor, Gwynedd
Post Code	LL57 2AS
E-mail	h.francis@bangor.ac.uk
Telephone	01248388339
Fax	01248382599

A5-1. Research reference numbers. Please give any relevant references for your study:

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number:

Protocol Version: 1

Protocol Date: 12/04/2014

Funder's reference number:

Project website:

Additional reference number(s):

Ref.Number	Description	Reference Number
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Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open

access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

Yes No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.

Pre-School Autism Communication Therapy (PACT) is an intervention aimed at improving social communication abilities in children with autistic spectrum disorders (ASD) and related social communication impairments, at either pre-verbal or early stages of language development (Aldred et al., 2011). Its principles draw on interventions for children with developmental language delays (Fey, Catts & Larivee's, 1995; as cited in Aldred et al., 2011).

PACT is a parent-mediated and video-aided intervention which targets core impairments in understanding, intentional communication and shared attention (Tomasello, 1995; as cited in Aldred et al., 2011). The rationale for PACT is based on research evidence suggesting that children with ASD require an interactive style that is specifically matched to their individual level of social communication (Yoder & Warren, 2001); the intervention thus focuses on changing the interaction of the parent-child dyad in order to improve child communication.

Green et al. (2010) suggest that parent-mediated interventions may be particularly efficacious in improving parents' perceptions and sensitivity to their child's communication needs, and that this effect may potentially generalise to benefit the child's family environment and thus generate cumulative effects in the child's development.

The main purpose of the present study is to explore the experiences of parents who received PACT sessions. Data will be collected through semi-structured interviews with parents who have completed PACT sessions, and Interpretative Phenomenological Analysis (IPA; Smith Flowers & Larkin, 2009) will be used to analyse the transcripts for themes.

A secondary aim of the current study is to consider how outcomes from randomised controlled trials are brought into clinical practice, where interventions are delivered within the constraints of what local services can provide. This will be assessed by analysing quantitative data collected from parents at pre-and post-intervention, and coding and analysing video clips of parent-child interactions in PACT sessions at pre-and post-intervention.

A6-2. Summary of main issues. Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Issues regarding the purpose of the study

The main purpose of the present study is to explore the experiences of parents who received Pre-School Autism Communication Therapy (PACT) sessions, to contribute further to the knowledge and evidence regarding PACT. Therefore this study goes beyond previous research which focussed on the effectiveness of PACT (Green et al., 2010) to understand the subjective experience of undergoing this intervention. This may inform how the intervention is delivered within service in the future.

Additionally, the current study aims to consider how outcomes from randomised controlled trials are brought into

clinical practice, where interventions are delivered within the constraints of what local services can provide. This may inform how the intervention is delivered within service in the future.

Issues regarding study design

Participants will be asked to take part in an interview with the primary researcher to talk about their experiences with PACT once they have completed their intervention sessions. This interview can take place between 1 and 6 months after the last PACT session. This meeting will last approximately one hour and will take place in a location of the participant's choosing (e.g. in their own home, at a clinic). The interview will be tape-recorded so that the conversation can be transcribed and analysed in detail by the lead researcher later. The interview will cover the following areas: the experience of taking part in PACT, what the participant thought about it and their opinion of it as a therapy. Some quotations from the conversation may be used to represent the themes and experiences expressed. It is important to note that the content of what is discussed in the interview will be kept confidential; however, confidentiality and its limitations in terms of safeguarding individuals at risk of harm will be discussed with participants. Once the interview recording has been transcribed, the recording will be deleted.

2) We will ask the participant's permission to use the questionnaires that are completed at the beginning and the end of the PACT sessions. These will be stored in the participant's child's clinical psychology file within the service.

3) We will ask the participant to give their permission to code and analyse video clips of their play sessions with their child. These video clips will be coded for social communication interactions such as parental synchronous response, child initiations with the parent and parent-child shared attention.

All participants will be fully debriefed at the end of the interview. Once the study has been completed, all participants who have indicated prior to the interview that they wish to receive feedback will be sent a brief summary of the main findings.

Issues regarding recruitment

Participants will be recruited from the Gwynedd and Anglesey integrated teams for children with disability, and the parent invited to take part in the research project will be the main parent who has received PACT. All children will have been referred to the service due to concerns regarding their social/communication development. Some children may have received a diagnosis of ASD; others will be receiving the therapy prior to formal diagnosis.

Parents will be made aware that a study regarding PACT is running by their main clinician. Once they have completed their PACT sessions, parents will be asked by their main clinician whether they are interested in hearing about the study, and if they are, they will be given a study invitation letter. The study invitation letter introduces the study and its aims to the parent, and invites them to provide their contact details via a return slip to the lead researcher, should they wish to participate in the study. It was decided to recruit participants after their treatment was completed in order to reduce the possibility of parents feeling under pressure to participate.

Once parents have consented to be contacted regarding the research study, the lead researcher will contact them and provide further information regarding the study, explaining fully what is involved and provide comprehensive study information sheets and a consent form.

The Inclusion criteria are: parent (male or female) of a child that is receiving a service from the Derwen (Integrated Team for Children with Disability, Gwynedd) or the Specialist Children's Service (SCS, Ynys Mon), and has difficulties with social and communication skills and has completed a minimum of four PACT sessions. Parents will be contacted between 1 and 6 months after completing their final PACT session.

The aim is to recruit between 6 and 8 parents to participate in the study. Given that the intervention is currently being run in the service, participant recruitment will begin as soon as ethical approval has been gained by the Bangor University School of Psychology and NHS Ethics committees.

In developing the design and recruitment procedure for the research study, the lead researcher met with a member of the North Wales Clinical Psychology Programme (NWCPP) People Panel, a service user panel whose members are interested in research and clinical practice.

The lead researcher met with a mother who has a child with a disability in order to discuss the proposed method for recruiting participants and also to review the participant invitation, the study information sheet, and the participant consent form. This allowed the lead researcher to consider the procedure for recruitment and the associated documents from a parent's point of view. Following this meeting, changes were made to the participant invitation, the study information sheet, and the participant consent form to reflect the feedback from the People Panel member, and to make the information provided more relevant and more sensitive to the needs of the intended audience.

The proposed method for participant recruitment was deemed acceptable by the parent from the People Panel, and therefore this was not changed.

Issues regarding consent

All participants will be informed of the research procedure before they give consent to participate. This information will be outlined in the study invitation letter, the participant information sheet and the consent form.

Participants will be told that their participation is voluntary, and that they may skip questions they do not wish to answer on questionnaires and during the semi-structured interview, and this is also discussed in the participant information sheet, the consent form and with the primary researcher before at the time of the interview.

A consent form has been designed for participants to give explicit written consent to eight separate points, to ensure that parents understand what the study entails. Parents will be asked to initial these points to confirm that they: -Have read and understood the participant information sheet, and had the opportunity to discuss any questions.

-Understand that their participation is voluntary, and that they can withdraw at any time without giving a reason, and that this will not affect their child's medical care or legal rights.

-Consent to information from questionnaires completed as part of the intervention being used in the study.

-Consent to being interviewed and also consent for the interview to be audio recorded.

-Consent to anonymised quotations from the interview being reported.

-Consent to their child's therapy video clips being coded and analysed as part of the study.

-Consent that their child's clinical psychologist be informed of their participation in the study and they are asked to provide the name of their child's clinical psychologist.

-Confirm that they understand that the researcher will contact their child's clinical psychologist if there is a concern regarding risk to their child or their family.

Parents will be given self-report questionnaires to complete as part of the intervention, which will be handed out and collected by the clinician working with the parent. There is an expectation that clinician's will give parent's the option to skip questions they do not wish to answer. If parents complete the questionnaires independently there is an expectation that parents will skip questions they do not wish to answer. The questionnaires used for the study will be made available to the primary researcher only if the parent has given consent to do so, and they will be used as they are, i.e. parents will not be contacted after the event to obtain missing information from questionnaires.

Issues regarding confidentiality and data protection

Participants will be informed that their information will be kept confidential with the exception to any reports of risk of harm to the participant's child and/or family, and should this occur during the study, this will be discussed with the participant.

The study is using Interpretative Phenomenological Analysis (IPA) to explore parent's experiences of participating in a therapy to help improve their child's social communication skills. This approach requires interviews to be transcribed for analysis, and one of the research supervisors will view samples of analyses based on the transcripts. Given that both research supervisors work clinically in the service hosting the study, it is likely that they may know the participants. In order to ensure that the possibility of participant confidentiality being compromised is minimised, every participant will be assigned a pseudonym/anonymised participant number at the point of transcription, and specific or potentially identifying information will be described in more general terms in those sample passages of analyses given to research supervisors.

If the primary researcher is made aware of a possible risk of harm to a child at any point throughout the research study the primary researcher will discuss these concerns with the parent, and with the child's clinical psychologist, and both research supervisors. Service guidelines and local safeguarding policies will be implemented as appropriate.

The participant consent form sets out in detail how various forms of data are handled and stored to comply with the requirements of the Data Protection Act 1998, as well as the relevant University and NHS policies and service guidelines. Audio recordings will be destroyed once transcription is complete. During the study interview transcripts will be stored on an encrypted pen drive provided by the North Wales Clinical Psychology Training Programme (NWCPP). Upon completion of the study, personal details and interview transcripts will be destroyed. The rest of the research data (questionnaire data and video clips) form part of the child's health care record and are stored in accordance with NHS policies and service guidelines.

Issues regarding risk or distress to participants

The study is using Interpretative Phenomenological Analysis (IPA) to explore parent's experiences of participating in a therapy to help improve their child's social communication skills. It is anticipated that this may be a sensitive topic, and that the nature of the experience may be distressing for some parents to discuss. The principal researcher is a trainee clinical psychologist and as such has the necessary skills to manage high levels of emotion and distress. Therefore the researcher will be able to maintain a sensitive attitude towards all participants and will stop the interview should this appear to be necessary or indeed requested by the participant.

Participants have been explicitly advised that they do not have to answer any questions they do not wish to, and that they may discontinue the interview at any time if they wish to do so. Where there appear to be significant levels of distress, the principal researcher may discuss with participants the benefit of seeking further support from a GP or signposting to charity organisations (e.g. The National Autistic Society) as appropriate. In addition, all participants will

be provided with contact details for the primary researcher and may use these to contact the primary researcher should they experience any distress following the interview.

Children under the age of 18 are only indirectly involved in the study in that video clips of parent-child play recorded as part of the intervention will be observed, coded and analysed to inform the extent to which the intervention impacted on parent-child interactions and social communication. These video clips will only be used for observation, coding and analysis if a parent has given explicit consent for the therapy video clips to be used in this way.

Issues regarding risk to the researcher

There may be occasions where the Trust's Lone Worker policy applies, in these cases the trainee will adhere to the policy. It is possible that some of the content discussed in interviews may be emotional and upsetting for the trainee. If this is the case the trainee will discuss this with her research supervisors and her training co-ordinator. No other risks have been identified.

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

Yes - proportionate review No - review by full REC meeting

Further comments (optional):

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. Please tick all that apply.

- Case series/ case note review
- Case control
- Cohort observation
- Controlled trial without randomisation
- Cross-sectional study
- Database analysis
- Epidemiology
- Feasibility/ pilot study
- Laboratory study
- Metanalysis
- Qualitative research
- Questionnaire, interview or observation study
- Randomised controlled trial
- Other (please specify)

Mixed methodology involving qualitative and quantitative (questionnaire and video coding) data.

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

What are the experiences of parents who have received Pre-School Autism Communication Therapy (PACT) as a therapeutic intervention?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

Does PACT achieve any measurable change in pre- and post-intervention questionnaire responses measuring

parental stress and child behaviour?

Does PACT impact on the child's communication as measured by pre- and post-intervention coding of video clips of interactive play between child and parent?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Autism, a severe neurodevelopmental disability, has an estimated prevalence of 1% for the broad autistic spectrum, while the prevalence of autism in its core form is thought to be 0.4% (Baird, Simonoff, Pickles et al., 2006). It is characterised by impairments in social interaction and communication, as well as repetitive behaviours (Oono, Honey, & McConahie, 2013). This pattern of behaviour is often apparent early in childhood, and diagnosis commonly occurs as early as three to four years of age (Chakrabarti & Fombonne, 2001). Despite early identification, the profound effect autism has on social development into adulthood (Howlin, Goode, Hutton, & Rutter, 2004), and the fact that the use of early psychosocial interventions has been advocated (Lord, et al., 2005; Oonos, Honey, & McConachie, 2013; Rogers & Vismara, 2008), such interventions have only recently been assessed rigorously (Green et al., 2010).

One such intervention is Pre-School Autism Communication Therapy (PACT; Green et al., 2010), which is aimed at improving social communication abilities in children with autistic spectrum disorders (ASD) and related social communication impairments, at either pre-verbal or early stages of language development, by developing parent-child interaction during play. In a randomised controlled trial PACT was found to reduce symptom severity as measured by the Autism Diagnostic Observation Schedule-Generic (ADOS-G, Lord et al., 2000). Furthermore, the intervention was found to improve parental synchronous response to their child, child initiations with the parent, and parent-child shared attention. Green et al. (2010) suggest that parent-mediated interventions may be particularly efficacious in improving parents' perceptions and sensitivity to their child's communication needs, and that the effect on parental behaviour can potentially generalise to benefit the child's family environment and similarly generate cumulative effects in the child's development. However these aspects of subjective experience of PACT have not been studied in previous research.

The main purpose of the present study is to explore the experiences of parents who received PACT sessions. Data will be collected through semi-structured interviews with parents who have completed PACT sessions, and Interpretative Phenomenological Analysis (IPA; Smith Flowers & Larkin, 2009) will be used to analyse the transcripts for themes. Using a qualitative approach will allow for the examination of parents' subjective experiences of PACT, and whether their experiences reflect those suggested by previous research (Green et al., 2010), thus contributing to the scientific understanding regarding PACT.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Design and Procedures

Clinicians in the Gwynedd Integrated Team for Children with Disabilities and the Ynys Mon Specialist Children's Service will identify parents on their case load who have received Pre-School Autism Communication Therapy (PACT). In their discussions with parents clinicians will make them aware of the fact that a research study regarding PACT is being conducted.

Once parents have completed their PACT sessions, their clinicians will ask them if they are interested in hearing more about the research study, and if they are, they will be sent a study invitation letter with a short introduction to the research, and a form to provide their contact details and consent for the lead researcher to contact them to discuss their participation.

When the lead researcher contacts the potential participant (either by telephone or by email, as indicated by the participant), the study will be explained in detail, and if the parent wishes to participate, the Participant Information Sheet will be posted to their home address, and an interview will be arranged. Interviews will be held at a time and place of the parents choice, either in their home or in the clinic. It is anticipated that interviews will last from approximately 40 minutes up to 90 minutes, and will be guided by a semi-structured interview schedule.

Before the interview begins, the lead researcher will collect demographic information from each participant, and will record this on a standardised form. This will give the lead researcher the opportunity to develop rapport with the participant and give the participant some time to feel at ease with the lead researcher. Interviews will be recorded on a hand-held recorder provided to the lead researcher by the University and will be stored on an encrypted USB pen drive provided for this purpose. The participant will have the opportunity for a brief debrief and to ask questions at the end of the interview. Transcription of the interview will occur as soon as possible. Once all interviews have been transcribed, the digital file will be deleted and the scripts will be stored on the encrypted USB pen drive also. Transcripts will be analysed using guidelines by Smith, Flowers, and Larkin (2010).

Once all interviews have been transcribed and the qualitative analysis has been completed, the quantitative data from

the questionnaires will be examined. The questionnaire data will be provided to the lead researcher by the research supervisors and will be input to SPSS on the premises of both services, to safe guard the raw data.

Therapy video clips of parent-child interaction are routinely made as part of PACT and are stored as part of the child's record. Specific video clips from the beginning and the end of PACT will be coded and analysis for those parents who have given written consent to this. Coding and analysis of video clips will occur within the clinic setting, and video clips will not be removed from the premises. These video clips will be coded for social communication interactions such as parental synchronous response, child initiations with the parent and parent-child shared attention. The videos will be coded using a manual developed by the service based on the manual used by Green et al. (2010).

Once the research has been completed and submitted, participants will be sent a brief summary of the main findings.

Measures

A demographic questionnaire will be administered prior to the interview detailing participants' family (including whether their child has a diagnosis), involvement in parenting of children, marital status, education and employment status, ethnicity, and the number of PACT sessions they attended.

Quantitative measures will be administered by the clinician delivering PACT to an individual family, and will be kept in the child's clinical psychology file stored within the service. These measures are:

Parent Stress Index (PSI; Abidin, 1990; 1995)

The PSI is a self-report measure to screen for stress within the parent-child relationship. It identifies dysfunctional parenting and predicts potential adjustment difficulties for the child within the family system. The measure has been developed for use with parents of children aged 12 years or younger. The long form consists of 120 items and yields a Total Stress Score as well as scaled scores for Parent Characteristics and Child Characteristics, while the short form consists of 36 items, which make up a Total Stress Score. The PSI has been found to have very good to excellent internal consistency (Reitman et al., 2002). Alpha reliability coefficients for the child domain, the parent domain and the Total Stress Sale have been found to be .89, .93 and .95 respectively (Loyd & Abidin, 1985). Test-retest reliability for the child domain and the parent domain across a three week period was strong, with $r=.817$ and $r=.706$ respectively (Burke, 1978; as cited in Loyd & Abidin, 1985).

Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997)

The DSQ is a widely used screening measure, which assesses behavioural and emotional problems in children aged 4 to 16 years. It consist of 25 statements, which parents rate on a three point Likert scale: "never", "sometimes" or "always". These items are divided into five subscales, Emotional Symptoms, Conduct Problems, Hyperactivity, Peer Problems, and Pro-Social Behaviour. A further Impact supplement was used, consisting of five items, which assess the impact of child difficulties (if any) on home life, academic achievements, peer relationships and leisure activities. It demonstrates good internal consistency, acceptable test-retest reliability, good discriminant validity, and strong correlations with other measures of psychopathology (Stone, Otten Engels, ermulst & Janssens, 2010). The SDQ3-4 was recently validated with 3-4 year olds (Ezpeleta, Granero, la Osa, Penelo & Domenech, 2012), and found to have similar properties to the SDQ4-16. I this sample the SDQ had good internal consistency ($\alpha=.80$).

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- Design of the research
- Management of the research
- Undertaking the research
- Analysis of results
- Dissemination of findings
- None of the above

Give details of involvement, or if none please justify the absence of involvement.

In developing the design and recruitment procedure for the research study, as wellas the associated documentation the lead researcher met with a member of the North Wales Clinical Psychology Programme (NWCPP) People Panel, a service user panel whose members are interested in research and clinical practice.

The lead researcher met with a mother who has a child with a disability in order to discuss the proposed method for recruiting participants and also to review the participant invitation, the study information sheet, and the participant consent form. This allowed the lead researcher to consider the procedure for recruitment and the associated documents from a parent's point of view. Following this meeting, changes were made to the participant invitation, the

study information sheet, and the participant consent form to reflect the feedback from the People Panel member, and to make the information provided more relevant and more sensitive to the needs of the intended audience.

The proposed method for participant recruitment was deemed acceptable by the parent from the People Panel, and therefore this was not changed.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

- main parent to have attended PACT sessions for their child due to social and communication difficulties
- participant to have completed at least 4 PACT sessions
- participants have completed their PACT intervention at least 1 month ago, but not more than 6 months ago

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

- participants that have completed fewer than 4 PACT sessions
- participants who either completed their PACT session less than 1 month or more than 6 months ago
- participants that do not speak fluent English, as all interviews will be conducted through English
- participants that have significant mental health difficulties that could be exacerbated by the research procedure - identified by the responsible clinician within the service
- participants with a significant communication or intellectual disability

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Made aware of PACT-related research study	1		10 minutes	Main clinician involved in delivering PACT session will mention that there is a study of PACT currently ongoing.
Approached regarding participation in the research study	1		15 minutes	Once the PACT intervention has been completed, the main clinician will give further details regarding the study, and give opt-in form for parents to provide contact details for lead researcher
Consent to discuss participating in the study - parent returns study invitation letter by post, giving consent to be contacted to discuss their possible participation	1		1 day	Parent to return the slip from the study invitation letter by post indicating their preferred method of contact by lead researcher,
Telephone call/email from lead researcher	1		20 minutes	Lead researcher to contact potential participant by phone or email to discuss the study. Study Information sheet sent out to parents who wish to participate
Giving consent and arranging interview	2		10 minutes each	Discussion of study information sheet, and agreement of appointment for semi-structured interview

Demographic questionnaire	1	15 minutes	Demographic questionnaire completed with participants prior to the interview detailing participants' family (including whether their child has a diagnosis), involvement in parenting of children, marital status, education and employment status, ethnicity, and the number of PACT sessions they attended.
Research Interview	1	45-90 minutes	Participant to give detailed description of their experiences of receiving PACT sessions.

A21. How long do you expect each participant to be in the study in total?

From initially being made aware of the research study to being sent a brief summary of the main findings at the end of the study, participants will be involved in the study for approximately 17 months. However, participants will only be actively involved in the research process for approximately 3 hours.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Participants will not be invited to take part in the study until they have completed their PACT intervention. This is to ensure that they do not feel their receipt of PACT sessions is in any way contingent in taking part in the research study. The lead researcher is aware that families may be going through a difficult time, as it is possible that their child may have received a diagnosis of autism or other developmental disorder. The lead researcher will behave sensitively towards participants throughout her dealings with them. Given that the research interviews are carried out by a trainee clinical psychologist, it is possible that participants may have particular expectations of the interview. However, the lead researcher will explain to participants that the research interview is not a form of therapy. Where there appear to be significant levels of distress, the principal researcher may discuss with participants the benefit of seeking further support from a GP or signposting to charity (e.g. The National Autistic Society) as appropriate. In addition, all participants will be provided with contact details for the primary researcher and may use these to contact the primary researcher should they experience any distress following the interview.

There is a small risk that participants may become upset during the interview. The principal researcher will maintain a sensitive attitude towards all participants and will stop the interview should this appear to be necessary or indeed requested by the participant. The principal researcher is a trainee clinical psychologist and has the necessary skills to manage high levels of emotion and distress. Participants have been explicitly advised that they do not have to answer any questions they do not wish to, and that they may discontinue the interview at any time if they wish to do so. This is outlined in the study information sheet and the consent form, and is also discussed with each participant prior to the interview.

Participants may find it difficult to give honest responses to questions. The participant information sheet explains that all data (interview, questionnaire, and video clip) used in the research will be anonymous, and that any further care they may need from the Derwen (Integrated Team for Children with Disability, Gwynedd) or the Specialist Children's Service (SCS, Ynys Mon) will not be affected by their participation in the research study. This will be explained again prior to the interview.

Regarding the questionnaire data, participants will be able to skip any questions they may not want to answer. With regard to the video clips, parents may not wish to consent for this information to be used. The consent form has been designed in such a way, that participants give explicit consent to the three parts of the study, and to make it easier for them to "opt-out" of any part they may not feel comfortable with.

It is possible that anonymity of the data may be compromised during the analysis of interview data. This is due to the fact that the lead researcher will provide samples of analysed data to research supervisors for comment. The research supervisors may be familiar with the families taking part in the study through their clinical work. In order to overcome this, the lead researcher will use pseudonyms at the point of interview transcription and make specific words more general in any passages provided to research supervisors for comment.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?



Yes No

If Yes, please give details of procedures in place to deal with these issues:

It is anticipated that parent's experiences of receiving PACT sessions may be a sensitive topic, and that the nature of the experience may be distressing for some parents to discuss. The principal researcher is a trainee clinical psychologist and as such has the necessary skills to manage high levels of emotion and distress. Therefore the researcher will be able to maintain a sensitive attitude towards all participants and will stop the interview should this appear to be necessary or indeed requested by the participant.

Participants have been explicitly advised that they do not have to answer any questions they do not wish to, and that they may discontinue the interview at any time if they wish to do so. Where there appear to be significant levels of distress, the principal researcher may discuss with participants the benefit of seeking further support from a GP or signposting to charity (e.g. The National Autistic Society) as appropriate. In addition, all participants will be provided with contact details for the primary researcher and may use these to contact the primary researcher should they experience any distress following the interview.

In terms of disclosures requiring action (such as safeguarding of children or protection of vulnerable adults), the study information sheet and the consent form explain clearly that confidentiality no longer applies with regard to such disclosures. If such a disclosure is made during the research study, this will be discussed with the participant in the first instance, and the participant's child's clinical psychologist will be contacted to discuss the matter and any action may be required.

A24. What is the potential for benefit to research participants?

While no direct therapeutic input will be provided, participants may benefit from being able to share their story and being listened to sensitively.

The participant information sheet explains that possible benefits include contributing to a better understanding of parent's experiences of PACT and that this is likely to influence future service provision. While participants may not directly benefit from this themselves, they may appreciate the opportunity to contribute to service developments that will improve the service/intervention for other families in the future.

Participants may find the summary of findings helpful so they can understand what their story has contributed to the understanding of parents' experiences of PACT and also learn about other parents' experiences in this way.

A26. What are the potential risks for the researchers themselves? (if any)

Lone working

The lead researcher will be interviewing parents alone and is offering a choice of locations, either in the parent's home or in the clinic. For interviews that take place within the participant's home, the lead researcher will contact one of her research supervisors before entering the property and again when the interview has been completed, in line with service lone working guidelines. All families that are eligible to take part in the study will be known to Derwen and the Specialist Children's Service, and any potential risks will be taken into account at the time of recruitment.

For interviews arranged to take place within the clinic setting, times will be arranged during office hours, and therefore other staff will be on the premises.

Dates and times for interviews will be arranged when they are convenient for participants; however, it is anticipated that most interviews will take place during the week and within working hours.

Managing distress

Conducting in-depth interviews will place emotional and concentration demands on the interviewer and the participant. The lead researcher will manage these during the interview by offering and taking breaks as appropriate, and seeking appropriate supervision.

Participating in the research study may raise issues for the participants that they themselves were not aware of before the interview. Participants will be supported throughout the interview process and any need for further support will be discussed with participants as appropriate. Any serious levels of distress will be discussed with research supervisors.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Clinicians working within Derwen (Integrated Team for Children with Disability, Gwynedd) and the Specialist Children's Service (SCS, Ynys Mon) will identify families whom they have delivered PACT sessions to. They will make parents aware of the study, and invite them to hear more about the study once their PACT intervention has been completed, and provided they meet the inclusion and exclusion criteria. Parents will communicate their interest in hearing more about the study by returning a slip on the study invitation letter. Clinicians within Derwen and the SCS have been informed about the research study and have agreed to speak to potential participants.

The researcher will contact potential participants by phone or email (as per their preferred method of contact indicated on the returned slip), and provide further information about the study. If parents are interested, the researcher will post them the study information sheet. This will be followed up with a phone call to discuss any queries potential participants may have, and to arrange an appointment for the interview. The consent form will be discussed prior to the interview.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

Yes No

Please give details below:

All participants will be recruited through the clinicians working within the service, therefore this will not be necessary.

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

Yes No

A29. How and by whom will potential participants first be approached?

Potential participants will first be approached by their clinician who is delivering their PACT sessions. The initial mention is just to make parents aware that a study is running. They will only be approached about their interest in participating in the study, once all their PACT sessions have been completed.

A30-1. Will you obtain informed consent from or on behalf of research participants?

Yes No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Initial consent to be contacted by the researcher to discuss the study will be obtained from potential participants by their clinician who delivered the PACT sessions.

Once potential participants have agreed to participate in the study, consent for the three separate aspects of the study (semi-structured interview, use of questionnaire data, use of parent-child play video clips) will be sought separately prior to the interview by the researcher. This will be discussed with each participant and consent will be sought in writing.

All information provided to potential participants (the initial invitation, the study information sheet, and the consent form), will be made available in English and in Welsh.

If you are not obtaining consent, please explain why not.

n/a

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

Yes No

A31. How long will you allow potential participants to decide whether or not to take part?

3 weeks.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? (e.g. translation, use of interpreters)

All study invitation letters, participant information sheets and consent forms will be made available to potential participants in English and in Welsh. However, due to the fact that the researcher is not able to speak Welsh, all interviews will have to be conducted in English.

Due to the nature of the research (participants being required to give detailed descriptions of their experiences, which are then transcribed verbatim and analysed) any parents who are felt to have significant communication or learning difficulties will not be able to participate in the study.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

All study invitation letters, participant information sheets and consent forms will be made available to potential participants in English and in Welsh. However, due to the fact that the researcher is not able to speak Welsh, all interviews will have to be conducted in English.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.

- The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- The participant would continue to be included in the study.
- Not applicable – informed consent will not be sought from any participants in this research.
- Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

If the data has been collected it will be used for the purposes of the research, in recognition of the time given to participate. Once the project is complete, a record of the change in consent will be kept, and the data will no longer be available for access by the research team.

If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)

- Access to medical records by those outside the direct healthcare team
- Electronic transfer by magnetic or optical media, email or computer networks
- Sharing of personal data with other organisations
- Export of personal data outside the EEA
- Use of personal addresses, postcodes, faxes, emails or telephone numbers
- Publication of direct quotations from respondents
- Publication of data that might allow identification of individuals
- Use of audio/visual recording devices
- Storage of personal data on any of the following:
 - Manual files including X-rays
 - NHS computers
 - Home or other personal computers
 - University computers
 - Private company computers
 - Laptop computers

Further details:

The researcher supervisors will give potential participants the study invitation letter for those potential participants interested in taking part to provide their contact details (phone or email address). Thus only those contact details of participants who want to find more about the study will be given to the researcher, with their consent to be contacted. If participants do wish to participate, the researcher will require their addresses to post out the study information sheet and potentially to arrange the interview, if the participant wishes to carry it out at home. Therefore only those addresses of participants who wish to participate will be collected from participants directly.

Direct quotations may be published in the write-up of the study, and these are anonymised. This will be clearly explained in the information sheet and there will be a separate box on the consent form to indicate whether the participant consents to this.

A digital audio recording of the interview will need to be made for the purposes of the research. Audio files will be password protected and saved to an encrypted USB pen drive. This will be transcribed verbatim, and will be anonymised at the point of transcription, and the resulting file will be created on and saved to a password protected USB pen drive provided by the North Wales Clinical Psychology Programme (NWCPP) specifically for this purpose. All files regarding the research will additionally be password protected individually.

The researcher will input data from questionnaire measures stored in the participant's child's health file directly on to an SPSS file, which will be password protected and saved on the encrypted USB pen drive. The only information accessed in the child's health file are the questionnaires completed by parents as part of PACT sessions, and will be assigned an anonymous participant number at the point of inputting into SPSS.

The researcher will save coded data from video recordings in a password protected SPSS document on the encrypted USB pen drive. All data will be assigned an anonymous participant number at the point of inputting into SPSS.

Health records and video recordings of parent-child play recorded as part of PACT sessions will be viewed on the premises of the services and will not be removed from these.

A38. How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.

All names, places, and other specific or identifying information relating to participants will be anonymised in order to avoid identification. Once the clinician delivering PACT has introduced the study to the potential participants, they will not have any knowledge as to who has consented to take part in the study, and what information the individual participant disclosed.

The participant consent form sets out in detail how various forms of data are handled and stored to comply with the requirements of the Data Protection Act 1998, as well as the relevant NHS policies and service guidelines. Audio recordings will be destroyed once transcription is complete. Upon completion of the study, personal details and interview transcripts will be destroyed. The rest of the research data (questionnaire data and video clips) form part of their child's health care record and are stored in accordance with NHS policies and service guidelines.

A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.

The researcher requires the telephone numbers and email addresses of potential participants in order to introduce the research study. The researcher will also require the addresses of potential participants in order post out the study information sheets and to arrange the interview (if the participant elects to be interviewed in their own home). This information will be provided to the researcher by the participant themselves, either through the return slip of the study invitation letter or in direct conversation with the researcher. This information will be destroyed once the interview has taken place.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- Less than 3 months
 3 – 6 months
 6 – 12 months
 12 months – 3 years
 Over 3 years

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

- Yes No

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

- Yes No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

- Yes No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

- Yes No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

Yes No

Please give details, or justify if not registering the research.

This research is not publicly funded and therefore will not be registered on a public database. It will be registered on a the Betsi Cadwaladr University Health Board database for the duration of the study, and a paper copy of the completed Doctoral Thesis will be stored at the Bangor University library.

Registration of research studies is encouraged wherever possible.

You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

- Peer reviewed scientific journals
- Internal report
- Conference presentation
- Publication on website
- Other publication
- Submission to regulatory authorities
- Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- No plans to report or disseminate the results
- Other (please specify)

All participants will receive a brief summary of the main findings. In addition, the results will be presented to the Derwen and Specialist Child Service teams.

A53. Will you inform participants of the results?

Yes No

Please give details of how you will inform participants or justify if not doing so.

A brief (one page) summary of findings will be sent to all participants.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? Tick as appropriate:

- Independent external review
- Review within a company
- Review within a multi-centre research group
- Review within the Chief Investigator's institution or host organisation
- Review within the research team
- Review by educational supervisor
- Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

A proposal of the research study has been submitted and approved by the research department of the North Wales Clinical Psychology Programme at Bangor University. This proposal was checked through by the research team. The project has also been approved by the Bangor University Psychology Ethics Committee.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A56. How have the statistical aspects of the research been reviewed? Tick as appropriate:

- Review by independent statistician commissioned by funder or sponsor
- Other review by independent statistician
- Review by company statistician
- Review by a statistician within the Chief Investigator's institution
- Review by a statistician within the research team or multi-centre group
- Review by educational supervisor
- Other review by individual with relevant statistical expertise
- No review necessary as only frequencies and associations will be assessed – details of statistical input not required

In all cases please give details below of the individual responsible for reviewing the statistical aspects. If advice has been provided in confidence, give details of the department and institution concerned.

	Title	Forename/Initials	Surname
	Professor	Richard	Hastings
Department	School of Psychology		
Institution	Bangor University		
Work Address	Brigantia Building		
	Bangor		
	Gwynedd		
Post Code	LL57 2DG		
Telephone			
Fax			
Mobile			
E-mail			

Please enclose a copy of any available comments or reports from a statistician.

A57. What is the primary outcome measure for the study?

The primary outcome of the research study is the qualitative analysis of interviews with parents who have completed PACT sessions.

A58. What are the secondary outcome measures? (if any)

For the quantitative aspect of the study, which forms the secondary research aim of this research study, there are three secondary outcome measures:

- parents' perception of stress within their relationship with their child as measured by the Parent Stress Index (PSI; Abidin, 1990; 1995), pre- and post-intervention comparison
- child behaviour and emotional difficulties as measured by the Strengths and Difficulties Questionnaire(SDQ; Goodman, 1997), pre- and post-intervention comparison

-synchronous parent-child interactions, as measured by coded video clips recorded as part of the PACT sessions, pre- and post-intervention comparison

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 10
 Total international sample size (including UK): 10
 Total in European Economic Area: 0

Further details:

Due to the nature of the qualitative method being used (Interpretative Phenomenological Analysis, IPA: Smith, Flowers and Larkin, 2009), recruitment will finish when data saturation occurs.

Ten is the maximum number that will be recruited. Smith et al., (2009) suggest this is the required number of participants for a Doctoral level qualitative study using IPA, and this was given further support through consultation with experienced researchers who have previously used the same theoretical model for qualitative data analysis.

Such a small will mean that analysis of quantitative data will be underpowered; however, in discussion with the North Wales Clinical Psychology Programme Research Department, it was agreed that this was acceptable, given that the primary outcome of the study is the qualitative analysis, and the quantitative aspect (secondary outcomes) only makes up a small part of the project.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

Due to the nature of the qualitative method being used (Interpretative Phenomenological Analysis, IPA: Smith, Flowers and Larkin, 2009), recruitment will finish when data saturation occurs.

Ten is the maximum number that will be recruited. Smith et al., (2009) suggest this is the required number of participants for a Doctoral level qualitative study using IPA, and this was given further support through consultation with experienced researchers who have previously used the same theoretical model for qualitative data analysis.

Such a small will mean that analysis of quantitative data will be underpowered; however, in discussion with the North Wales Clinical Psychology Programme Research Department, it was agreed that this was acceptable, given that the primary outcome of the study is the qualitative analysis, and the quantitative aspect (secondary outcomes) only makes up a small part of the project.

A61. Will participants be allocated to groups at random?

Yes No

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

The qualitative method selected for this research study is Interpretative Phenomenological Analysis (IPA: Smith, Flowers and Larkin, 2009), as it captures the lived experiences of individuals and how they make sense of particular phenomena, such as taking part in Pre-School Autism Communication Therapy (PACT). This approach allows for the flexible use of a semi-structured interview schedule, thus facilitating the collection of rich data relating to the most salient aspects of parents' experience of PACT.

Given the small sample size, the quantitative data analysis of questionnaires and coded video clips will focus on a pre- and post-intervention comparison using t-tests. Given that the sample size is already very small, any participants with missing data will be excluded from analysis.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title Forename/Initials Surname
	Dr Helen Healy
Post	Clinical Tutor and Clinical PSychologist
Qualifications	PhD DClinPsy
Employer	North Wales Clinical Psychology Programme & Betsi Cadwaladr University Health Board
Work Address	North Wales Clinical Psychology Programme School of Psychology, Bangor University Brigantia Building, Bangor, Gwynedd
Post Code	LL57 2AS
Telephone	01248388442
Fax	01248383718
Mobile	
Work Email	h.healy@bangor.ac.uk

	Title Forename/Initials Surname
	Dr Helen Delargy
Post	Clinical Psychologist
Qualifications	DClinPsy
Employer	Betsi Cadwaladr University Health Board
Work Address	Derwen Integrated Team for Disabled Children Bron Hendre, South Road Caernarfon
Post Code	LL57 2HB
Telephone	01286674686
Fax	01286682539
Mobile	
Work Email	Helen.delargy@wales.nhs.uk

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

- Status: NHS or HSC care organisation
- Academic
- Pharmaceutical industry
- Medical device industry
- Local Authority
- Other social care provider (including voluntary sector or private organisation)
- Other

If Other, please specify:

Commercial status: **Non-Commercial**

Contact person

Name of organisation Bangor University School of Psychology

Given name Hefin
 Family name Frances
 Address School of Psychology
 Town/city Brigantia Building, Penrallt Road
 Post code LL57 2AS
 Country UNITED KINGDOM
 Telephone 01248388339
 Fax 01248382599
 E-mail h.francis@bangor.ac.uk

Is the sponsor based outside the UK?

Yes No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

- Funding secured from one or more funders
 External funding application to one or more funders in progress
 No application for external funding will be made

What type of research project is this?

- Standalone project
 Project that is part of a programme grant
 Project that is part of a Centre grant
 Project that is part of a fellowship/ personal award/ research training award
 Other

Other – please state:

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

Yes No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

Title Forename/Initials Surname
 Mr Sion Lewis
 Organisation Betsi Cadwaladr University Health Board
 Address Research and Development
 Ysbyty Gwynedd
 Bangor, Gwynedd
 Post Code LL57 2PW

Work Email Sion.Lewis@wales.nhs.k
 Telephone 01248384877
 Fax
 Mobile

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/06/2014

Planned end date: 30/09/2015

Total duration:

Years: 1 Months: 3 Days: 30

A71-2. Where will the research take place? (Tick as appropriate)

- England
 Scotland
 Wales
 Northern Ireland
 Other countries in European Economic Area

Total UK sites in study 2

Does this trial involve countries outside the EU?

Yes No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:

- NHS organisations in England
 NHS organisations in Wales 1
 NHS organisations in Scotland
 HSC organisations in Northern Ireland
 GP practices in England
 GP practices in Wales
 GP practices in Scotland
 GP practices in Northern Ireland
 Social care organisations
 Phase 1 trial units
 Prison establishments
 Probation areas
 Independent hospitals
 Educational establishments
 Independent research units
 Other (give details)

Total UK sites in study: 1

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (NHS sponsors only)
- Other insurance or indemnity arrangements will apply (give details below)

Bangor University will meet the legal liability of the sponsor for harm to participants arising from the management of the research. Please see attached sponsorship letter.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (protocol authors with NHS contracts only)
- Other insurance or indemnity arrangements will apply (give details below)

Bangor University will meet the legal liability of the sponsor for harm to participants arising from the design of the research. Please see attached sponsorship letter.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
- Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

NHS Indemnity scheme applies as participants will be NHS patients.

Please enclose a copy of relevant documents.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

Research site		Investigator/ Collaborator/ Contact	
Institution name	Derwen Integrated Team for Disabled Children	Title	Dr/Dr
Department name	Bron Hendre	First name/ Initials	Helen/Helen
Street address	South Road	Surname	Healy/Delargy
Town/city	Caernarfon		
Post Code	LL57 2HB		
Institution name	Specialist Children's Service (SCS) Ynys Mon	Title	Dr/Dr
Department name		First name/ Initials	Helen/Helen
Street address	Hen Ysgol y Graig	Surname	Healy/Delargy
Town/city	Llangefni		
Post Code	LL77 7JA		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
 - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
 - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
 - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
 - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
 - May be sent by email to REC members.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication*(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

- Chief Investigator
- Sponsor

- Study co-ordinator
 Student
 Other – please give details
 None

Access to application for training purposes (*Not applicable for R&D Forms*)

Optional – please tick as appropriate:

I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Miss Emily Bloxham on 06/06/2014 14:39.

Job Title/Post: Trainee Clinical Psychologist

Organisation: Bangor University/BCUHB

Email: psp0c6@bangor.ac.uk

Signature:

Print Name:

Date: (dd/mm/yyyy)

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

This section was signed electronically by Mr Hefin Francis on 05/06/2014 13:58.

Job Title/Post: School Manager for Psychology

Organisation: Bangor University

Email: h.francis@bangor.ac.uk

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by Dr Helen Delargy on 06/06/2014 14:37.

Job Title/Post: Clinical Psychologist
Organisation: NHS
Email: helen.delargy@wales.nhs.uk

Academic supervisor 2

This section was signed electronically by Dr Helen Healy on 05/06/2014 08:41.

Job Title/Post: Clinical Psychologist
Organisation: BCHUB
Email: h.healy@bangor.ac.uk

COLEG IECHYD A GWYDDORAU YMDDYGIAD
COLLEGE OF HEALTH & BEHAVIOURAL SCIENCES

YSGOL SEICOLEG
SCHOOL OF PSYCHOLOGY

**RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**



Dear Prospective Participant,

Re: research study into parents' experiences of Pre-School Autism Communication Therapy (PACT)

You and your child have recently been offered a number of PACT therapeutic sessions with . PACT is a parent-mediated and video-aided therapy for children with social communication difficulties. We would like to share some information about a PACT related research study we hope to complete. Both Helen and I are supervising a Trainee Clinical Psychologist, Emily Bloxham, with her research thesis which she is completing at Bangor University. This study has obtained full ethical approval from the Bangor University Ethics Committee and the North Wales Research Ethics Committee West. We are writing to all parents who have been offered PACT, where appropriate, to tell them about this research study.

The aim of this study is to explore the experiences of parents who have received Pre-School Autism Communication Therapy (PACT)

The study consists of three parts:

- a) we would like parents who have participated in PACT to participate in a general interview,
- b) we would like to include data from short questionnaires that you completed at the beginning and end of your sessions,
- c) we would also wish to review the video clips of play sessions between you and your child to identify and code the number of times your child initiated social interaction, and the number of times you responded.

If you are interested in taking part, please complete the contact form below, and return it using the stamped self-addressed envelope enclosed.

If you have any questions please don't hesitate to contact Emily Bloxham, the lead researcher for the study, by email on psp0c6@bangor.ac.uk or you can phone or send her a text on 07540 181562, and she will phone you back as soon as she can to answer any questions you may have about the study. Alternatively you can always contact either Helen or myself at the Bron Hendre number (01284 674686).

Thank you for reading this letter.

Yours sincerely,

Dr Helen Delargy (Clinical Psychologist)

Dr Helen Healy (Clinical Psychologist)

✂-----

--

I am interested in hearing more about the proposed research study into the experiences of parents who have received Pre-School Autism Communication Therapy (PACT), and I give permission for Emily Bloxham, lead researcher of the study, to contact me to discuss my possible participation.

Parent Name:

..... *Please tick preferred method of contact*

...

(please write in block capitals)

Contact Number:

Mobile:

.....

Home:

.....

Email Address:

.....

...

When is it most convenient for me to telephone you?

.....

.....

Signature:

Date:

.....

.....

...

...

COLEG IECHYD A GWYDDORAU YMDDYGIAD
COLLEGE OF HEALTH & BEHAVIOURAL SCIENCES

YSGOL SEICOLEG
SCHOOL OF PSYCHOLOGY

**RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**



Participant Information Sheet

A research study into parents' experiences of Pre-School Autism Communication
Therapy (PACT)

Dear Parent,

PACT is a parent-mediated and video-aided therapy which aims to improve social communication skills in children who have social communication difficulties.

We would like to invite you take part in a research study which aims to explore in some detail parents' experiences of receiving this form of therapy. We hope to extend invitations to parents both in Gwynedd and Ynys Mon who have completed PACT sessions. Please read the following information carefully and discuss it with others if you wish. Please contact the lead researcher Emily Bloxham, either by email at psp0c6@bangor.ac.uk or by phone on 07540 181562 if anything is not clear, or if you would like more information.

What is the purpose of the study?

We are inviting you to help us find out about parents' experiences of PACT as a therapeutic approach. We are also interested in evaluating any effects of the therapy on children's and parents' shared social interaction and we will do this by examining the video clips of play sessions between you and your child. In addition, the study will look at any changes in some of the short questionnaires you completed at the beginning and end of your PACT sessions.

Why have I been chosen?

You have been invited to take part in the research study because you are a parent who has been offered PACT through either Derwen (Integrated Team for Children with Disability, Gwynedd) or Specialist Children's Services (SCS, Ynys Mon). Where appropriate as many parents as possible will be invited to take part in the study.

Do I have to take part?

Participation in the research study is completely voluntary. You do not have to take part or give a reason for not doing so. If you decide to take part you will be asked to sign a consent form. Also if you decide to take part, you are still free to change your mind and to withdraw at any time, without giving a reason. A decision not to take part or to withdraw from the study will not affect the service you or your child will receive from Derwen or SCS in any way.

What will it involve?

Taking part will involve doing three things.

1) You will be asked to take part in an interview with the primary researcher (Emily Bloxham) to talk about your experiences with PACT once you have completed your sessions. This interview can take place between 1 and 12 months after your last PACT session. This meeting will last approximately one hour and will take place in a location of your choosing (e.g. in your own home, at a clinic). The interview will be tape-recorded so that the conversation can be written up and studied in detail by the lead researcher later. The interview will cover the following areas: your experience of taking part in PACT, what you thought about it and your opinion of it as a therapy. Some quotations from the conversation may be used to represent the themes and experiences expressed. It is important to note that the content of what is discussed in the interview will be kept confidential; however, if you disclose that either you, your child, or another person is at risk of serious harm I will have to inform others, and this is a professional requirement. Once the interview recording has been written up, the recording will be deleted.

2) We will ask you for permission to use the short questionnaires you completed at the beginning and the end of the PACT sessions. These will be stored in your child's clinical psychology file.

3). We will ask your permission to watch video clips of your play sessions with your child to allow us to identify and code the number of times your child tried to get your attention and how you responded.

It is important to stress that the lead researcher will look at these videos within Derwen's offices and they will not be removed from the premises. All video clips and questionnaires will be securely stored by the service and will not be removed from the premises. Also the interview recording will be done with a special encrypted digital tape and the transcribed or written interview will not have any identifying names on the transcript. All written data will be destroyed at the end of the research study (October 2015)

What are the possible benefits of taking part?

Understanding more about parents' experiences of PACT and how it may have effected families could help inform and shape future service provision. We will also share our findings with all parents who agree to take part. The results of the study will be presented to the Gwynedd and Ynys Mon Integrated Teams.

What are the possible disadvantages or risks of taking part?

There is a very small risk that you might be upset by talking about you and your child's experience with this therapy. You do not have to reply to any questions you feel uncomfortable answering, and you can end the interview or withdraw from the study whenever you wish, without giving a reason.

What if something goes wrong?

If you have any concerns about any aspect of the study, you can contact Emily Bloxham. If you want to make a formal complaint, you can do this by contacting either:

- Complaints Department, Betsi Cadwaladr University Health Board, Ysbyty Gwynedd, Bangor, Gwynedd, LL57 2PW
Email: complimentsandcomplaints.bcu@wales.nhs.uk
- Mr Hefin Francis, School Manager, School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2DG
Email: h.francis@bangor.ac.uk

Will my taking part in the study be kept confidential?

During the interview, if you tell the researcher something which makes them concerned that there may be a risk to you, your child, or another person, this information may be shared with other people. If possible this matter will be discussed with you beforehand.

All personal information and interview recordings will be treated as confidential and kept securely. Your personal information will not be shared, and your data will be given an anonymised participant number; any published information will be anonymised in accordance with the Data Protection Act 1998. The interviews will be audio-recorded and transcribed, and all participants will be assigned a pseudonym (different name) at the point of transcription of the recordings. This will be used in all documentation throughout the study. Audio recordings will be destroyed once transcription is complete. During the study interview transcripts will be stored on an encrypted pen drive provided by the North Wales Clinical Psychology Training Programme (NWCPP). Upon completion of the study, personal details and interview transcripts will be destroyed. The rest of the research data (questionnaire data and video clips) form part of your child's health care record and are stored in accordance with NHS policies and service guidelines.

What will happen to the results of the study?

The results of the study will be used to inform the development of clinical psychology services for children with social communication difficulties and their families. The results will also be prepared for publication in a scientific journal and shared with the Gwynedd and Ynys Mon Integrated Teams for Children with Disability. We would like to use some quotations from the interviews but you will not be identified in any report or publication. We will also write to you with a summary of our main findings.

Further information

If there is anything that is not clear to you, or you would like further information about the study, please email Emily Bloxham at psp0c6@bangor.ac.uk or phone her or

send a text message on 07540 181562, and she will phone you back as soon as is possible.

Who is organising and funding this research?

The study is Emily Bloxham's research project, and will be submitted in partial fulfilment of the final award of Doctorate in Clinical Psychology. The study is funded by the North Wales Clinical Psychology Programme, School of Psychology, Bangor University. The research project is being supervised by Dr Helen Delargy (Clinical Psychologist) and Dr Helen Healy (Clinical Psychologist). Both Supervisors work in Derwen (Integrated Team for Children with Disability) and their clinical catchment area extends to Ynys Mon.

Who has reviewed the study?

This study has been reviewed and approved by the School of Psychology, Bangor University Research Ethics Committee (reference number: 2014-11784) and the NISCHR Research Ethics Committee Wales REC 7 (reference number: 145311).

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

RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME

**Evaluation of Parents' Experiences of Participating in Pre-School Autism
Communication Therapy (PACT)**

Researchers: Emily Bloxham, Dr Helen Healy and Dr Helen Delargy

Consent Form

Please initial in the box

1. I confirm I have read and understood the participant information sheet
(Version 4: 11th March 2014). I have had the opportunity to ask questions
and have received satisfactory answers.
2. I understand participation is voluntary. I am free to withdraw at any time
without giving a reason, and without my child's medical care or legal
rights being affected.
3. I agree for the researcher to use the information from questionnaires that I
already completed at the beginning and end of my PACT sessions.
4. I agree to attend the interview and consent for this to be audio recorded.
5. I agree that quotations from the interview can be reported, and I
understand that nothing that identifies me will be reported.
6. I agree to my child's therapy video clips being coded and analysed.
7. I agree that my child's clinical psychologist can be told that I am taking
part in the study. My child's clinical psychologist is
8. I understand that the researcher will contact my child's clinical
psychologist if they are concerned about my safety or my family's safety.
They will try to talk with me before doing this.

Signed Date

Name (please print)

**A research study into parents' experiences of Pre-School Communication Therapy
(PACT)**

Semi-Structured Interview Schedule

Demographic Information (for the researcher to complete as part of the interview)

Background Details

Child's Age: Gender: M F

Your Age: Gender: M F

Your relationship to child:

- | | |
|---|---|
| <input type="checkbox"/> Biological Parent | <input type="checkbox"/> Step-parent |
| <input type="checkbox"/> Parent's partner (living together) | <input type="checkbox"/> Adoptive parent |
| <input type="checkbox"/> Foster parent | <input type="checkbox"/> Other adult relative (state) |

Child's Health and Development:

Does your child have a diagnosis related to their development or behaviour?

- Yes (please specify)
- No

Has your child ever been in foster care?

- Yes (please specify for how long)
- No

Other Household/Family Members

What is your marital status?

- | | |
|---|--|
| <input type="checkbox"/> Single, never married | <input type="checkbox"/> Married |
| <input type="checkbox"/> Separated | <input type="checkbox"/> Widowed |
| <input type="checkbox"/> Divorced | <input type="checkbox"/> Living together |
| <input type="checkbox"/> In relationship but living apart | |

Spouse's/partner's relationship to child:

- | | |
|---|---|
| <input type="checkbox"/> Biological Parent | <input type="checkbox"/> Step-parent |
| <input type="checkbox"/> Parent's partner (living together) | <input type="checkbox"/> Adoptive parent |
| <input type="checkbox"/> Foster parent | <input type="checkbox"/> Other adult relative (state) |

How involved is your partner with the upbringing of your child?

- Not at all
- Low (e.g. lives apart, sees once/week or less)
- Mid (e.g. sees everyday but not much involvement)
- High (e.g. sees everyday and carries out a lot of childcare or activities with the child)

Are there any other children in your household?

Does your child have a diagnosis related to their development or behaviour?

Child 1:

Yes (please specify)

No

Child 2:

Yes (please specify)

No

Child 3:

Yes (please specify)

No

Child 4:

Yes (please specify)

No

Child 5:

Yes (please specify)

No

Employment

Are you employed?

Yes (please specify what your employment is)

No

Is your partner employed?

Yes (please specify what their employment is)

No

Demographics

What ethnicity/race would you describe yourself as?

White/North European

Mediterranean (e.g. Greek, Italian, Turkish)

Black Afro-Caribbean

Indian Subcontinent

SE Asian/Chinese

Mixed parentage

Not known

Other (please describe):

What ethnicity/race would you describe your partner as?

- | | |
|---|---|
| <input type="checkbox"/> White/North European | <input type="checkbox"/> Mediterranean (e.g. Greek, Italian, Turkish) |
| <input type="checkbox"/> Black Afro-Caribbean | <input type="checkbox"/> Indian Subcontinent |
| <input type="checkbox"/> SE Asian/Chinese | <input type="checkbox"/> Mixed parentage |
| <input type="checkbox"/> Not known | <input type="checkbox"/> Other (please describe): |

Education – at what age did you leave school or finish education?

- | | |
|---|--|
| <input type="checkbox"/> Left school before 13 | <input type="checkbox"/> Left school 13-16 |
| <input type="checkbox"/> Further secondary 16-18 | <input type="checkbox"/> Secretarial/technical qualification |
| <input type="checkbox"/> Professional qualification without degree (e.g. SRN) | <input type="checkbox"/> Degree |
| <input type="checkbox"/> Masters | <input type="checkbox"/> PhD or Doctorate |
| <input type="checkbox"/> Other (please specify): | <input type="checkbox"/> Not known |

Education – at what age did your partner leave school or finish education?

- | | |
|---|--|
| <input type="checkbox"/> Left school before 13 | <input type="checkbox"/> Left school 13-16 |
| <input type="checkbox"/> Further secondary 16-18 | <input type="checkbox"/> Secretarial/technical qualification |
| <input type="checkbox"/> Professional qualification without degree (e.g. SRN) | <input type="checkbox"/> Degree |
| <input type="checkbox"/> Masters | <input type="checkbox"/> PhD or Doctorate |
| <input type="checkbox"/> Other (please specify): | <input type="checkbox"/> Not known |

Language

What is your first language?

- English
- Welsh
- Other (please specify):

PACT

How much time has passed since last PACT session?

How many PACT sessions completed/offered?

Has your child received any other form of therapy in addition to PACT?

- Yes (please specify)
- No

Feedback

Would you like to receive feedback about the results of the research study once it has been completed?

If so, please provide postal address:

.....
.....

Semi-structured Interview Schedule:**Preamble:**

Thank you very much for agreeing to take part in this research study. We are interested in hearing about how you feel about PACT therapy. You have given your consent to be interviewed, and for questionnaire and PACT video data to be analysed. I would like to stress that your participation is voluntary, and that you may withdraw from the interview and the research study at any time, without giving a reason. This will not effect the service your child receives from either Derwen or the Specialist Children's Service Ynys Mon. All information you provide will be kept securely, and the content of this interview will be kept confidential. Although the content of the conversation is confidential, you have given your permission for anonymised quotes to be used as part of the research. If you give me any cause for concern regarding your safety, or the safety of any other person, I may have to break confidentiality. If this situation occurs I will discuss this with you. Is there anything that you would like to ask me?

Question 1:

Tell me about the PACT you and <CHILD> participated in

Possible prompting...

What was it like doing it?

What did you like/dislike?

Was it hard/easy?

What about doing the home practice?

Question 2:

Do you think doing PACT has affected things at all?

Possible prompting...

In what way?

Who has it affected? Has it affected you? Your child? Anyone else?

Your communication with your child? Your feelings?

Any other ways is has affected things?

Question 3:

What do you think of the health service and local authority providing this kind of therapy for parents and children?

Possible prompts...

Is it the kind of thing you would have expected?

Was it the right kind of approach for your family?

Was it at the right time for your family?

Was it the right number of sessions (or would you have wanted more or fewer)?

Has it affected what you think about getting a service now or in the future?

Question 4:

What would you say to another family thinking about having PACT?

Question 5:

Looking back, what would have made PACT better for you?

Possible prompts...

What would you change about it?

Is there anything the service could have done differently?

Question 6:

Is there anything else you would like to add?

Correspondences Regarding Ethics Submission

Email Sent to Local Research Ethics Service Manager

Emily Bloxham

Mon 09/06/2014 17:51

To: Rossela Roberts (BCUHB - Research & Development)
<Rossela.Roberts@wales.nhs.uk>;

Hi Rossela,

Following submission of my IRAS NHS REC form on Friday, where I was advised that it would go for Proportional Review, I have been told today by the Health Research Authority that it has to in fact go for full review. Diane Catterall, who reviewed my application today, has agreed to forward it to the Wales REC 5, but has advised me that the next meeting on June 19th was full. My understanding was that, if the NHS REC was submitted through IRAS by today, it would be in time for the meeting on June 19th?

If it is not possible to attend the meeting on June 19th, when is the July meeting scheduled for? Alternatively, is it possible for me to send the NHS REC form to a different Wales REC for review before the next meeting is due in Bangor?

Best Wishes,
Emily

Response from Local Research Ethics Service Manager

Rossela Roberts (BCUHB - Research & Development) <Rossela.Roberts@wales.nhs.uk>

Tue 10/06/2014 09:33

To: Emily Bloxham;

Dear Emily-

Has the REC in Manchester centre transferred your application to another committee?

If not you can send it to another committee yourself, just phone the CBS again.

My June committee is full and the deadline has closed at 12 yesterday – but if you wish to have this reviewed in Bangor you can request to be allocated to the July meeting (17th, - deadline on the 7th)

Regards
Rossela

Confirmation of Receipt of Ethics Application with New Research Ethics Committee

Sue Byng (BSC - LREC) <Sue.Byng@wales.nhs.uk>

Tue 10/06/2014 11:49

To: Emily Bloxham;

Cc: Helen Healy; Helen Delargy; Hefin Francis; Sion Lewis

Thank you for submitting your research ethics application to the Wales REC 7 via the Central Booking System.

Please find attached an acknowledgement letter accepting your application onto the agenda of our meeting on 19 June. I note you will be taking part in the meeting by telephone conference and I would be grateful if you could provide a convenient telephone number to ring at 3pm on that day. You will be on speakerphone in the meeting room and therefore a landline number would be preferable if possible but a mobile number will be acceptable. Please note we will try and ring on time but it is possible there may be delays depending on the review of the previous applications.

I look forward to hearing from and if you have any queries please let me know.

Best wishes

Sue

Sue Byng
Manager
WALES REC 7
PO Box 108
Building 1
Jobswell Road
St David's Park
Carmarthen SA31 3WY
(SA31 3HB for sat nav/courier purposes)
Tel: 01267 225045

Website: www.hra.nhs.uk

IRAS website: www.myresearchproject.org.uk

The HRA is keen to know your views on the service you received – our short feedback form is available at <http://www.nres.nhs.uk/applications/providingfeedback/>

IMPORTANT - visit <http://www.hra.nhs.uk/research-community/booking-submission-changes-spring-2014/> for details of significant changes to the REC booking and submission process

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

NISCHR

Gwasanaeth
Moeseq
Ymchwil
Miss Emily Bloxham
50 Tyddyn Isaf
Menai Bridge
Isle of Anglesey
LL59 5DA

RES | Research
Ethics
Service

WALES REC 7
PO Box 108
Building 1
Jobswell Road
St David's Park
Carmarthen SA31 3WY
(for sat nav/courier purposes SA31 3HB)

Telephone : 01267 225045
E-mail : sue.byng@wales.nhs.uk
Website : www.hra.nhs.uk

10 June 2014

Dear Miss Bloxham

Study title: Evaluation of parents' experiences of PACT
REC reference: 14/WA/1041
IRAS project ID: 145311

Thank you for your application for ethical review, which was received on 10 June 2014. I can confirm that the application is valid and will be reviewed by the Committee at the meeting on 19 June 2014.

Meeting arrangements

The meeting will be held in the Public Health Service meeting room, Building 1, St David's Park, Carmarthen on 19 June 2014. The Committee would find it helpful if you could attend the meeting to respond to any questions from members. Other key investigators and a representative of the sponsor are also welcome to attend. This may avoid the need to request further information after the meeting and enable the Committee to make a decision on the application more quickly.

If you have a disability and need any practical support when attending the REC meeting you may wish to contact the REC office so appropriate arrangements can be made if necessary.

If you are unable to attend the meeting the Committee will review the application in your absence.

The review of the application has been scheduled for 3.00pm. Please note that it is difficult to be precise about the timing as it will depend on the progress of the meeting. We would kindly ask you to be prepared to wait beyond the allocated time if necessary.

If you cannot attend, it would be helpful if you could be available on the telephone at the time of the review.

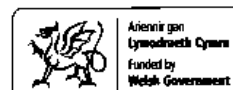
Please let me know whether or not you would be available to attend the meeting or be available on the telephone.

Committee meetings are occasionally attended by observers, who will have no vested interest in the applications under review or take any part in discussion. All observers are required to sign a confidentiality agreement.



Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys

The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board



Email Regarding Response from Ethics Committee

Sue Byng (BSC - LREC) <Sue.Byng@wales.nhs.uk>

Fri 20/06/2014 11:43

To: Emily Bloxham;

Cc: Hefin Francis; Sion Lewis; Helen Delargy; Helen Healy

Please find attached a decision letter with regard to the above research ethics application which was reviewed yesterday by the Wales REC 7. Please upload your amended document via your IRAS account and email me a copy at the same time.

If you have any queries please let me know.

Regards

Sue

Sue Byng

Manager

WALES REC 7

PO Box 108

Building 1

Jobswell Road

St David's Park

Carmarthen SA31 3WY

(SA31 3HB for sat nav/courier purposes)

Tel: 01267 225045

Website: www.hra.nhs.uk

IRAS website: www.myresearchproject.org.uk

The HRA is keen to know your views on the service you received – our short feedback form is available at <http://www.nres.nhs.uk/applications/providingfeedback/>

IMPORTANT - visit <http://www.hra.nhs.uk/research-community/booking-submission-changes-spring-2014/> for details of significant changes to the REC booking and submission process

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Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



WALES REC 7
PO Box 108
Building 1
Jobswell Road
St David's Park
Carmarthen SA31 3WY
(for sat nav/courier purposes SA31 3HB)

Telephone : 01267 225045
E-mail : sue.byng@wales.nhs.uk
Website : www.hra.nhs.uk

Miss Emily Bloxham
Trainee Clinical Psychologist
Betsi Cadwaladr University Health Board
North Wales Clinical Psychology Programme
Brigantia Building, School of Psychology
Bangor University
Bangor
Gwynedd
LL57 2DG

20 June 2014

Dear Miss Bloxham

Study title: Evaluation of parents' experiences of participating in Pre-School Autism Communication Therapy (PACT)
REC reference: 14/WA/1041
IRAS project ID: 145311

The Research Ethics Committee reviewed the above application at the meeting held on 19 June 2014. Thank you for participating by telephone to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Ms Sue Byng.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

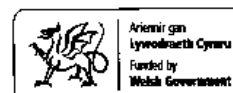
The favourable opinion is subject to the following conditions being met prior to the start of the study.

- 1) The Consent Form should be amended to make it clearer that the participant did not have to complete all sections if they did not want to take part in all aspects of the study.



Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys

The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board



Email Confirming Submission of Revised Consent Form

Emily Bloxham

Mon 23/06/2014 13:18

Sent Items

To: Sue Byng (BSC - LREC) <Sue.Byng@wales.nhs.uk>;

Cc: Hefin Francis; Sion Lewis; Helen Delargy; Helen Healy

Hi Sue,

Many thanks for your prompt response.

I have made the amendments to the consent form as requested by the Research Ethics Committee; please see attached a copy.

I have also uploaded the amended document to my IRAS account in the "My Documents" section.

Please let me know if there is anything further I should do.

Best Wishes,
Emily

**RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**

**Evaluation of Parents' Experiences of Participating in Pre-School Autism
Communication Therapy (PACT)**

Researchers: Emily Bloxham, Dr Helen Healy and Dr Helen Delargy

Consent Form

Please initial in the appropriate boxes to indicate which parts of the study you consent to participate in.

1. I confirm I have read and understood the participant information sheet (Version 4: 11th March 2014). I have had the opportunity to ask questions and have received satisfactory answers.
2. I understand participation is voluntary. I am free to withdraw at any time without giving a reason, and without my child's medical care or legal rights being affected.
3. I agree for the researcher to use the information from questionnaires that I already completed at the beginning and end of my PACT sessions.
4. I agree to attend the interview and consent for this to be audio recorded.
5. I agree that quotations from the interview can be reported, and I understand that nothing that identifies me will be reported.
6. I agree to my child's therapy video clips being coded and analysed.
7. I agree that my child's clinical psychologist can be told that I am taking part in the study. My child's clinical psychologist is
8. I understand that the researcher will contact my child's clinical psychologist if they are concerned about my safety or my family's safety. They will try to talk with me before doing this.

Signed Date

Name (please print)

Email and Letter Confirming Ethics Approval

Sue Byng (BSC - LREC) <Sue.Byng@wales.nhs.uk>

Tue 24/06/2014 09:32

To: Emily Bloxham;

Cc: Hefin Francis; Sion Lewis; Helen Delargy; Helen Healy

Please find attached an 'acknowledgement of additional conditions' letter which, together with the 'favourable opinion with additional conditions' letter issued on 20 June 2014, finalises the ethical review process.

If you have any queries please let me know.

Best wishes

Sue

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



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Miss Emily Bloxham
50 Tyddyn Isaf
Menai Bridge
Isle of Anglesey
LL59 5DA

24 June 2014

Dear Miss Bloxham

Study title: Evaluation of parents' experiences of participating in
PACT
REC reference: 14/WA/1041
IRAS project ID: 145311

Thank you for your email of 22 June 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 20 June 2014

Documents received

The documents received were as follows:

Document	Version	Date
Participant Consent Form	4	22 June 2014

Approved documents

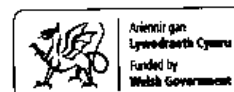
The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
REC application form	1	06 June 2014
Research protocol	1	13 September 2014
CV for Chief Investigator – Emily Bloxham		
CV for Dr Helen Healthy (Supervisor)		
CV for Dr Helen Delargy (Supervisor)		
Participant Information Sheet	4	11 March 2014
Letter of invitation to participant	4	11 March 2014



Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys

The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board





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Chairman/Cadeirydd – Dr Nefyn Williams PhD, FRCGP
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Tel/Fax: 01248 384 877

11 July 2014

Dear Miss Bloxham,

Re: Notification that local governance checks are not satisfied

Study Title Evaluation of parents' experiences of participating in PreSchool
Autism Communication Therapy (PACT)
IRAS reference 145311

Thank you for submitting your R&D application and supporting documents.
The above study was reviewed by the BCUHB R&D Internal Review Panel in its meeting of the 10 July 2014

Below, please find a list of documents you have submitted for review:

Document:	Version	Date
R&D Checklist	-	-
R&D Form	-	10/06/2014
SSI Checklist	-	-
SSI Form	-	10/06/2014
Protocol	-	13/09/2013
Participant Information Sheet	4	11/03/2014
Consent Form	3	11/03/2014
Study Invitation Letter	4	11/03/2014
Semi-Structured Interview Schedule	4	11/03/2014
Strengths & Difficulties Questionnaire – Parents of 2-4 year olds	-	-
Strengths & Difficulties Questionnaire – Parents of 4-17 year olds	-	-
Parenting Stress Index Short Questionnaire	-	-
Insurance Documents	-	-
CV of Investigators	-	-

Unfortunately, we have been unable to satisfy all the local governance checks for your study.
Below are the details of the governance check(s) that we have been unable to satisfy:

Protocol assessment

The Panel requested a clarification of the plan to achieve the sample size if the uptake of the PACT intervention is not similar to the previous years' uptake or there is a large attrition rate.

If you are able to provide additional information or further clarification to resolve these issues, we will review the relevant local governance checks again. If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the Committee

Authority to consider your response and to confirm the Panel's final opinion has been delegated to the Chairman.

The Panel will issue a final opinion on the application within a maximum of 60 days from the initial receipt of application, excluding the time taken by you to respond fully to the above points.

Should you decide not to proceed with this study, please inform us as soon as possible.

Please do not hesitate to contact us if you require any further information or assistance.

Yours sincerely,



Dr Nefyn Williams PhD, FRCGP
Associate Director of R&D
Chairman Internal Review Panel

Copy to:

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COLEG IECHYD A GWYDDORAU YMDDYGIAD
COLLEGE OF HEALTH & BEHAVIOURAL SCIENCES

YSGOL SEICOLEG
SCHOOL OF PSYCHOLOGY

**RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME**



Dr Nefyn Williams PhD, FRCGP
Associate Director of R&D
Chairman Internal Review Panel
Betsi Cadwaladr Univeristy Health Board
R&D Internal Review Panel
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

17th July 2014

Dear Dr Williams,

Re: Notification that local governance checks are not satisfied - Response

Study Title: Evaluation of parents' experiences of participating in Pre-School
Autism Communication Therapy (PACT)

IRAS Reference: 145311

Thank you for your response following the review of my R&D application and supporting documents on 10th July 2014.

The Panel requested clarification of the plan to achieve the sample size if the uptake of the PACT intervention is not similar to the previous years' uptake or there is a large attrition rate.

The maximum number of participants required for the study is 10 participants. Given that the principal research question is concerned with the experiences of parents who have received PACT as a therapeutic intervention, interpretative phenomenological analysis (IPA) has been chosen as the most appropriate method of data analysis. Smith et al. (2009) suggest between four and 10 interviews may be suitable for a professional doctorate study. In particular, the authors point out that the exact sample size may be difficult to determine at the outset, as the sample size may be driven by

the quality rather than the quantity of the interviews. Clinicians delivering the intervention anticipate the chosen methodology will elicit rich data, as parents typically take part in the intervention when they are experiencing a lot of adjustments in their lives (understanding that their child's development may not be typical, accepting a possible diagnosis, engagement with different services, impact on family life, etc), and such issues are likely to generate a lot of reflection within interviews. Therefore the aim of the present study is to recruit between four and 10 participants. It has been pointed out that "IPA studies usually benefit from a concentrated focus on a small number of cases" (Smith et al., 2009, pp. 51), and it is therefore felt that the present study can still be carried out successfully even if the maximum sample number of 10 participants is not achieved.

The PACT intervention is a relatively new therapy which has been introduced into the services in the last 12 months. To date none of the parents who have been offered the PACT intervention have declined it. Furthermore, high attrition rates are not anticipated in view of the short and focussed nature of the intervention, as well as informal feedback from parents which suggests that PACT is a highly valued and welcomed therapy.

As stated in section A59 and A60 of the R&D form, the quantitative aspect of the study is primarily descriptive, and it is accepted that such low numbers do not allow for any meaningful statistical analyses.

On the basis of the above we are truly confident that we can recruit between four and 10 participants and will this satisfy the criteria for a rigorous and valid study.

Yours sincerely,

Emily Bloxham
Trainee Clinical Psychologist



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24 July 2014

Dear Miss Bloxham,

Re: Confirmation that R&D governance checks are complete / R&D approval granted

Study Title Evaluation of parents' experiences of participating in PreSchool
Autism Communication Therapy (PACT)
IRAS reference 145311

The above research project was reviewed at the meeting of the BCUHB R&D Internal Review Panel

The Committee is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

Thank you for responding to the Committee's request for further information.

The R&D office considered the response on behalf of the Committee and is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

The R&D office considered the response on behalf of the Committee and is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

Please note that this approval does not automatically confer the right to access primary care sites; it allows you to approach individual GP practices and seek permission to conduct your research.

The Internal Review Panel is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board sites as described in the application.

The documents reviewed and approved are listed below:

Documents Reviewed:	Version	Date
R&D Checklist	-	-
R&D Form	-	10/06/2014
SSI Checklist	-	-
SSI Form	-	10/06/2014
Protocol	-	13/09/2013
Participant Information Sheet	4	11/03/2014
Consent Form	3	11/03/2014
Study Invitation Letter	4	11/03/2014
Semi-Structured Interview Schedule	4	11/03/2014
Strengths & Difficulties Questionnaire – Parents of 2-4 year olds	-	-
Strengths & Difficulties Questionnaire – Parents of 4-17 year olds	-	-

Parenting Stress Index Short Questionnaire	-	-
Insurance Documents	-	-
CV of Investigators	-	-
Response to R&D	-	17/07/2014

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (2009). An electronic link to this document is provided on the BCUHB R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the Betsi Cadwaladr University Health Board.

If your study is adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that the Chief Investigator will be required to regularly upload recruitment data onto the portfolio database.

To apply for adoption onto the NISCHR CRP, please go to:

<http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=31979>.

Once adopted, NISCHR CRP studies may be eligible for additional support through the NISCHR Clinical Research Centre. Further information can be found

at: <http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=28571> and/or from your NHS R&D office colleagues.

To upload recruitment data, please follow this link:

http://www.crncc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment.

Uploading recruitment data will enable NISCHR to monitor research activity within NHS organizations, leading to NHS R&D allocations which are activity driven. Uploading of recruitment data will be monitored by your colleagues in the R&D office.

If you need any support in uploading this data, please contact wendy.scrase2@wales.nhs.uk or sion.lewis@wales.nhs.uk

If you would like further information on any other points covered by this letter please do not hesitate to contact me.

On behalf of the Committee, may I take this opportunity to wish you every success with your research.

Yours sincerely,



Dr Nefyn Williams PhD, FRCGP
Associate Director of R&D
Chairman Internal Review Panel

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General Thesis Appendices

Appendix 3a: Semi-structured Interview Schedule

Preamble:

Thank you very much for agreeing to take part in this research study. We are interested in hearing about how you feel about PACT therapy. You have given your consent to be interviewed, and for questionnaire and PACT video data to be analysed. I would like to stress that your participation is voluntary, and that you may withdraw from the interview and the research study at any time, without giving a reason. This will not affect the service your child receives from either [service] or [service]. All information you provide will be kept securely, and the content of this interview will be kept confidential. Although the content of the conversation is confidential, you have given your permission for anonymised quotes to be used as part of the research. If you give me any cause for concern regarding your safety, or the safety of any other person, I may have to break confidentiality. If this situation occurs I will discuss this with you. Is there anything that you would like to ask me?

Question 1:

Tell me about the PACT you and <CHILD> participated in

Possible prompting...

What was it like doing it?

What did you like/dislike?

Was it hard/easy?

What about doing the home practice?

Question 2:

Do you think doing PACT has affected things at all?

Possible prompting...

In what way?

Who has it affected? Has it affected you? Your child? Anyone else?

Your communication with your child? Your feelings?

Any other ways it has affected things?

Question 3:

What do you think of the health service and local authority providing this kind of therapy for parents and children?

Possible prompts...

Is it the kind of thing you would have expected?

Was it the right kind of approach for your family?

Was it at the right time for your family?

Was it the right number of sessions (or would you have wanted more or fewer)?

Has it affected what you think about getting a service now or in the future?

Question 4:

What would you say to another family thinking about having PACT?

Question 5:

Looking back, what would have made PACT better for you?

Possible prompts...

What would you change about it?

Is there anything the service could have done differently?

Question 6:

Is there anything else you would like to add?

Appendix 3b: Example of data analysis based on transcript excerpt

Emergent Themes	Line	Original Transcript	Initial Notes & Exploratory Comments
Slowing down in interaction	189	<u>Participant</u> : Yeah, just, I think again just slowing, slowing down, cos, you know,	Slowing down
	190	he, um, especially with different people coming in, and with the psychology, he'd	
	191	get quite excited, and I think that's just natural. Um, but Philip would, he would	Excitement of new people is natural
Difficulties in interactions with others, knowing the rules	192	focus a bit more on the game and, um, take turns and, which often he found quite	Difficulty with interactions & learning how the game works, "the rules"
	193	difficult and just, um, just learning the concept of the game, which, you know he	Speech developing, more participation
	194	couldn't do before really. And vocalising - by the end being able to say, you	
	195	know 'It's my go'...'Philip wan' and just vocalising it. So, yeah I felt that, you	
Others notice changes	196	know, as the weeks, you know, went on, and then, you know, [clinician] could	Over time...Others could see changes, validating? Reassuring to be told not many sessions are needed?
	197	see , and was saying as well, cos she said quite quickly 'I don't think you're going	Loving sessions, enjoyment
	198	to need too many sessions', although we were loving them [both laugh]...she was	
	199	like 'I don't think you need too many', yeah, [laughs].	
	200	<u>Interviewer</u> : Um, is it, is it the kind of thing you would have expected?	
	201	<u>Participant</u> : [pause] The sessions?	
	202	<u>Interviewer</u> : Yeah. Or the therapy.	
Not knowing what to expect	203	<u>Participant</u> : Yeah, um. Like I say I don't think you really know what to expect,	No expectations
	204	but I, it was, yeah, no, it was very good. It was very, sort of, relaxed. And, cos it's	Very good, positive, Felt relaxed
Role of own behaviour in interaction	205	just something you do every day anyway, you know you play with your child but	
	206	you don't really realise, I don't think, what you, how much impact you're having	Not aware of own impact
Small changes can have an impact	207	really, what, um, little things, just changing little things, and holding back, and	Changing little things.....Doing less
	208	not maybe doing what you want, you know, straight away what you want is to	
Wanting to help child	209	help and point out. But just leave...you know, try and see if they can take your	Acting against urge to help, giving child chance to interact
	210	lead and just ask you, and I think it really, you know, you did see a difference	Visible changes as a result of changing own behaviour
Changes are visible	211	doing it.	Identifying as playful, social family
	212	<u>Interviewer</u> : Do you feel that it was the right kind of approach for your family?	Lots of time spent together
PACT good fit with family	213	<u>Participant</u> : Yeah, definitely. I think we're a very playful family, we love, you	
	214	know, being together and I think, yeah, it was definitely, yeah. We spend a lot of	Improvement in social skills
	215	time doing crafts and things like that, and Philip just loves that. And, I think, just	Therapy vs social? Something different
	216	Philip going to therapy sessions and meeting different people, he's...his social	Social family
	217	skills have come on so much as well, so...not just what he was gaining from the	Child used to avoid social situations
	218	therapy side of it, but actually the social side of it as well. Cos we're a very social,	
Making sense of change: then/now comparisons, giving examples of changes in child	219	you know, family, but Philip could often be in an environment where he could	Social now, loves being around people
	220	take himself away from it, but he's not...he's not...it's...it's...he's so social now,	Going to school, 1:1
	221	he really is, and he loves being around people and in school he's in the full-time	Much change noticed
	222	mainstream school (I: OK) with one-to-one and, yeah, he's just come on so much,	
	223	and I think this has all helped him. Yeah.	

