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Implementation Fidelity and Acceptability of Parent-Mediated Interventions for Children Suspected or Diagnosed with Autism Spectrum Disorder

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**Implementation Fidelity and Acceptability of Parent-Mediated Interventions for
Children Suspected or Diagnosed with Autism Spectrum Disorder**

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PRIFYSGOL
BANGOR
UNIVERSITY

Submitted in part fulfilment of the degree of

Doctorate in Clinical Psychology

June 2020

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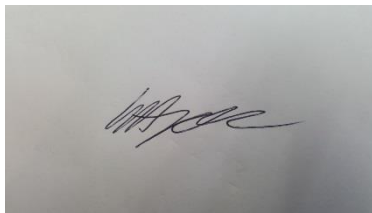
Dedication

I dedicate this thesis to my Nan, the matriarch of our family who dedicated her time and energy to us selflessly.

I learned my strength in motherhood and diligent work ethic from you Nan. You were an integral part of my learning journey and I'm sorry you didn't get to see me finish it; you would have been so proud.

Declaration

I hereby declare that this thesis is the result of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.

A rectangular area containing a handwritten signature in black ink on a light-colored background. The signature is cursive and appears to be 'W. A. J. J. J.'

Signed:

Date: 02.07.20

Thesis Abstract

This thesis explores implementation and intervention fidelity within parent-mediated interventions for children suspected or diagnosed with autism spectrum disorder. The first chapter is a systematic literature review exploring the measurement and the methodological quality of reporting implementation and intervention fidelity within parent-mediated randomised controlled trials (RCTs) for children. A literature search returned 2253 papers, 23 met inclusion criteria for systematic review for fidelity components dose, adherence, responsiveness and quality of delivery. The review highlights the inconsistent approach to reporting intervention and implementation fidelity for both the clinician and the parent. Methodological quality of reporting was most often moderate and very few studies linked fidelity to outcomes. This highlights the need for future research to focus on a consistent theoretical framework for the measurement of fidelity within parent-mediated RCT's.

The second chapter presents the parent's perspectives of participating in a parent-mediated intervention, Paediatric Autism Communication Therapy (PACT) delivered in a clinical community setting. The semi-structured interview was conducted with eight participants and designed to illicit parents' views of the acceptability of the intervention and analysis was guided by principles of thematic analysis. Two superordinate themes and six subordinate themes emerged from the data representing parents therapeutic learning journey and is discussed within the theoretical framework of acceptability.

The third chapter reflects on the theoretical and clinical implications that emerged from the first two papers, highlighting the need for a consistent implementation fidelity framework within the field of ASD to ensure the translation of EBP into routine clinical care. The thesis concludes with my personal reflections on the process of researching and writing during a global pandemic.

Chapter 1
Systematic Literature Review

An Evaluation of Implementation and Intervention Fidelity in Parent-Mediated Interventions for Young Children with ASD: A Systematic Review of measurement and quality

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This paper will be submitted to The Journal of Autism and Developmental Disorders (JADD) and will therefore follow submission guidelines for the journal:

<https://www.springer.com/journal/10803/submission-guidelines#Instructions%20for%20Authors>

Abstract

Early intervention for children suspected or diagnosed with autism spectrum disorder (ASD) is recommended best practice and there is a growing evidence-base for parent-mediated interventions (PMI) that target behaviour, developmental and communication skills. During PMI RCTs clinicians facilitate parents to learn therapeutic techniques and parents then implement newly learned techniques with their children, thus increasing the opportunity for children to receive the intervention. How RCTs measure and report implementation and intervention fidelity during RCTs is important information that can facilitate the translation of evidence-based practice (EBP) into routine clinical care. A literature search returned 2253 papers, 23 met inclusion criteria for systematic review for fidelity components dose, adherence, responsiveness and quality of delivery. The current review highlights the inconsistency of reporting intervention and implementation fidelity for both the clinician and the parent in RCTs. Methodological quality of reporting was most often moderate, and very few studies linked fidelity to outcomes. This highlights the need for future research to focus on a consistent theoretical framework for the measurement of fidelity within PMI RCTs. Recommendations for future research and limitations of the review are discussed.

Keywords: Autism; Parent-mediated; Implementation; Systematic Review

It is estimated that the global prevalence of autistic spectrum disorder (ASD) is 1.04%, the equivalent of 700,000 people in the UK, with diagnosis of children around 1.6% of the population (Mackay et al., 2017; Baird et al., 2006; Brugha et al., 2012). Given that a diagnosis of ASD has a lasting impact on effective functioning in areas of communication, social interaction and behaviour, it is important that children with ASD (or those with social communication difficulties pre diagnosis) have access to interventions across the life-span (Maglione, Gans, Das, Timbie & Kasari, 2012). Early detection and intervention for young children is a growing body of research with a wide variety of evidence-based treatment approaches (Magan-Magnato et al., 2017; Wong et al., 2015; Odom, Boyd & Hume, 2010). One type of intervention that falls into both of these categories and supports the ongoing development of children with ASD are parent-mediated interventions (PMI; McConachie et al., 2007; Oono et al., 2013) .

PMI that target behaviour, developmental and communication skills are well established within early intervention services for children with ASD (Schopler & Reichler, 1971; Narzisi, Colombi, Balottin, & Filippo, 2014). Previous meta-analyses exploring a range of PMI randomised controlled trials (RCT) have evidenced their effectiveness, showing small yet significant improvements in parent-child interactions, autism symptom severity, behaviour and parent reported language comprehension (Oono et al., 2013, Roberts & Kaiser, 2011; McConachie & Diggle, 2007). PMI RCTs involve clinicians teaching parents therapy techniques through a combination of education, training, coaching, modelling or reflective feedback. Parents then implement the newly acquired knowledge and skills during interactions with their child and daily practice. This may increase the opportunity for the child to receive the intervention during the day from their parent (or carer), aiming to ensure generalisability of skills and maximise treatment outcomes within naturally occurring interactions and settings (McConachie et al., 2007; Odom et al., 2013; Brookman-Frazee et

al., 2009; Wetherby & Woods, 2008; Wainer and Ingersoll, 2013). It is unclear whether parents continue to use the intervention techniques when outside of the research context or beyond intervention completion, particularly in naturalistic contexts. Therefore, it is important to evaluate parental mastery of skill, and the frequency and accuracy with which they implement these skills with their children (Patterson, Smith & Mirenda, 2012).

Whilst clinicians providing community services for ASD share positive opinion relating to EBP, Stahmer and colleagues (2005, 2007 & 2009) have shown that they struggle to implement parent training with fidelity in routine clinical practice. Factors including clinical expertise, organisational attitudes and child and family characteristics may limit or facilitate implementation of evidence-based practice (EBP) in routine clinical care. It has been proposed that better understanding of implementation and intervention fidelity may help bridge the gap between research and practical application, resulting in improved outcomes for young children with ASD (Dane & Schneider, 1998; Durlak & Dupree, 2008; Wainer & Ingersoll, 2013). When programs are implemented with fidelity to the original model (taking into consideration local context and individual need) they are more likely to replicate results observed in research trials (Arthur & Blitz, 2000; Dingfelder & Mandell, 2010). Therefore, there is a clear need to understand how fidelity of implementation practices are measured and how that impacts on outcomes when conducting RCTs (Bellg et al., 2004; Breitenstein et al., 2012).

A number of implementation science frameworks have been developed that conceptualise implementation practices that focus on the fidelity and integrity of an intervention and its benefits to the recipients (Carroll, Patterson, Wood, Booth, Rick & Balain, 2007; Rudnick, Freeman & Century, 2012; Damschroder et al., 2009).

Implementation practices highlight the ‘how’ components of interventions and can be defined as methods and techniques that influence the outcomes, quality, adoption and sustainability of

clinical interventions (Proctor et al., 2013; Damschroeder et al., 2009; Carroll et al., 2007; Dunst et al., 2013). In contrast, *intervention practices* concern the methods and procedures used by clinicians to influence the change and outcomes in individuals receiving the intervention. This is essential information to understand the mechanisms that influence the outcomes produced by the intervention (Proctor et al., 2013; Durlak & Dupree, 2008; Dunst, Trivette & Raab, 2013).

Documentation of implementation and intervention strategies should not be ignored because it provides the information required to replicate the intervention and improves knowledge of the factors that influence effectiveness. It is important to measure because the variables may not only moderate the relationship between an intervention and its outcomes, but its assessment may also prevent potentially false conclusions being drawn about the intervention's effectiveness. Fundamentally, how well it was carried out is crucial to establishing internal, external, construct and statistical validity of the outcome.

Implementation of PMI occurs at two levels, the implementation of parent training by the clinician and the use of strategies with the child. Given that parents act as a conduit for the transference of techniques from clinician to the child it is reasonable to suggest that fidelity is measured at two levels; at the level of implementation practice and at the level of the intervention practice (Wainer & Ingersoll, 2013; Kaiser & Roberts, 2015). Understanding intervention outcomes requires the measurement of both, an example is provided in Table 1 and Figure 1 for ease of reference (Kaiser & Roberts, 2015; Wainer and Ingersoll, 2013).

Measuring fidelity of implementation and determining the relationship between fidelity and intervention outcomes facilitates the translation of evidence-based practice from RCTs into routine practice (Damschroeder et al., 2009; Dusnebury, Brannigan, Falco & Hansen, 2003; Proctor et al, 2013; Kaiser & Roberts., 2013). RCTs are considered to be the most robust study design for addressing questions of effectiveness in clinical trials. When choosing an

Table 1. Example of parent-mediated intervention fidelity component

	Definition	Clinician delivery of intervention to Parent	Parent delivery of intervention to child	Suggestions of measures
Adherence	Training techniques in PMI protocol delivered with fidelity (content, coverage)	What strategies were taught? To what extent did parents participate in training sessions	What strategies did the parent acquire and use?	Checklist of parent strategy use, rating of adherence to training protocol, video observation
Dose	Frequency, number, length of parent training sessions	How often did training occur, How long were the sessions for?	How often do parents use strategies with their child? How long do they use those for? Is the child receiving the strategies?	Diary for parents to record time spent using strategies, Record of clinician contact hours. Log of sessions parents attended.
Quality	Quality of which parent/clinician implemented techniques as described.	How effective was the clinician, Content delivered clearly, Multiple teaching strategies? Facilitation strategies	Did parents master the skills taught?	Video-observation, skill and mastery checklist, clinician rating of quality of parent skill enactment
Responsiveness (social validity)		Attrition rates, Interventionist buy-in, Did they observe change in parent / child? Relationship with parent	Parent buy-in, observation of changes in child, self-efficacy and confidence	Clinician and self-report rating of attitudes and opinions towards the intervention, interview with parents/clinicians
Differentiation	Extent to which only planned components were delivered, how much did two programs differ and match underlying theories	Ratio of amount of time spent engaged in parent coaching between intervention and control group	Number of times a parent correctly uses procedure at baseline in each group. Differences between external program provision beyond intervention	Clinician report of unplanned training components, exit interviews with participants to assess difference and similarities in intervention / control

intervention to implement within routine clinical care, clinicians often turn to RCT in their decision-making process. Therefore, it is pertinent to understand how PMI RCTs report their implementation practices.

There are five elements of intervention fidelity that are necessary for determining the quality of an intervention; dose, adherence, quality, differentiation and responsiveness. Dose refers to how much intervention is intended to be delivered and is necessary information to enable replicability and transferability of evidence-based practices into routine care.

Adherence to implementation can have a direct effect on outcomes, and measurement can improve the quality and reliability of the results. Quality concerns how well the clinician delivers the programme, (e.g. ability to engage, pacing, appropriateness) and the mastery of skill by the parent delivered to their child (Table 1). Responsiveness refers to how well the intervention engages, and is received by recipients, and also includes the views of clinicians towards the attributes of the intervention (Rogers, 2003). Differentiation refers to the

evaluation of essential programme components that determine its success (Table 1; Dusenbury et al., 2003; Caroll et al., 2007).

In PMI it is expected that parents will deliver the intervention strategies to their child. A conceptual framework for implementation fidelity has been adapted for PMI research from Dusenbury et al., (2003) and Caroll et al., (2007) and is based on a triadic model of early intervention service delivery (Salisbury & Cuching, 2013). This is depicted in Figure 1 along with how the intervention fidelity elements may be considered for both clinicians and parents (Ingersoll & Wainer, 2013, Kaiser & Roberts, 2015; Lieberman- Betz, 2015;). Intervention fidelity of implementation can be considered at two levels, at the level of the intervention practice and at the level of the implementation practice (Kaiser & Roberts., 2013). Therefore, intervention implementation fidelity at both the clinician and parent level deserve thorough measurement to enable outcomes of the research to be fully understood (Wainer & Ingersoll, 2013; Kaiser & Roberts, 2015; Lieberman-Betz, 2015).

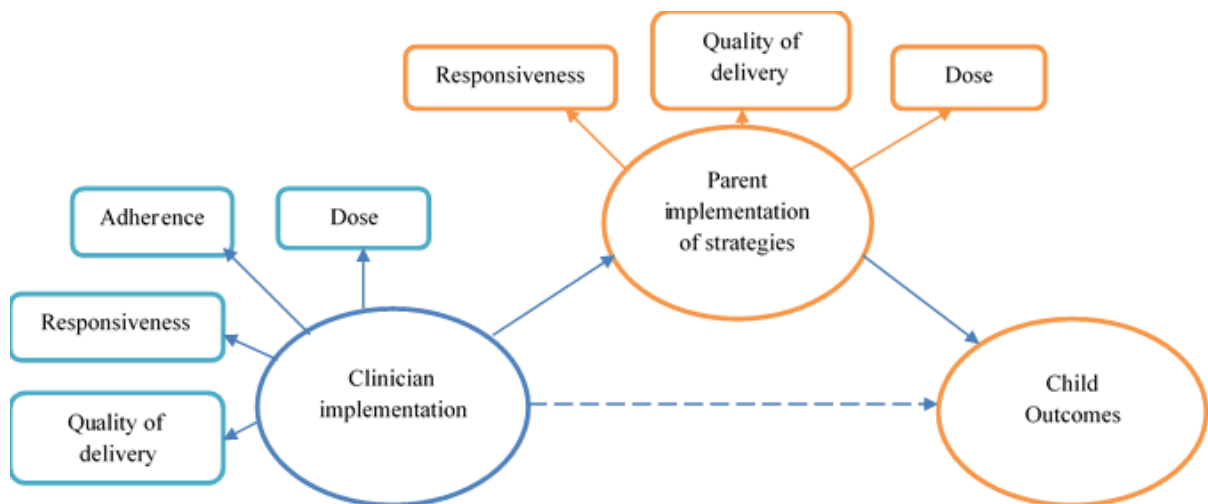


Figure 1. Triadic model of early intervention PMI process with four intervention fidelity elements adapted from Lieberman-Betz, (2015).

Previous reviews of the literature examining PMI have found that reporting of fidelity of implementation measurement from parent to child is relatively low. Roberts and Kaiser (2011) in their review of parent-mediated language interventions reported that 72% of studies

did not measure treatment fidelity and half failed to report parent training procedures. Barton and Fettig (2013) found that 79% of studies included some measure of fidelity with only 29% reporting clinician fidelity in training parents to use strategies. Oono et al., (2013) found that whilst most studies reported on the adherence of training delivered by the clinician to parent, only five reported parent level implementation of procedures to the child. Neville, Lecavalier & Startis (2018) found marginally larger effect sizes associated with the dose of intervention from parent to child for those receiving 20 hours of intervention or more. They also found that receiving less than 20 hours dose resulted in small treatment effects for communication and language development. The small effect sizes were attributed to inconsistent reporting in the quality (Table 1; responsiveness and quality) and quantity (Table 1; dose and adherence) of intervention.

A systematic review of factors influencing outcomes and generalisability of parent-mediated interventions (Trembarth et al., 2019) found both significant and non-significant results for the impact of fidelity on intervention outcomes. Suggesting that more sensitive and fine-tuned measures of change in parent behaviours were associated with change in child socialisation behaviours. Howard (2019) measured treatment response in parent-mediated early intervention and found that parental satisfaction and confidence (responsiveness to the intervention, Table 1) within the treatment group were high. The studies included a measure of parent skill level and fidelity (quality of delivery, Table 1) to show how well the intervention developed skills in the parent, which was linked to outcomes for the child. However, they did not differentiate between the different elements of intervention implementation fidelity.

To address this Lieberman-Betz (2015) conducted a systematic review of fidelity of implementation in parent-mediated early communication studies focusing on dose, adherence, quality and responsiveness. Intervention dose as delivered by the clinician to the

parent was measured most often (Figure 1), and at the parent to child level of implementation adherence was reported most often. With low rates of reporting for quality of delivery for the clinician and low-level reporting of dosage of parent to child. A strength of the Lieberman-Betz review is that they conceptualised fidelity of intervention implementation at both parent and child levels. However, they did not measure the quality and validity of the reporting of intervention fidelity elements, nor did they focus on RCT or a broad range of parent-mediated interventions.

There has been an increasing interest in intervention fidelity within the field of autism research and a call to review how studies are reporting their implementation processes (Wainer and Ingersoll, 2013; Green et al., 2018). Reporting fidelity elements will enable any changes and outcomes in the child to be appropriately ascribed to the intervention and shed light on how, why and for whom a particular PMI works (Dusenbury et al., 2003). Previous reviews have found a link between the reporting of fidelity components and reported child outcomes for both delivery of clinician to parent, and delivery of intervention from parent to child. However, with the exception of Lieberman-Betz (2015) they have not specifically evaluated the reporting of fidelity of intervention implementation components in PMI. This review differs in that we class the mastery of skills by the parent as ‘quality of delivery’, and the parent delivery of learned skills to the child as ‘dose’ as opposed to ‘parent adherence’ for reasons described earlier. Therefore, this review extends current literature by focusing on RCT, broadening the range of PMI reviewed and including a methodological quality rating of the reporting of intervention fidelity elements (Table 2).

Aims

The aims of the review were as follows:

Aim 1: Identify which implementation fidelity elements have been measured in parent-mediated interventions for young children suspected or diagnosed with Autistic Spectrum Disorder

Aim 2: Identify how implementation fidelity elements have been measured

Aim 3: Score the methodological quality of the reporting of dose, adherence, quality of delivery and responsiveness (Table 2)

Methods

Search Strategy

A systematic literature search was undertaken in February 2020. To identify relevant publications a systematic search using the following databases was conducted; CINAHL, ERIC, Embase, PubMed and PsychINFO. Date (2010-2020) and age (0-6 years) restrictions were applied as parameters to capture literature spanning 10 years, in order to review any changes to implementation reporting across the time frame. Search terms included the following: *“feasibility studies”* OR *“evaluation studies”* OR *implementation* OR *evaluation* OR *fidelity* OR *adherence* OR *dose* OR *delivery* OR *responsiveness* OR *differentiation* OR *quality* OR *process* OR *dosage* OR *completeness* OR *compliance* OR *adaptation* OR *feasibility* OR *satisfaction* OR *adoption* OR *“quality improvement”* AND *“empirically supported treatment*”* OR *“evidence based practice*”* OR *“evidence based treatment*”* OR *“evidence based intervention”* OR *“best practice*”* OR *innovation** OR *guideline** AND *“parent mediated”* OR *caregiver** OR *“Caregiver mediated”* OR *“parent based”* OR *“parent implemented”* OR *“parent directed”* OR *“parent intervention”* OR *“early intervention”* OR *“behavioural intervention”* OR *“parent training”* OR *“communication intervention”* OR *“early communication intervention”*. The full search strategy is

documented in Appendix 1. As illustrated in Figure 1, 2253 articles were initially returned. An additional 46 papers were identified via hand search of the following journals: Autism (1), Autism & Developmental Language Impairments (21), Autism Research (5), Journal of Autism and Developmental Disorders (19) and 558 duplicates were removed. Following the initial search, 1741 titles and abstracts were screened. Fifty-five articles were included for full text review based on the following exclusion and inclusion criteria:

Inclusion criteria:

- Children considered within the early intervention age range, 0-6 years and identified as either suspected or diagnosed with autism spectrum disorder.
- Intervention was carried out by parents during the treatment phase through the assistance of coaching, strategy modelling, feedback or education
- At least one fidelity component as described by Dusenbury et al., (2003) and Carroll et al., (2007) as an outcome measure
- Evaluating fidelity with quantitative methods (questionnaires, observations, interviews, log-books)
- Peer-reviewed
- Articles published in English
- Randomised Controlled Trials

Exclusion criteria:

- Population 7 or older
- Qualitative methods of evaluating fidelity only
- Pilot studies
- Web-based studies (e.g. teletherapy, ipad based parent training, remote parent training). PMI interventions utilising this approach are in their infancy, no RCTs

were identified within the literature search. Furthermore, the efficacy of web-based PMIs has not yet been evaluated and they do not include an element of modelling by the clinician delivering treatment which is included in face to face PMIs.

A total of 22 papers were excluded and 23 papers have been included in this systematic review. There was a total of sixteen different interventions which targeted a range of difficulties including communication, behaviour, focused attention and attachment (see table 3 for more information).



PRISMA 2009 Flow Diagram

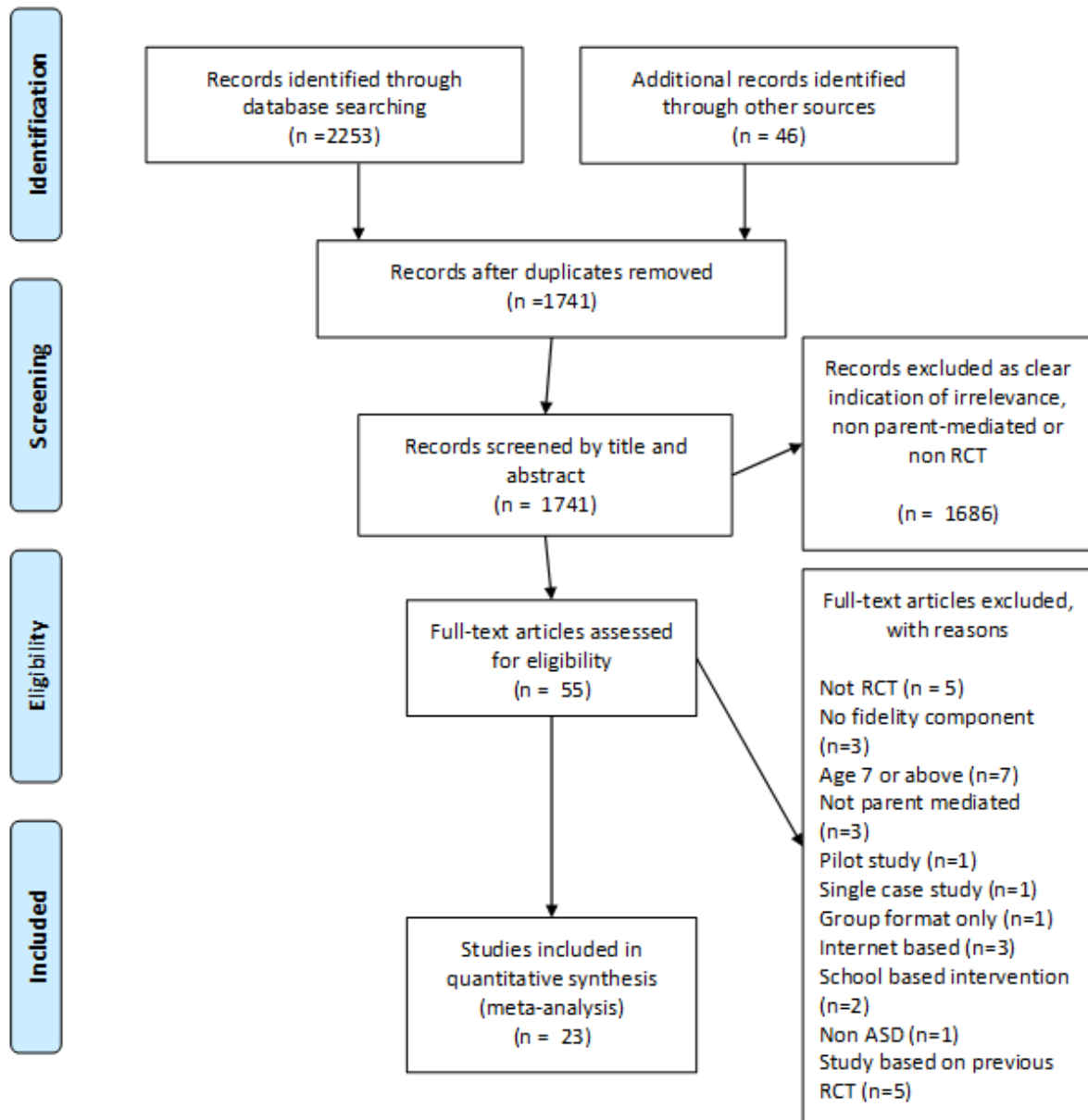


Figure 2. Prisma flow diagram of search strategy *From:* Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement.* PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

Data Extraction and Coding

A data extraction form was developed to identify which, and how, fidelity components were measured and is included in Appendix 3. Information was collated on author, year of publication, country of origin, type of intervention and their characteristics, setting and measures of implementation fidelity.

Data was extracted for each of the fidelity components; dose, adherence, quality and responsiveness. We omitted differentiation from this review as the focus is on parent and clinician involvement, and not the evaluation of the essential elements of programme success. We included the following information: Definition of fidelity component, method and timing of data collection, target of evaluation (parent, clinician), summary of the results as a mean value or range and whether this was linked to programme outcomes or not.

Coding of Implementation Fidelity

Dose was evaluated by the reporting of intended duration and frequency of the programme delivery on two levels, amount of dosage delivered by clinician and the intended dose by the parent to child. **Adherence** was evaluated at the clinician level as the degree to which the intervention was delivered as prescribed, using self or other checklists and/or observational coding. Adherence was omitted at the parent level as it was felt after looking through the papers that any measurement of parent to child delivery was relating to skill acquisition and refers to quality (e.g., skill mastery and enactment) or dose (e.g., time spent using intervention as home practice) rather than ‘adherence’. **Quality** was evaluated as the degree of competence with which the clinician or parent delivered the elements of treatment, and/or the frequency of skill enactment. Although the rate of parental skill enactment had been labelled elsewhere as adherence (Knoche et al., 2010), it is also true that an individual delivering an intervention skill at a higher frequency or quality may be providing more opportunity for their child to learn, thus increasing the quality of the intervention. Parental

skill enactment will be counted as ‘quality’ (see Table 1) for the purposes of this review.

Responsiveness refers to the degree to which parents and children are engaged by, interested in and committed to carrying out the intervention and was deemed to be present when the following was measured by clinician observation or self-report: attrition to the programme, parent satisfaction, self-efficacy, confidence or parent implementing strategies.

Quality Assessment

Table 2: Criterion for scoring the methodological quality of the reporting of intervention fidelity elements (taken from Schapp et al., 2018)

Criterion	Positive Score	Negative Score
1. Level of evaluation	if the fidelity component was evaluated on two or more levels (i.e. parent, clinician, child)	if the fidelity component was evaluated on only one level (i.e. parent, clinician, child)
2. Operationalisation of fidelity element	if the fidelity component was defined or operationalised	if only the name of the fidelity component was provided and not further defined or operationalised
3. Data collection methods	if two or more techniques for data collection were used (triangulation)	if only one technique for data collection was used
4. Quantitative fidelity measure	if measurement of the fidelity component was performed with adequately described methods	if only one technique for data collection was used
5. Frequency of data collection	if the fidelity component was measured on more than 1 occasion (e.g. pre, during after delivery)	if the fidelity component was measured on only 1 occasion
6. Relation of fidelity element and programme outcome assessed	if tested whether the fidelity component was related to programme outcomes	if not tested whether the fidelity component was related to programme outcomes

This review assessed the quality of methods used to measure specific implementation fidelity components (e.g. dose, quality, responsiveness and adherence, Dusenbery et al., 2003; Carroll et al., 2007). The efficacy of parent-mediated interventions has been previously reviewed and is not the focus of this review (Oono et al., 20013; Neville et al. 2018). No standardised quality of assessment measure exists for implementation fidelity. Therefore, the quality assessment was a modified version of criteria developed for previous process reviews assessing health promotion programmes (Schapp et al., 2018; Wierenga et al., 2013; Naylor et al., 2015). For the purposes of this review, we omitted three quality criteria from the

original process evaluation that were deemed irrelevant to the methodological quality of reporting fidelity components; the model or framework used for evaluation, qualitative data measures and reported number of process variables. Methodological quality was scored using the remaining six specific criteria as documented in Table 2. Appendix 3 and 4 provides full details on the quality scoring and criteria and Table 5 provides an overview of the methodological quality scores for fidelity. The criterion was applied to each of the fidelity components in each study and scored either positively (+) or negatively (-). There was a slight variation in the way that the criterion number two was applied to adherence; a score of NA was applied as it was not possible to evaluate this component on two or more levels as adherence only relates to the clinician for the purposes of this review.

A sum quality score (percentage of total positive scores of the six criteria) was calculated for each fidelity component, resulting in a score between 0% (all criteria negative) to 100% (all criteria positive). For the fidelity component of adherence whereby a score of NA was given, a sum was calculated based on 5 criteria. The methodological quality rating for each fidelity component were based on previous reviews (Schapp et al., 2018; Wierenga et al., 2013; Naylor et al., 2015) and deemed high (75% or above), moderate (50-75% or low (less than 50%). A full outline of the quality assessment can be found in Appendix 3.

Results

Study Characteristics

A total number of 1,921 children aged between seven months to six years ten months participated in sixteen different interventions detailed within the 23 RCT studies reviewed. Tables 3 and 4 provide an overview of the study characteristics described here. Studies were undertaken in six different countries, the majority of which were in the United States (N=15,

65%). All studies bar one (Thailand) was conducted in western civilization. The majority of studies were conducted within the home environment (N=10, 57%), four were conducted at a research facility or centre based (17%) and six were a combination of home and centre based (26%). Ten studies were conducted using 1:1 parent-mediated coaching methods only (44%), seven included parent-mediated plus clinician modelling (30%), four combined parent group

Table 3. Study Characteristics

Characteristic	Number of studies	%
Publication Year		
• 2010-2013	9	39%
• 2014-2016	10	44%
• 2017-2020	4	17%
Geographical location		
• America	15	65%
• Canada	2	9%
• UK	2	9%
• Netherlands	1	4%
• Australia	2	9%
• Thailand	1	4%
Intervention Type		
• Play and language for autistic youngsters (PLAY)	1	4%
• Joint attention mediated learning (JAML)	1	4%
• Hanen more than words (HMTW)	1	4%
• Joint attention symbolic play engagement and regulation (JASPER)	3	13%
• DIR/Floortime	2	9%
• Video Feedback Intervention to promote positive parenting (VIPP-AUTI)	2	9%
• Building Blocks	1	4%
• Focused Playtime Intervention (FPI)	2	9%
• PEBM	1	4%
• Pivotal Response Training (PRT)	1	4%
• Social ABC's	1	4%
• Behavioural	1	4%
• Parent implemented early start Denver model (P-ESDM)	3	13%
• Family implemented TEACHH for toddlers	1	4%
• Adapted response training (ART)	1	4%
• Parent autism communication training (PACT)	1	4%
Setting		
• Home	13	57%
• Centre Based	4	17%
• Both	6	26%
Delivery format		
• Group based plus 1:1 parent sessions	4	17%
• 1:1 Parent mediated only	10	44%
• 1:1 Parent mediated plus clinician:child modelling	7	30%
• Individual parent training & 1:1 parent mediated	2	9%

Components of fidelity		
• Dose	23	100%
• Adherence	19	83%
• Quality	15	65%
• Responsiveness	12	52%
Number of components per study		
• One component	1	4%
• Two components	5	22%
• Three components	9	39%
• Four components	8	35%

training with 1:1 parent session (17%) and two studies combined individual parent coaching or therapy with 1:1 parent mediated coaching (9%). In total 23 studies reported 81 (50%) out of a potential 161 fidelity elements reported at clinician and parent level (as described in Figure 1). All studies (N=23, 100%) reported the intended dose of the intervention, as expected for parent-mediated interventions. However, only seven (30%) of studies included information pertaining to the dose of parent to child. Next was adherence (clinician, N=19, 83% NA for parent), quality (N=15, 52%; parent level N=15, 65% clinician level N=0, both, N=1, 4%), and lastly responsiveness (N=12, 65%, clinician level=6, 26%, parent level=3, 13%, both=4, 17%). The majority of studies reported on three fidelity components (N=9, 39%), followed by four components (N=8, 35%), two components (N=5, 22%) and one component (N = 1, 4%). Each of the fidelity components are described in more detail, including a description of what fidelity components were measured (aim 1, Figure 1 and Table 4), how they were measured (aim 2, Appendix 2) and the methodological quality scores for the reporting of the fidelity component (aim 3, Table 2 and 5). Appendices 2, 3 and 4 provide detailed information of data extraction and the quality assessment tool.

Dose

Intended dose (number of sessions and session length) were reported at the clinician level in all 23 studies (100%), defined as either the intervention, programme, number, proportion or amount of sessions or visits. All studies detailed the characteristics of the intervention (100%) and 22/23 studies gave adequate details of the intended number and

length of intervention sessions. Ten studies (43%) reported the dose received by parents, stated as either the mean number of visits, range attended, sessions completed, percentage completed or declined. No studies reported the method of parent attendance data collection. Seven studies (30%) included information pertaining to the required amount of time that parents should spend implementing the learned strategies and 2 of those studies (9%) reported the time parents spent engaging with their child using intervention strategies during home-practice recorded via self-reported logbook (Solomon et al., 2014; Pajareya & Nopmaneejumruslers, 2011).

Methodological quality scores for reporting dose range between 33% and 83% (M=47%). Dose scored methodologically low (N=6, 26%), for example, Rogers et al., (2012) only reported on the intended dose of intervention and did not relate this to outcome. Moderate quality of reporting (N=14, 61%) and high (N=3, 13%). Those studies with high quality of reporting scored on 5/6 criterion, for example Gengoux et al., (2018) stated the intended dose to parent and dose of parent to child, plus included the amount of intervention received by the parents (but did not relate this to outcomes). Criterion number 2 (operationalisation) scored the highest (N=22, 96%) and relation to fidelity component scored the lowest (N=0, 0%) (Table 3). Two studies related the amount of dose to intervention outcomes (Pajareya & Nopmaneejumruslers, 2011; Kasari et al., 2014). Kasari et al., (2013) found a significant correlation between the number of sessions the treatment group received from clinicians and parental response to joint attention. These were not maintained at one year follow up. Pajareya & Nopmaneejumruslers, (2011) related the amount of parent dose of intervention to child which showed a non-significant difference that parents who reported >10 hours of intervention per week showed greater gains on the Functional Emotional Assessment Scale than parents who added less than 10 hours per week.

Adherence

Adherence was measured at the clinician level and reported in 83% (19) of studies and a definition was provided in all of them (Table 2). Adherence was most commonly referred to as fidelity to treatment, treatment integrity, intervention adherence, fidelity to protocol and treatment implementation. Measurements of adherence varied in description, most commonly conducted via observation of recorded intervention sessions (N=14, 61%), to score for fidelity of implementation. Followed by clinician self-report checklist (N=2, 9%), end of treatment file review (N=1, 4%), live observation behind one-way glass (N=1, 4%), live observation of session (N=1, 4%) and 2 studies did not state measurement methods (9%) (Appendix 2). Frequency of data collection was measured more than once on 11 occasions. None of the studies directly related measurement of adherence to intervention outcomes.

Methodological quality scores for the reporting of adherence ranged from 20%-66% (M=46.3%). Five (22%) studies reported low methodological quality, for example, Brian et al., (2017) only operationalised adherence as fidelity and stated that it was maintained throughout without elaboration. Moderate quality score was in 8 (35%) studies and 6 (26%) times high (Table 3). Green et al., (2010) scored highly because they stated how it was measured, included supplementary information detailing the criteria checklist, and double blind coded. Criterion 2 (operationalisation) and 3 (multiple data collection methods) were highest scoring (N=19, 83%) and no studies linked adherence to intervention outcomes.

Quality

Fifteen (65%) studies included a measurement of quality (see Table 5), the majority of which were evaluated at the parent level, with only one study measuring quality at both clinician and parent level. Kasari et al, (2010) included clinician rating of caregiver quality of involvement scale plus observation of video recorded parent skill mastery and was the only

fidelity component to score 100% on the quality rating. All 15 studies operationalised quality; eight referred to it as parent fidelity or implementation, four parent (or sensitive) responsiveness, one mastery of skills taught, one parental perception of competence and one performance of quality of strategies learned. The methods used for data collection were observation and coding of recorded parent:child interactions (N=9, 39%) and questionnaires utilising Likert scales (N=6, 26%), all were measured on more than one occasion. Seven (30%) of the measures were administered by an independent rater, five (22%) studies were measured by the clinician, one (4%) used a computer system and one (4%) measure was self-administered by the parent. Eight studies (35%) linked the results to intervention outcomes. Rogers et al., (2018) and Brian et al., (2017) both used video observation and checklist of parent skill mastery (labelled adherence in the research) to outcomes and showed that improvement was related to higher parent fidelity over time. Kasari et al., (2010) found higher weekly clinician ratings of caregiver quality of involvement predicted increased joint engagement at post treatment whereas parent self-report had no association with outcome. Casenheiser et al., (2013) observed that after 12 months of intervention parents' skill mastery moved up one level on the MEHRIT scale which was developed to rate clinician adherence. Parent improvements were associated with child social communication. Whereas Rogers et al., (2012) found no significant relationship between parent and child after 12 weeks of intervention. Seven (30%) studies included inter-rater reliability (Appendix 2).

Methodological quality scores for fidelity elements relating to the quality of delivery ranged from 33-100% (M=67%) and scored twice low (9%), e.g., Turner-Brown et al (2016) did not provide descriptive information on the intervention rating checklist of parent implementation. Eight (35%) studies rated moderate quality and five (22%) rated high quality (Table 3). The highest criterion score was through operationalisation of the

component (N=15, 65%) and the lowest criterion was the level of evaluation (N=1, 4%), with studies mainly reporting at the parent level.

Table 4: Study characteristics and reporting of fidelity components

Study	Country of origin	Sample size (T/CT) / months mean, range	Intervention	Intervention qualification	Dosage		Adherence		Quality		Responsiveness	
					CLIN	PAR	CLIN	PAR (NA)	CLIN	PAR	CLIN	PAR
Bearss et al. (2015)	America	180, (36-83m)	Behaviour intervention	Masters level or more	X		X				X	
Brian, Smith, Zwaigenbaum, and Bryson (2017)	Canada	30,32 (16-30)	Social ABC's	Bachelor level degree	X		X			X	X	X
Carter et al. (2011)	America	32,30 M=20.25 (15-25)	Hanen more than words	SaLT, certified by Hanen Centre	X		X			X	X	X
Casenheiser, Shanker, and Steiben (2011)	Canada	25,26 M=42.5 (24-59)	DIR / Floortime	Licensed SaLT or OT	X	X				X		
Dawson et al. (2010)	America	24,21 (18-30)	ESDM	Trained therapist with baccalaureate degree	X	X	X					
Gengoux et al. (2019)	America	24,24 (24-60)	Pivotal response Training	Masters level clinician	X	X				X		X
Green et al. (2010)	UK	77,75 (24-60)	PACT	SaLT	X	X	X					
Green et al 2015	UK	28,26 (7-10)	iBASIS-VIPP	Graduate SaLT	X		X			X	X	
Kasari, Gulsrud, Wong, Kwong and Locks (2010)	America	19,19 (21-36)	Joint Engagement Intervention	Graduate student in Ed. Psychology	X		X		X	X		X
Kasari et al. (2014)	America	60,52 41.9 (24-60)	JASPER	Trained clinician	X		X			X		X

Study	Country of origin	Sample size (T/CT) / M age (range months)	Intervention	Intervention qualification	Dosage		Adherence		Quality		Responsiveness		
					CLIN	PAR	CLIN	PAR (NA)	CLIN	PAR	CLIN	PAR	
Kasari et al. (2014)	America	32,34 M=22.37	Focused Playtime Intervention	Trained Clinician	X		X				X		
Kasari, Gulsrud, Paparella, Hellemann, Beryy (2015)	America	43,43 M=31.5 (22-36)	JASPER	BA / Phd psychology candidates	X		X						
Pajareya & Nopmaneejumruslers (2011)	Thailand	16,16 M=56.6 (24-72)	DIR / Floortime	Degree rehabilitation medicine	X	X							
Poslawsky et al (2015)	The Netherlands	40,38 M=42.2 (16-61)	VIPP-AUTI	Nursing, psychologist, social work 3+ yrs experience	X		X					X	
Roberts et al. (2011)	Australia	27,28	Building Blocks	Teachers, SaLT, OT's psychologist	X		X				X		
Rogers et al. (2012)	America	(14-24)	Early Start Denver Model	Highly experienced and credential therapists	X		X				X	X	
Rogers et al. (2018)	America	N=45 (12-30)	P-ESDM	ESDM certified psychologist, SaLT, behaviour specialist	X		X				X	X	X
Shertz, Odom, Baggett and Sideris (2017)	America	73, 71 (16-30)	Joint attention mediated learning	Intervention Co-ordinator	X	X	X				X	X	

Study	Country of origin	Sample size (T/CT) / M age (range months)	Intervention	Intervention qualification	Dosage		Adherence		Quality		Responsiveness	
					CLIN	PAR	CLIN	PAR (NA)	CLIN	PAR	CLIN	PAR
Siller, Hutman and Sigman. (2013)	America	70	Focused Playtime Intervention	Graduates and post-doctoral students' psychology and counselling	X		X			X		
Solomon, Van, Egeren, Mahoney, Quorn Huber, and Zimmerman (2014)	America	64,64 M=49.9 (32-60 month)	PLAY	PLAY consultants (1 OT, 2 SaLT, 3 special educators)	X	X	X					
Tonge, Brereton, Kimall, Mackinnon, and Rinehart (2014)	Australia	70, 37 30-60m	PEBM	Special educators and psychologists	X		X					
Turner-Brown, Hume, Boyd and Kainz (2016)	America	32,17	FITT	Licensed social workers	X		X			X	X	X
Watson et al 2017	America	45, 42	Adapted response teaching	Professionals experienced in ASD (e.g. teachers and therapists)	X		X			X		

Table 5: Validity and quality of implementation fidelity elements

Criterion	(N) of studies
Dose	
1. Level of evaluation	7
2. Operationalisation fidelity component	22
3. Multiple data Collection Methods	12
4. Quantitative fidelity measure	20
5. Frequency of data collection	10
6. Relation fidelity component and outcome	2
Methodological quality for reporting of Dose	
• Low (less 50%)	6
• Moderate (50-75%)	13
• High (more than 75%)	3
Adherence	
1. Level of evaluation	NA
2. Operationalisation fidelity component	19
3. Multiple data Collection Methods	19
4. Quantitative fidelity measure	11
5. Frequency of data collection	11
6. Relation fidelity component and outcome	0
Methodological quality for reporting of Adherence	
• Low (less 50%)	5
• Moderate (50-75%)	8
• High (more than 75%)	6
Quality	
1. Level of evaluation	1
2. Operationalisation fidelity component	15
3. Multiple data Collection Methods	10
4. Quantitative fidelity measure	12
5. Frequency of data collection	14
6. Relation fidelity component and outcome	6
Methodological quality per component	
• Low (less 50%)	2
• Moderate (50-75%)	8
• High (more than 75%)	5
Responsiveness	
1. Level of evaluation	3
2. Operationalisation fidelity component	11
3. Multiple data Collection Methods	2
4. Quantitative fidelity measure	10
5. Frequency of data collection	6
6. Relation fidelity component and outcome	1
Methodological quality per component	
• Low (less 50%)	6
• Moderate (50-75%)	5
• High (more than 75%)	1

Responsiveness

Twelve studies measured responsiveness and 11 labelled or operationalised it. Three labelled this as parent, consumer or treatment satisfaction, two reported attrition rate, two social validity, two adherence to treatment, one measured perceived self-efficacy and one measured response to therapist. Measurement was conducted mainly by parent self-report questionnaire (N=8, 35%). Four studies (17%) measured this at the clinician and parent level, for example Brain et al (2017) administered two questionnaires, one focusing on parents perceived self-efficacy and one on parent satisfaction of treatment (Appendix 2). Four studies measured at the clinician level only, and 4 studies measured at the parent level only (Table 3). Ten studies (43%) included enough detail to replicate the measures by either explaining the content, providing a reference or inclusion within supplementary information. Six studies (26%) reported measuring on more than one time point. One study related the measure to treatment outcomes, Kasari et al., (2010) explored the relationship between weekly self-report 'adherence to treatment' and competence and found it was not associated with outcomes (whereas clinician rated parental quality of delivery was associated with treatment outcomes, as reported earlier).

Methodological quality for reporting responsiveness ranged from 33%-83% (M=41%) and six studies (26%) showed low methodological quality. For example, Poslawsky et al., (2015) reported client satisfaction at one time point and didn't include supporting information. Five (22%) studies scored moderate quality and one (4%) high (Table 3). Criterion 2 (operationalisation) was rated most often (N=11) and criterion 6 (relationship to outcomes) rated least often.

Discussion

The purpose of this review was to examine the reporting of implementation and intervention practices in parent-mediated interventions. Aim 1 investigated which fidelity

elements have been measured within parent-mediated interventions. In total 23 studies reported 81 (50%) out of a potential 161 fidelity components. Out of a potential seven fidelity measures (four at clinician level, three at parent level), three studies reported two elements of fidelity, eleven studies reported three, three studies reported on four, and five studies reported on five elements (Table 5). No studies reported either six or seven components. The highest level of reporting was for dose at the clinician level with 23 (100%) of studies and quality at the parent level with 15 (65%). Whilst the lowest reporting was quality at the clinician level with only one (4%) and both responsiveness and dose at the parent level at seven times each (30%). It is concerning to note that studies used the term implementation fidelity and adherence interchangeably to refer to different fidelity components. Where definitions were provided, they were very short, and no studies referenced implementation frameworks or methodology.

Although this review has highlighted an increase in reporting of fidelity components when compared to Leiberman-Betz et al., (2015) it also supports previous findings of the paucity in reporting procedures at both the parent and clinician level. Given that parent-mediated interventions are intended to increase the skill and mastery of parents to use the skills long term and across different setting this finding is concerning (Wainer & Ingersoll; Kaiser & Roberts, 2015). The appropriateness, fit, acceptability of the intervention and training practices influence parent implementation and is an important moderator for parental engagement in the intervention (Durlak & Dupree, 2008; Breitenstein et al., 2010; McConachie & Diggle, 2007; Coleman & Karaker; 1998; Callahan, Henson & Cowan, 2008; Carroll et al., 2007). Parents mastering skills increases the quality of interventions for their child, as they are exposed to more opportunity to learn throughout the day in their natural environment. Therefore, an important element to determine the efficacy of the intervention is to measure the time (and quality) spent practicing the skills with their child and the impact

that this might have on the outcomes for the child over a long-term period. Studies to date have included the intended dose of intervention but rarely document the amount that parents receive or the amount they deliver to their children. In order to explore the relationship between outcomes, duration and intensity of the intervention studies need to improve measuring and reporting of implementation both at the parent to child level and the clinician to parent level.

Quality scores were derived from the parent level with the exception of one study that also included a quality review at the clinician level. This is in part due to the classification of parent mastery of skill as quality, when it was largely classed as ‘adherence’ in the studies. The quality of delivery at the clinician level is an important consideration in implementation of parent mediated interventions. This differs from adherence in that quality relates to the competency of the clinician in delivering the skills to the parent and the quality of the relationship. Whereas adherence relates to whether the clinician delivered the intended content of the intervention. If the quality of methods for delivering the intervention are low this may impact on the ability of the parent to master the skills, thus resulting in poorer outcomes for the child. Due to the paucity of information regarding the clinician quality of delivery, teaching strategies used and effectiveness of the clinician, it was impossible to ascertain how the quality impacts on outcomes. The training and supervision of clinicians, and the techniques deployed in parent delivery, are important implementation information and should be reported on (Proctor, Powell & McMillen, 2013; Damshcroeder et al., 2009).

Responsiveness received the widest variety of labels and only two studies referred to it as social validity, the closest terminology to responsiveness. Furthermore, measurement was only present in 50% of studies despite being vitally important to understand parental engagement, acceptability and uptake of the intervention (Fruehar et al., 2012; Stahmer et al., 2017). Understanding how both parents and clinicians respond to the intervention would

increase the flexibility of the intervention to adapt to the needs of individuals (Ingersoll & Dvotcsak, 2006). Higher buy-in is likely to increase motivation to practice the skills with their child resulting in increased outcomes (Callahan, Henson, & Cowan, 2008).

The second aim evaluated 'how' studies measured the fidelity components.

Adherence was mainly measured through observation of recorded sessions and refers to the fidelity to implement the intervention as it was intended. In all cases, although adherence was measured and reported upon in terms of clinician fidelity to the treatment model no studies directly tested for the association with treatment outcomes. It is likely that an assumption was made that clinician adherence directly related to treatment outcomes. Dose was most often measured at the clinician level and parent reporting showed a slight increase on previous reviews (Lieberman-Betz, 2015). The lack of reporting of data collection methods concerning the amount of dose that parents received is a methodological flaw which has implications for the replicability of the studies. Although studies described that intended dose, they rarely reported on the actual dose received or the attrition rates. Quality was measured most often by observation of parent child interaction either recorded or live. Responsiveness was mainly measured through questionnaires and checklists. However, it is important to note that few were blind to the condition, rated by an independent researcher or included an inter-rater reliability measure. Many studies included unpublished measures designed specifically for their study and have not been tested for validity. The measurement of fidelity components appears to be highly heterogeneous both conceptually and methodologically with varying operationalisation of fidelity components and this finding appears to be consistent with previous implementation reviews (Barton & Fetting, 2013; Lieberman-Betz, 2015; Chaudoir, Dugan & Barr, 2013; Nilsen, 2015). Clear labels and consistent guidelines would improve the measurement for each fidelity component. In line with previous reviews (Schertz et al., 2012; Oono et al., 2013 the time spent and quality of

parent delivery of the intervention to their child is typically not reported. This review highlights the need for standardisation of fidelity terminology, improved reporting of intervention fidelity beyond clinician level adherence and the development of a conceptual framework that includes fidelity of implementation at the parent level. This needs to be measured against clinical outcomes to enable a full picture of the influences on outcome to be observed.

Aim three assessed the quality of implementation fidelity reporting through the use of a quality assessment tool. Quality of reporting was variable across studies and fidelity components, largely due to the heterogeneity of reporting practices and methods used. High quality of fidelity of intervention reporting within studies was scarce (N=15, 9%). Studies most often deployed moderate reporting practices (N=34, 36%). Low methodological quality in reporting implementation practices was seen in dose and responsiveness (Table 5). Despite the importance of measuring fidelity components comprehensively in order to determine the degree to which interventions are implemented as planned it may not be feasible to do so in parent-mediated interventions. Measuring fidelity of intervention implementation alongside the delivery of an RCT are essential and the quality of reporting requires improvement (Borrelli, 2011). One way this could be achieved is by the introduction of qualitative interviews with clinicians and parents which may allow for exploration of the variation in factors influencing fidelity (Lorenцatto et al., 2013). The reliability and validity of measures used to measure implementation fidelity is rarely reported and needs to be addressed in the literature.

Research Implications

These findings have implications for the future of implementation reporting practices in research pertaining to parent-mediated interventions. It is clear from this research that a

myriad of parent-mediated interventions exists within early intervention for children suspected or diagnosed with ASD, indeed sixteen different interventions were reported for 23 studies. Common flaws observed within the studies included small numbers of participants in each treatment group and few large-scale studies, risk of bias from attrition rates which were selectively reported in only a few studies, varied descriptions of conceptualising the name of fidelity components and a wide variety of outcome measures used over varying time points. There are no standardised protocols for the measurement of fidelity components (e.g., manualised, methods and parent delivery, treatment outcomes). These issues together with low levels of reporting fidelity measurements renders the interpretation of findings quite difficult. Therefore, there is a need for improved quality and consistency in both study design and implementation reporting practices (Damschroeder et al., 2009; Proctor et al., 2013; Borelli, 2011). Furthermore, the context within which the intervention is delivered, e.g., home and community and the resources that an individual possess creates differences that require consideration and an individualised approach to treatment delivery.

The fidelity of intervention implementation plays a key role in the interpretation of findings (McArthur et al., 2012). When studies reported ‘parent dose to child’ they showed that the larger dose was associated with greater gains, albeit insignificant. Other studies have also highlighted that higher quality dose may be related to greater gains (Rogers & Visamra, 2008). Therefore, future studies need to monitor and report on treatment dose, adherence, quality of delivery and responsiveness at the parent level. This warrants close attention as they have significant implications on both research outcomes and engagement in treatment, which is important for parent and child success (Carroll et al., 2007; Rogers & Vismara, 2008). However, collection of data at both the clinician and parent level is fraught with difficulty and it is important to consider the barriers that impede data collection for researchers, for example, data collection at the parent level relies heavily on parent report

which may be subject to bias. Furthermore, despite recommendations for keeping records of attrition within early intervention research (Lord et al., 2015) attrition rates were only reported in five (22%) studies and it was limited to reporting the rates rather than discussing the factors contributing to attrition. Understanding these factors can yield better retention and treatment outcomes for those attending treatment. Studies should include more frequent reporting of their practices and attrition rates. Including qualitative information pertaining to the views of parents engagement in the intervention will 1) identify which aspects of the intervention have been most/least helpful for them, their child and their family system 2) highlight barriers and facilitators for engaging in the recommended home practice, 3) determine the strength and quality of the therapeutic alliance 4) understand reasons for attrition.

There was a resounding majority of western based interventions, this leads to questions concerning the cultural validity of interventions studied. Furthermore, it may be useful to consider the ecological validity of the intervention given that they are likely to be delivered in naturalistic settings yet measured in only one setting (e.g., in clinic or home). Siller et al., (2013) were the only study to address this through multiple measurement on different days and in different settings (home and clinic). Future studies should address this discrepancy in research methodology.

Clinical Implications

In order to engage parents in the intervention it is vitally important to choose an approach which fits the needs of the population and the buy-in from an organisational perspective. Measurement of dose received by the parent and the optimum formula for parent training that results in sustained and maintained skill acquisition is important. In order to do this effectively consistent implementation and intervention measurement needs to be

employed by the clinician when transferring EBP into routine clinical care to allow the clinical team, and those commissioning services, to ascertain whether the intervention is a good fit for their population and service delivery model. At a clinical level this can include reporting the number, length and duration of parent training sessions, the amount of dose of parent to child and parent generalisation and maintenance. At an organisational level this could involve gathering information on the attitudes of clinicians and stakeholders towards the intervention, holding regular supervision sessions to ensure fidelity to the treatment model and collecting fidelity of implementation data to inform service delivery and practice.

Whilst reporting adherence to treatment fidelity for clinicians has improved, reporting of the quality of that delivery has not. This may be in part due to the challenge in operationalising this fidelity component. The clinician may be able to show fidelity to the skill, yet the delivery techniques may influence the ability of the parent to learn it. Measuring the facilitation of clinician implementation could include information about how the therapist was trained, their experience in delivering the intervention, continuous feedback for fidelity of intervention and ongoing supervision.

Limitations

This is the first review assessing the quality of implementation practices in parent-mediated interventions for children suspected or diagnosed with ASD. There are limitations to the study that require acknowledgement. Firstly, the data extraction and quality assessment has been undertaken without an independent second reviewer and would be strengthened by inter-rater reliability. Secondly, the quality tool has been adapted from studies that do not measure parent-mediated interventions. Dose was assumed to be measured at several time points when the study reported the number of sessions attended at the parent level. This rule was also applied when studies reported attrition. This may skew

the data on validity of the measurement, but it was felt to be appropriate in these circumstances. Thirdly, many parent-mediated interventions report outcomes at the child level, arguably children respond to the intervention by increasing their skills in initiation, child response to parent could be considered a measure of fidelity reporting, particularly for responsiveness or quality. However, measuring responsiveness at the child level was beyond the scope of this review.

Conclusion

A challenge in evaluating fidelity components and reporting in parent-mediated interventions is the wide range of descriptions and measures used within the field of research. Some measures included in this review were not intended to measure implementation practices, nor were they described as such despite the ability of them to do so. The field of implementation science within autism research is growing, and more recent studies described here have improved reporting practices, which is encouraging. It would be pertinent for researchers to consider how they may standardise operationalisation and measurement for dose, quality, responsiveness and adherence and link these to treatment outcomes. Clinicians can then make an informed decision about the elements of the intervention most likely to achieve outcomes within routine clinical care.

Chapter 2

Empirical Paper

***"It's like climbing the stairs": Parent acceptability of paediatric
autism communication therapy, a qualitative analysis***

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This paper will be submitted to The Journal of Autism and Developmental Disorders (JADD)
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[https://www.springer.com/journal/10803/submission-
guidelines#Instructions%20for%20Authors](https://www.springer.com/journal/10803/submission-guidelines#Instructions%20for%20Authors)

Glossary of terms

Interactional ‘meshing’: Two-way communication whereby parent and child respond to one another which increases their ability to understand and relate to others

Synchronous communication: Communication acts which seek to support the child’s current focus of attention and comment on the child’s play or activity

Asynchronous communication: responses from parent that seek to direct/redirect the child’s attention, thus placing demands on the child

Contextual signals: non-verbal communication cues e.g, pointing, eye gaze, facial expressions

Referential understanding: understanding that gestures and words refer to objects and events

Reciprocity: back and forth interaction between people, during which the behaviour of each person influences the behaviour of the other person

Dyadic Communication: mutual face-to-face verbal communication between two persons sharing thoughts and behaviour

Semantic contingency: response through actions and speech to the child’s focus of attention

Language mapping: process of learning the meaning of words, attaching meaning to new words and being given additional experiences with the word in meaningful environments

Modelling: learner imitates a target behaviour performed by a ‘model’ e.g. the trainer or parent

Shared attention: the ability to share a common focus, object or action with another person

Abstract

This paper presents the perspectives of parents who participated in a parent-mediated intervention, Paediatric Autism Communication Therapy (PACT) which was delivered in a clinical community setting. Semi-structured interviews were conducted with eight participants, designed to illicit parents' views of the acceptability of the intervention. Analysis was guided by principles of thematic analysis. Two main themes were identified *'It's like climbing the stairs: A Collaborative Learning Journey'* and *'I can't see another way of doing it: Components, Structure and Effectiveness'* which are discussed within the theoretical framework of acceptability. Implications for clinical practice and limitations are discussed.

Autism spectrum disorder (ASD) is a neuro-developmental disability in which core impairments in language, communication and reciprocal social interaction have a profound influence on children's social development into adulthood (Naber et al., 2008). Impairments in social communication are amongst the first symptoms to arouse parental concern, usually around the age of 24 months (Howlin & Moore, 1997; Lord, Risi, DiLavore, Shulman, Thurm & Pickles, 2006). Children with ASD exhibit weak and unusual communication including deficits and delays in non-verbal communication, communicative intentionality, joint attention and orientating to social signals (Wetherby, Prizant & Hutchison, 1998; Greenspan, 2000; Drew, Baird, Taylor, Milne & Charman, 2002). Such difficulties are pervasive, persistent, highly predictive of future social and educational outcomes and strongly associated with severity of behavioural symptoms.

The impact of these impairments on parent-child interaction is significant and can be bewildering for parents, reducing the opportunity for bonding (Aldred & Pollard, 2001). The child's communicative signals may be subtle and difficult to interpret therefore, parents may engage in a more directive parenting style (Nassan & Romanczyk, 1999). This may increase 'asynchronous' communication which decreases language learning opportunities. While a more directive parental style is not incompatible with sensitivity, supportive and sensitive parental responses support the development of joint attention and the learning of language (McCathren, Yoder & Warren, 1995). This may be particularly important in children whose developmental impairments lead to difficulties in accommodating demands to shift focus, and to regulate several competing demands on attention (Legerstee, Varghee & Beck, 2002).

Initial exploratory studies compared the parent-child interaction of children with specific language impairment, ASD and normally developing young infants and supported the use of a dyadic communication approach. The maternal characteristics of synchrony and responsivity, identified as important in interactions with typically developing prelinguistic

infants, were found also to facilitate enhanced communication and interaction in children with autism (Watson, 1998). However, children with autism required a heightened degree of sensitivity and an increased response level from parents (Yoder & Warren, 2001).

These aforementioned findings were central to the development of an early intervention for children diagnosed with ASD, Paediatric Autism Communication Therapy (PACT). PACT is a parent-mediated and video-aided intervention designed to improve social communication competencies in children with emerging or diagnosed autism spectrum disorders (Aldred, Green & Adams, 2004; Green et al, 2010). Shared attention is vital to referential understanding and key to the development of vocabulary for all children regardless of their neurological beginnings, a lack of shared attention is associated with delayed development (Siller & Sigman, 2002). Therefore, therapists work directly with parents with the intention to influence a change in parent communication and the home environment. Sustaining long-lasting improvements in these areas would ultimately help children develop social interaction and language.

The PACT model also incorporates other language facilitation techniques including semantic contingency, adapted language input, language mapping and modelling. The intervention utilises broad questions, comments and specific probing to guide parental observation and discussion during the stages of treatment. The questions aim to encourage the parent to identify the behaviours and responses during play which relate to child communication. This builds parental skill and resourcefulness, so they may respond to their infant's contextual, verbal and non-verbal signals with the aim of increased child initiations and enhancement of parent-child reciprocity.

Aldred and colleagues (2010) first demonstrated the potential effectiveness of this intervention in a large-scale randomised control trial involving 152 children with core autism. In this study children were either assigned to treatment as usual or one-to-one parent-

mediated communication-focused Preschool Autism Communication Trial (PACT) intervention. This study saw a clear benefit for parent-child interaction with parents reporting fewer difficulties in core symptoms including social communication and repetitive behaviours. These improvements were evidenced in a follow up study conducted six years later (Pickles, et al., 2016). The children had maintained relative improvement in social engagement, communication initiation and repetitive behaviours. It is of note that when reviewing the literature for fidelity components, Green et al., (2010) did not report any measure of parental adherence to treatment in order to link parent fidelity to treatment outcomes. Due to the strength of the evidence base for PACT in highly controlled environments it has been included in the recommended curriculum for Children and Young People's Improving Access to Psychological Treatment (IAPT) programme in England. Therefore, PACT has been adapted for community clinical intervention and implemented within the local health board.

Meta-Analysis have shown modest evidence that parent-mediated interventions are effective when implemented in highly controlled environments. However, when they were applied in real world settings, they did not always achieve the same results (Dawson & Bernier, 2013; Odom, 2009; Odom & Fettig, 2013; Odom et al, 2013). Implementation science studies how EBP is disseminated within clinical and community settings and can bridge the gap between research and practice to enable the uptake of interventions (Curran et al., 2012). There are a range of interacting factors that influence the successful uptake and dissemination of interventions that are often complex in nature (Damschroeder, Aron, Keith, Kirsh, Alexander & Lowery, 2009). Damschroeder et al., (2009) proposed five domains that encapsulate the myriad of ways that implementation can be affected. These include the characteristics of the intervention, the inner and outer setting, the individuals involved in the intervention (stakeholders, clinicians and recipients) and the implementation process.

Of particular importance in parent-mediated interventions are the individual attitudes and skill in delivering the intervention. This relies on the clinician and parent developing an adequate understanding of (and enthusiasm for) the intervention with which they are engaged in. The degree to which parents have a positive affective attitude towards an intervention can influence parent buy-in and potential outcomes (Rogers, 2003). Furthermore, the more confident an individual feels in the enactment of intervention skills, the more likely they are to adopt the changes necessary to implement it with success (Howard, 2019). Taken together these factors suggest that cognitive and emotional factors may moderate how responsive parents are to an intervention (Sekhon, Cartwright & Francis, 2017).

Parental responsivity, or acceptability has been highlighted as a key factor that influences the uptake and outcomes of an intervention (Proctor, Powell & McMillen, 2013; Sekhon, et al., 2017). A theoretical framework for acceptability has been proposed by Sekhon and colleagues (2017) to encapsulate seven acceptability factors that can influence those delivering or receiving a healthcare intervention and depicted in figure 1.

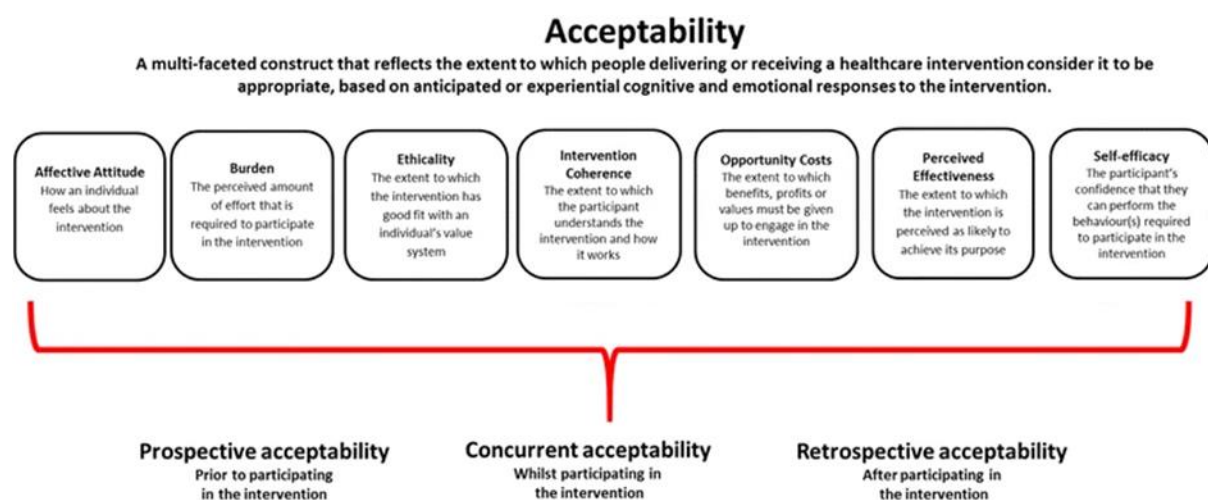


Figure 1. Theoretical Framework of Acceptability, (Sekohn et al., 2017)

PACT is delivered within the home environment and requires parents to play with their child whilst being video recorded. They then watch the video together with a clinician

and the clinician supports the parent to learn through active reflective questioning and parent are asked to practice daily. Although a highly controlled randomised trial (Green et al, 2010) has evidenced the treatment efficacy of the PACT programme, currently no studies to date have evaluated the acceptability of PACT within a clinical community setting. Differences exist between the RCT and how it is delivered within routine clinical care. Two such differences are the context in which PACT is delivered and the length of the intervention. The RCT was conducted within a highly controlled clinic setting whereas the local health board delivered PACT within a community setting. The length of the intervention delivered was variable and flexible to accommodate individual need and demand on the service. It is important to understand how acceptable the PACT intervention is to parents when applied in the community setting and is essential information recommended by leading guidance in the health sciences (Craig et al., 2008; Eldridge et al., 2016). Therefore, it is important to consider how the implementation of PACT is experienced by families to ensure acceptability of the intervention

How acceptable an intervention is, impacts on the likelihood of adherence to intervention recommendations and clinical outcomes. Understanding parents' perceptions of the acceptability of the PACT intervention may enhance opportunity for services to increase uptake and sustainability (Sekhon et al., 2017). Retrospective acceptability can be assessed qualitatively focusing on parents' experience of the intervention from initiation to completion, when no further treatment is planned (Sekhon et al, 2017). PACT has been adopted by a local NHS organisation as an early intervention strategy for improving dyadic parent-child communication and is the chosen setting to explore acceptability.

Aims

This study aims to gain an understanding of parental acceptability of the PACT intervention as it was delivered in routine clinical practice in a community setting. It is envisaged that important implications relating to the acceptability of the intervention will be highlighted to augment the future delivery of PACT and enhance adherence to treatment and therapeutic outcomes. Therefore, the main research question is: How acceptable is the PACT intervention to parents of children with social communication difficulties?

Method

Participants

Seven semi-structured interviews were undertaken with an opportunistic sample of eight parents who had participated in the PACT intervention, five mothers, one father and one mother/father dyad. All participants had completed the PACT programme within 1-12 months and had received between six and 18 sessions. Children's ages ranged between two and 11 years of age and they had been referred to PACT due to the presence of significant communication impairments. Their characteristics are summarized in Table 1. All participants were awaiting an ASD assessment on commencement of the PACT intervention, four had received a diagnosis of Autism Spectrum Disorder whilst participating in the PACT intervention and the remainder were still awaiting assessment at the time of interview. Inclusion criteria included parents or carers (father, mother or both) who had completed PACT (e.g., 6-18 sessions) or attended one or two sessions and then declined the intervention. Participants had ended PACT between six months to twelve months of the commencement of the study. Pseudonyms have been allocated to parents and children to maintain their confidentiality.

Design

A qualitative methodology utilising thematic analyses to retrospectively explore the acceptability of PACT to parents was deemed appropriate for this study (Braun & Clarke, 2013). The design of semi-structured interviews was guided by the theoretical framework of acceptability (TFA) which distinguishes constructs that capture dimensions of acceptability (Sekhon et al, 2017). Interviews were audio-recorded, transcribed verbatim and analysed using thematic analyses (Braun & Clarke, 2013) to allow for novel and unanticipated instances. The interview comprised open ended questions with additional follow-up questions used if appropriate to do so. All participants consented to participate prior to the interview.

Procedure

Ethical consideration for this study was sought from Bangor School of Ethics and NHS Research Ethics Committee, London-Queen Square and registered with the local health board (Appendix 7). Participants were recruited opportunistically through clinicians delivering the PACT intervention within a Welsh Government grant funded service set up to deliver PACT within the NHS. The intervention was delivered by several clinicians from differing specialties (Speech and Language Therapist, Assistant Psychologist, Clinical Psychology) within a Psychologist-lead multidisciplinary team. Initially, clinicians within the team approached potential participants by post with an invitation pack containing information about the study and an opt-in form. Clinicians followed with a phone call to offer additional verbal information regarding the study and to collect consent to be contacted by the researcher. The lead researcher contacted potential participants by telephone, they answered any questions and provided further information regarding the study aims and procedures. The location of interviews was flexible to provide the best opportunity for parents to participate at a mutually agreed time. All participants chose to be interviewed within their own home whereby full details relating to the participation in the study was

explained and informed consent was obtained. Ethical approval was obtained from Bangor University Psychology Research Ethics Committee and the NHS Research Ethics Committee, London-Queen Square Appendix 7).

Data Collection

Semi-structured interviews guided by an interview schedule were carried out with individual participants in their own homes, the length of interviews ranged from thirty minutes to 74 minutes. An interview schedule was developed in line with the acceptability research and informed by clinicians delivering the intervention (Sekhon et al., 2017).

Interviews were focused on the experiences of parents' interaction with various aspects of the intervention, for example intervention components, the process of receiving information in relation to the intervention and choosing to participate. Participants were encouraged to speak freely, and the interview schedule was used flexibly to allow participants' stories to unfold unconstrained if necessary.

Data Analysis

Thematic Analysis is a highly flexible theoretical approach that can be adapted to fit the needs of the study (Braun & Clarke, 2006). It provides a systematic framework for the identification of patterns within the data which was performed adopting a critical realist epistemological stance (Braun & Clarke, 2013). By adopting a critical realist viewpoint, the researcher adopted the position that knowledge is subjective in the context of expectations, beliefs and external forces (Braun & Clarke, 2013). The researcher sought to understand the impact of the PACT intervention and whether this influenced parent's perspectives of themselves and their children. The experience of participating in the PACT intervention was understood as a transaction shaped by external factors such as the social context, the child's stage of development and communication difficulties, and the skills of the clinician

delivering the intervention. Semi-structured interviews were designed using the Theoretical Framework of Acceptability in mind, as described by Sekhon et al., (2107), and thus the author acknowledges that their position in relation to the research aims is shaped by this knowledge and understanding of implementation and acceptability literature. In view of this, the researcher was careful to honour the inductive nature of thematic analysis and followed the process according to Braun & Clarke (2013). Transcripts were read several times, annotated on paper with researcher reflections and coded electronically. Emergent themes were derived from the codes. Selections of transcripts, the combined codes and resultant theme tables were subject to credibility checks by an experienced qualitative researcher who oversaw the analytic process. This ensured the quality of the analyses and examples are provided in Appendix 4,5 and 6 for further clarification. Inductively, codes were directed by content from the data, based on participants experiences. These are described narratively within the results section and organised by their relationships into subordinate and superordinate themes. Themes were considered within the theoretical constructs derived from the acceptability research (Sekhon et al., 2017) and are discussed in relation to the acceptability literature, therefore data are broadly interpreted within an implementation and acceptability theoretical and ideological framework.

Results

Two main themes were identified *'It's like climbing the stairs: A Collaborative Learning Journey'* and *'I can't see another way of doing it: Components, Structure and Effectiveness'* with six superordinate themes, described in Table 2.

Theme 1: *'It's like climbing the stairs'*: A Collaborative Learning Journey

Parents' felt positive about PACT and they described the process of their learning journey in which they developed new skills and identified ways to communicate more

effectively with their children, strengthening their emotional and relational connection. The way in which the intervention was implemented appeared key to parents acquiring new skills by building a strong and collaborative clinical relationship. Parents reflected on their feelings towards their relationship with the clinician and indicated that this relationship helped bolster intervention coherence and parental self-efficacy.

1.1 *'Every session you go up another step'*: Process of developing new skills

Following the initial introduction to PACT parents cited a number of reasons why they chose to engage in the intervention. For some the relational aspect of communication was important as George explained that *"the reason we went on it was because Richard doesn't speak, and he was quite into being directed with things, he wouldn't initiate stuff for himself communication wise"*. Others cited that it was important for them to help their child build skills and were intrinsically linked to language development as Carrie noted that *"the talking which was obviously the main issue for us"*. Lastly, parents cited emotional reasons for participating as described by Carrie *"if I tried to get down on the floor and play with him he'd just get up and walk away ...so I just got a bit worried about him"*.

All parents reflected to some degree on the qualities, characteristics and skills that they needed to employ in order to engage with the intervention and learn the skills to facilitate communication. Some parents recognised that prior knowledge and skills were not applicable to engaging a child with communication difficulties, and that initiating the usual 'rules' of play and communication created a barrier to shared attention and mutual engagement with their child. Whilst other parents felt that prior knowledge and skills helped them to engage with the process more fully, for example, having a positive attitude or having been involved in specialist training and education. Jessica reflected that a *"parent has to be ready to listen and learn and reflect, and without that with anything in life, it won't work"*.

This suggestion that one must be ‘ready’ to engage in the intervention was evident throughout as parents commented on their ability to engage in play, notice the positives, hear the feedback, and ultimately change their behaviour with their child.

Parents viewed PACT as a staged process, with each session leading onto the next with new learning being acquired incrementally. Maria described feeling hesitant and apprehensive at the beginning, pondering how the style of the intervention would influence change *“at first, obviously when they explained that it was sort of like playing and things like that, I was a bit like ‘oh how’s this going to make a difference’”*. As she engaged with the intervention, her ability to sustain mutual engagement increased. Jessica eloquently described PACT as a progressive journey *“it’s like going up the stairs every session you go up another step that’s how I felt”*. Similarly, other parents used terms such as *“as time went on”* and *“as the sessions went on”* or *“the more sessions you get more in tune”*. Indicating that parents acquired new skills in an incremental way, developing throughout the intervention, in line with the way in which PACT is implemented by the team.

Parents developed an awareness of the various ways in which they, or their children, were behaving that acted as barriers to communication with their children. A few parents noted that before the intervention they would anticipate their child’s needs too quickly, by reading their non-verbal cues, thus circumnavigating their child’s need to initiate verbal communication. Jessica noted *“why would she need to speak if I knew exactly what she wanted”*. Becoming aware of their own behaviours allowed parents to shift how they relate to their child *“giving more time”* or *“allowing space”* resulted in increased initiation from their child. Ben reflected on his role as father and teacher, he saw *“the good and not so good”* ways to encourage Jonathan to engage in play and recognised that traditional means were unhelpful *“oh yeah but you can’t do it like that mate, ..it was a case of ‘no’, you just let the child do it because he’s the child and I’m the grown-up”*. Parents described the process

of learning to understand their child's communication cues as they *'step into their child's world'* and *"letting them lead play"* or *"watching them more"* by *"finding their interests"*. Therefore, prior to PACT parents may have tried to initiate engagement through traditional 'rules' of play or *"natural ways of communicating"* and subsequently missed their children's subtle cues of communication. Through engaging in PACT, parents learned to appreciate and notice subtle forms of intentional communication, prompting parents to pay greater attention to cues, and seek out occasions that demonstrate their intention, likes and dislikes.

1.2 *'Follow their lead'*: Outcomes and increased emotional and relational connection

All parents described the play sessions favourably and spoke of acquiring knowledge and skills that enabled them to *"follow their child's lead"*, citing this as the biggest outcome of participating in PACT. Parents described working at their child's pace by being responsive to their behavioural and emotional cues. They also tailored the sessions by noticing and building on activities the children were initiating through making *"eye contact"* or *"backing into me"*. George reflected that *"looking at Richards response, and his non-verbal responses to things, you know when he looked like he was enjoying things, or when he would do things"*, a common experience across all parents. This suggests that the intervention, although requiring effort, was not only perceived as beneficial but also achieved its aims in encouraging parents to notice and attempt new ways to communicate with their child.

All parents recognised positive benefits and outcomes for both themselves and their children as a result of participating in PACT. Over the course of the intervention parents learned to sustain mutual engagement through the recognition of subtle communication cues which appears to have had a positive impact on how they relate to their children. Parents understand how what they pay attention and respond to, influences the way in which they

relate and communicate with their child. With increased skills influencing interaction and communication Sally noted that over time

Brandon was able to play more differently, we went from lining up to tea party, to involving someone else, so it was a shock...but it was through techniques that they told me to do, is introduce things slowly don't force it and it worked.

Parents noticed that their children have '*increased confidence*', recognised children's attempts at '*increased initiation*' and are '*more responsive*', likely due to parents having learnt and implemented the skills they have acquired through doing PACT over time. This in turn had a positive impact on children's behaviour and mood.

Through a process of learning and adaption to their children's communication cues, parents described the development of a closer connection to their children. Carrie explained that

even though Charles wouldn't sit down, I'd carry on reading it from the beginning to the end, because he would stop and you know even he would listen but not sit down, but now I've got him to the point where he will sit on my lap and actually let me read the book that he's holding now, so you do come a very long way with them yeah.

This newfound understanding of how, and in what ways, their child communicates has resulted in the ability to persist with engagement in activities with their child. Parents showed an appreciation of the improvements observed in their children at the end of the intervention. Some parents pointed out that the maintenance of skills continued beyond the end of the intervention with Carrie noting that "*you know the steps continue, you've learnt*

the basics of it, this is what you need to do to encourage communication". Furthermore, it fostered a greater sense of connection to their child.

1.3 Clinician Skills, Characteristics and Relationship Building

When parents reflected on the skills they had obtained through participation in PACT, they attested to the skills of the clinician in the delivery and enactment of the intervention. The clinician supported parents to feel contained within their therapeutic relationship. Jessica noted that

the things that have stuck are what needed to improve on but I didn't feel bad...if someone said to you, 'you're not doing this or this', I don't think it would be beneficial to a parent how they feel, but the way it was done was really positive

Parents' felt that the non-authoritarian, positive reflective stance that clinician's maintained throughout therapy was helpful, allowed them to receive any feedback without negative affect and enabled them to make improvements. Clinicians encouraged noticing of positive instances of communication thus increasing self-efficacy of skills, indeed there were many instances of parents noting the "*positive encouragement*" and "*positive feedback*" received during the intervention. This positive reinforcement is encapsulated by Julie who said

there weren't much feedback to be given um negatively you know,, making me more conscious about how I was interacting with him... to push me to do it more and to spend more time with him in these play scenarios.

Parents were appreciative of the collaborative stance of "*working with clinician*" who were often deemed as "*responsive*", not just to parents needs and differing ways of communicating but also to their children. Parents noted that clinicians had a good

relationship with their child, thus modelling responsivity to attempts their children made to communicate with them. Clinicians positioned themselves in the same boat as the parent, a couple of parents noted the “*clinician found it difficult to play with my child*”, no doubt further increasing parental self-efficacy. Parents favourably described the clinical relationship, appreciating “*the way we’d look into, and reflect on it*” and offered clarity of instances of communication via “*clear feedback*” which supported the development of understanding of their children’s communication needs by “*helping me understand what I should be looking for*”.

Parents commented on the clinician’s ability to recognise when they may need additional support to aid their learning, by going beyond the recommended reflective questioning to offer guidance. Parents noted that “*you know you’ve got the support*” and that clinicians “*gave advice*” or if “*struggling would comment and suggest things*”. Clinicians offered this guidance with gentle observation, with many parents echoing Carrie’s statement that

“if she’d [clinician] pick up on something, and she’d point it out on the video and say, ‘oh look Charles was doing this on that certain part, and you know he really took interest in that’”

All parents cited several characteristics such as “*enthusiastic*”, “*openness*” and “*honesty*” that contributed to the overall tone of the learning environment and development of a trusting relationship. Building a successful and strong therapeutic relationship has been highlighted as an important feature to encourage willingness to engage in interventions (Feldstein & Glasgow, 2008). Many parents noted that their relationship was “*brilliant*” and that they felt “*at ease*” because their clinician was “*easy going*” and “*friendly*”. The ability of clinicians to build a positive therapeutic relationship ameliorated negative affect

experienced by some participants, for example Carrie noted that “*she would always make you feel at ease so you didn’t feel guilty*’ and George noted that “*she’s just got the type of personality that I don’t think you could fail, I don’t think you can not want to do something that she wanted you to do for the benefit of the child*”.

One parent felt that this may have hindered the process because “*she was fantastic and brilliant, but maybe the relationship was too good where he was too comfortable....she didn’t get to see what he’s like outside of the sessions*”. Suggesting that they considered the intervention as lacking insight into the difficulties they perceived outside of familiar environments.

Several parents described that approaching video feedback with a positive attitude enabled them to learn from it, Carrie who thought “*it was important to work as a team and not to take it like an offence*”. Other parents talked about the need to ‘ask questions’ when they had reached the level of their understanding and had done “*everything they could think of*”. Suggesting parents place the clinician in the role of the “expert” and consider it important to remain openminded and unafraid of requesting help when needed. This characteristic of placing “*clinician as expert*” made it more difficult for a few parents to fully engage with the process of parent-mediated training, as a few spoke of wanting “*more guidance*” or “*more suggestions of what to do*”. It is possible that those parents may not have fully understood, or have the capacity to participate in, the intervention as a self-reflective, collaborative process. Nor did they fully understand that the skills they developed through PACT were generalisable across situations and environments.

Evidently, clinicians were able to facilitate learning through a collaborative approach, thus fostering a productive learning environment which largely bolstered parental self-esteem and self-efficacy.

2. *'I can't see another way of doing it'*: Components, Structure and Effectiveness

This theme captures participants' perceptions of the most salient element of PACT and describes parents' views of the components and structure of the intervention, barriers and facilitators to engagement and their overall experience of participating in the PACT intervention.

2.1 *'I didn't notice until I watched the video's'* – Overcoming emotional barriers, guidance and reflective feedback

This sub-theme captures the way in which all parents experienced self-conscious awareness at the beginning of the intervention towards being filmed and found ways to overcome their initial barriers to engagement. In the therapeutic space formed with the clinician, parents engaged in self-observation and appreciated a more distant perspective of their parent-child relationship. Therefore, a salient aspect for parents was their affective attitude towards participation in filming and video-feedback. The affective component of attitude refers to the emotions and drives stimulated by the prospect of performing the behaviour, in this case the process of being filmed playing with their child and the subsequent reflective feedback with clinician. Many parents initially perceived enhanced scrutiny and expressed initial feelings of “*pressure*” “*awkwardness*” “*apprehension*” and “*uneasiness*” at the prospect of being filmed playing with their child. Maria described that initially “*the first few sessions..you were a bit like 'oh well I've got to do something magnificent here, I need to perform for the camera..try too hard'*” but after engaging in the process and working alongside the clinician discovered that “*after a few sessions you forgot it was there...you know there was no pressure*”. Two parents commented that they felt “*fine*” about being filmed and didn't experience any negative affect, largely due to the positive relationship they

had already built with their clinician and the view that *“playing and communicating is natural and automatic”*.

Parents overcame their initial apprehension in a number of ways. Firstly, with a combination of a selfless attitude and desire to do the best for their children, illustrated by Jessica who shared that *“my daughters needs are more important than mine”* and Carrie who noted that *“you always think about your child first and not my own feelings”*. Secondly, through repeated exposure and habituation parents *“get used to it”* and *“forget the camera is there”*. Thirdly, the clinician facilitated a positive environment conducive to learning through play as Sally shared *“I found it quite easy, quite relaxing, they sat down with you first, talk to you to make sure your child was nice and relaxed, that I was relaxed and then they start”*. Lastly, the process of watching and reflecting on the interaction with their child facilitated the development of a new perspective and new feelings as described by Ben who noted that *‘I didn’t like seeing myself back, no..you got to see what worked for Jonathan, what we did that worked for Jonathan...I loved every minute of it because it was so educational for me..’*

However, for Ben’s partner, Elizabeth, her negative appraisal of being filmed remained constant *“nobody likes being videoed, so I was happy to sit out of them, that’s the thing that maybe put me off going to so many sessions because I didn’t want to sit there and watch myself”*. Through active non-engagement with the process, and stepping back to allow her husband to participate, Elizabeth was unable to habituate to the process and find new meaning.

All parents spoke of not being aware of all the communication cues their child displayed prior to engaging in the PACT intervention. Watching the video enhanced their ability to notice and consider the interaction between themselves and their child, parents

observed what they missed in the moment and reflected on their interactions in a useful and helpful way, illustrated by Julie's that *"you were able to see how you're interacting with your child um, able to see actually how happy your child is ..that maybe you don't notice at the time"*. Through close observation of the parent-child interaction, parents increased their understanding of their child's attempts to initiate communication by becoming aware of *"facial expression"*, *"eye contact"* and *"small vocalisations"*. Maria reflected that *"watching the video back you'd see a lot that...in the moment playing with him I hadn't actually noticed"*. Parents increased their effort to attend to their children as George noted that after watching the interaction *"you'd start watching Richards response to things a little bit more closely"* and Elizabeth noticed the *"things we missed, gestures, his way of saying something"*. Parents also increased awareness of aspects of their own behaviour that supported or hindered effective engagement with their child commenting that they *"pushed too hard, did too much"* and all parents made reference to noticing the *"good"* and *"not so good"* ways in which they interacted with their child. Parent's perceived that this new information *"helped us improve"* and sally commented that *"I had trouble playing with him to begin with and I didn't notice until I watched the video's...I was able to change it made it a lot easier for me then cos I realised I had to watch him"*.

Interestingly, all parents referenced that despite those initial feelings of discomfort, the filming, observation and feedback was an integral part of the intervention and a necessary torch that shone a spotlight on their interaction. New information available to them facilitated a change in attitude and behaviour that was threefold, towards their child, towards themselves and towards the process of filming and feedback, as described by Jessica

'I can't see another way of doing it...to try and look back after even two minutes afterwards you won't be able to recall as much as watching it, without filming you can't see what could be improved'.

Several parents described that they approached feedback with a positive attitude which enabled them to learn from it, described by Elizabeth

“You’ve got to look at the positives, there’s no point in you sitting there looking at all this feedback and going ‘we did that wrong, we couldn’t do that’ because you’re never going to get anywhere”

However, many also spoke of the way in which their *“child disrupted the process”*, having received positive attention from their parent during the intervention they then continued to seek attention when the parent was watching back the video with their clinician. Some parents had partners to entertain their child whilst others used distraction, albeit with varying success with Elizabeth noting that *“feedback easier with two, could sit and entertain for them to go back over it”*. For most, the delivery of feedback was an acceptable process, George noting that *“it was always quite clear”* and others deemed it *“fascinating, lovely, interesting and helpful”* especially when *“pointing out things I had missed”* as described by Maria. Further evidence that the clinician showed skill in balancing reflective guided discovery with understanding the parent’s capacity for reflection. However, Elizabeth said the feedback wasn’t enough, *“could of done with looking back and just going over to see what’s improved on that struggle”* suggesting she needed more feedback to fully understand the improvements. Some parents also felt that a written report following the intervention would be a useful memory aid to the skills and gains made through participating in the intervention.

Parents affective attitude towards being videoed playing, watching and receiving feedback changed as they engaged with the intervention and new information emerged, parents recognised the benefits of PACT and after just a few sessions habituated to the process of being filmed, facilitated by clinical skill in fostering a positive learning

environment. Through guided discovery they learned the communication cues their children displayed, which enhanced attuned interactions through greater reciprocal action. Parents highly valued filming and feedback as a necessary and integral element for recognising their own attempts at communicating whilst gaining an understanding of their child's communication needs.

2.2 Components and Structure of PACT

Prior to engagement in the intervention all parents were introduced to PACT through receipt of an initial information pack and brief introductory session at their home. Parents views towards the information were mixed, for some it prompted the need to "*look for local information*" whilst others "*searched the internet*" to bolster their understanding. Some parents valued evidence-based research explaining the benefits of PACT and a few parents were keen to have more local information explaining how the intervention would be implemented in their local health board.

Most parents received PACT at home and were appreciative of being able to receive the intervention in a familiar environment, parents cited the home as a "*place of safety*" where you were likely to get "*more natural interaction*" because children were described as "*less anxious*" and "*more relaxed*" in a familiar environment. Parent's felt "*valued*" and the home was considered a less clinical and more naturalistic setting within which to conduct the intervention. For one family the home environment was not conducive to PACT as it was "*too busy*", therefore they received the intervention at the clinic which they found a positive experience. Flexibility appeared to be key to families in relation to the delivery of the intervention.

The home practice and record keeping component of the intervention received mixed reviews with parents citing barriers and facilitators of successful home practice with a

dichotomy emerging between those who found the home practice ‘easy’ and those who found it ‘hard’. Facilitators of home practice were centred around “*time*” and “*flexibility*” with all parents citing that weekends were generally easier. Most parents adopted a flexible approach to fit in practice “*as and when*” or they found what works for their routine and family structure. Some parents noticed how home practice became easier over time as emphasized by Sally who commented that “*30 minutes was easy..after a bit I was able to increase it and do 30 minutes in the morning and then 30 minutes at night so I was able to add to it*”. Further indicating that their ability to remain in mutual joint attention with their children increased over the course of the intervention.

Barriers to participation in the home practice included factors relating to their child and external pressures. Maria felt that “*when you are both working and you know you’re trying to juggle everything it is hard to find that time*”, an experience echoed by many parents, especially when other children require attention. Child personality and emotional factors that affected home practice were cited by some as reasons not to participate for example George cited that

it was a like a no now win situation, if you try to do things with him he’d get annoyed because he wasn’t having his tea, or if you give him tea his bath and then try to do things, he wouldn’t do it then, wouldn’t be interested because after his bath. He’s got his jammies on and stuff like that, he just wants to relax so we just struggled to fit it in in any sensible way that would help him

Some parents described a negative affect when reflecting on practicing the skills when their children “*aren’t in the mood*” or “*don’t want to do it*”, therefore still at times finding communication “*difficult*” and “*frustrating*” and feeling like a “*failure*”. Ameliorating these

barriers parents found flexible ways to engage in practice by “*splitting it down into smaller chunks*”, “*involving their children*” or simply by “*staying consistent*”.

All parents struggled to make a written record of their home practice finding this burdensome within the constraints of busy family life. Higher value was placed on ‘doing’ the practice rather than ‘writing’ about it, as emphasized by Maria who shared that

“it was better that I was doing it than, you know, I could of filled out the form and lied, but it was better that I was actually doing it and not filling out the form”.

Overall parents showed good intervention coherence, understanding the process and different elements of the programme well.

2.3 Unmet Needs and Expectations, Grief and Loss and the Endorsement of PACT

Parents expressed a dichotomy when they considered the intervention dosage and the ending of PACT, for some it “*ended abruptly*” and created a sense of loss but others found it “*opened doors and avenues*” to other support. Some parents experienced a sense of loss, having built a strong connection through intense weekly contact with an experienced clinician, as Elizabeth laments

“because that gave us so much positive, so much that helped, so much, and then once it was finished it was finished there was the door, wasn’t even open, it was there you go, you’re gone”.

Other families experienced the ending differently and the feelings of loss were ameliorated by the gradual distancing of gaps between sessions, as Sally noted that “*it was once a week, and then to every two weeks so it didn’t just stop, it reduced before it stopped so I think it was perfect*”. In addition, a few parents experienced the ending as a lack of continuity and were

concerned that any progress made was hindered by the lack of follow up, disappointed by the lack of communication after PACT ended Elizabeth felt that “*since he finished with [pact clinician] we’ve had no feedback, I just think there’s a lack of communication after as well is very poor*” and George shared that “*any progress made has not necessarily been able to be pushed forward because of the lack of follow up, I suppose that’s the biggie*”. Suggesting that further follow up would help them to notice their skills and build on any progress made.

In addition to feelings of loss parents also discussed unmet needs and expectations, with the main expectation being that their child would be able to talk. Parents talked about how they may of misunderstood the aims and have different expectations to that of the clinician as Carrie highlighted “*at the beginning I was a bit naïve and thought at the end he might start talking but that was obviously my misunderstanding*”, indeed George felt that although progress was made he was left with unanswered questions stating that

nobody can give us sort of an answer as to why he’s not speaking, obviously it helped bring him on in terms of um sounds he makes but nothing in terms of as I say changing those noises into words and we just don’t understand why

Despite some negative affect towards participating in filming, a need to seek further information to understand the intervention more fully, and disappointment at initial needs and expectations not being met, there was an overwhelming sense of growth and positivity towards the intervention. Throughout the interviews all parents endorsed PACT in several ways highlighting the positively perceived effectiveness of the intervention. Some parents reflected on the impact that PACT had on their children’s development as Ben declared that ‘*I don’t think he’d be the same child today if he hadn’t had that [PACT]*’, whereas others shared the positive emotional reaction their child had to the intervention as George encapsulated with this sentence, “*it was done mainly through play so he obviously enjoyed*

that and was good to see". Carrie further highlighted reasons why she would recommend the intervention, *"if they have a child who has no interest in you know, um relationships or wanting to be alone and not taking an interest in toys I'd definitely recommend it and do it again"* indicating the effectiveness of the intervention in strengthening the child-parent bond. Maria echoed the helpfulness of the PACT intervention for both parent and child by stating that *"I think for Robert it's definitely helped...having the PACT has been really really helpful for us"*. Sally reflected on her personal feelings towards PACT sessions *"They were really good I was more than happy with them I'd do them all over again because they help"* whereas Elizabeth endorsed the strength of the relationship with clinician *"she was like a relative he was going off to play with his aunty, she was fantastic with him"*. Jessica advocated for the service to continue *"I think it's a really good project and I think it should be there for the long run"*. These endorsements of the PACT intervention were scattered at different time points throughout all of the interview transcripts, showing the overall strength of acceptability of the intervention to parents included in this study.

Discussion

This is the first study to explore how acceptable the PACT intervention is and provides a unique insight into parents' perspective of the intervention and is intended to enhance the understanding of how the implementation of PACT is perceived within a community setting. The aim was to understand the successes, challenges and outcomes that parents experienced when considering the acceptability of the intervention. An inductive process was chosen to produce a rich and broad understanding of the perspectives of parents, allowing for novel and unanticipated instances. The concept of 'data saturation' is hotly debated within the thematic analysis research and have ranged between six to sixteen interviews, however this is not consistent with the values and assumptions of reflexive thematic analysis (Braun & Clarke, 2019). Whilst there is no concrete guidance for

determining how meaning is generated through interpretation of the data, sufficient depth of understanding was found within the quality of the data collected with the eight participants interviewed. All codes and reported themes were evident in all interviews and discussions with colleagues working in the field of ASD interventions and qualitative research elucidated that the themes rang true, based on their professional opinion. Results suggest that PACT is a highly acceptable intervention, parents' remarks were largely positive and indicative of acceptability constructs. A few parents struggled with some elements of the PACT process, considering it challenging given the constraints of family structure and unmet needs and expectations. Arguably, this could reflect a poor fit with parent's value base and expectations for their children. Implementation processes such as coaching and intervention strategies were indicated in the interviews conducted, as were contextual factors relating to where, when and how long the intervention was delivered (Blasé & Fixen, 2013; National Implementation Research Network). Parents' perceptions on constructs within the Theoretical Framework of Acceptability outlined by Sekhon et al., (2017) provide information regarding whether PACT was deemed an acceptable intervention and in what way. Therefore, it seems pertinent to discuss the findings under the framework headings to provide an overview as to how acceptable parents found the intervention.

Intervention Coherence

PACT is designed to enhance parent's ability to notice and act on children's interests, body language, verbal and non-verbal communication (Green et al, 2010). Parents in this study also referred to gaining this awareness, suggesting they understood the premise of the intervention, further supporting post-intervention reports from the initial PACT trial in which parents also noted increased attention and communication (Green et al., 2013).

Within the intervention there are multiple levels of implementation that include clinician-child, clinician-parent and parent-child (Wainer & Ingersoll, 2013). Although parents refer to all three levels of implementation within their accounts of the PACT intervention, they mainly recount the clinician skill in relation to themselves and their child. Barton and Fettig (2013) indicate the manner in which parents are coached is very important for parent engagement. In this study parents valued the collaboration and partnership built with their clinician. However, despite this approach being considered more effective than the didactic teaching, some parents expected more directive information and guidance (Kemp & Turnball, 2014).

Parents understanding of the intervention appeared to evolve as they engaged with it over time. Initial information packs and discussion with clinician led parents to seek further information through their own means. Some parents thought that local information relating to the intervention would be a useful addition to the information packs and allow them to fully understand the process better. Some parents expressed their naivety towards their understanding of outcomes, expressing that they thought their children would be talking by the end of it, suggesting that initially, they may not have fully understood the subtle ‘communication’ cues the intervention was intending them to pick up on. One possible reason for this is that nonverbal children are less likely to make conventional communication (e.g., verbalisations, pointing and gesturing) than typically developing children and parents of children with disabilities tend to be more directive (Mederios & Cress, 2016) and less responsive (Roach, Bareatt, Miller and Leavitt, 1998). Infrequent, idiosyncratic and unclear communication is less easily recognised by parents (Doussard-Roosevelt et al., 2013). By the end of the intervention they understood it was to encourage the ‘*building blocks*’ of communication that support speech development, increasing their responsivity to their child’s communication cues, further suggesting good intervention coherence. Parents fully

understood the process of the intervention, why filming and home practices were necessary aids to learning communication cues and embedded the skills necessary to enact the intervention.

Perceived Retrospective Effectiveness

All participants endorsed PACT as useful and worthwhile and considered it to be an effective intervention that they would gladly repeat. Consistent with previous qualitative studies of parent-implemented interventions, factors that influenced parents perceived effectiveness included the style of the clinician coaching, helpfulness of feedback and the strength of relationship and interactions with the clinician (Freuler et al., 2014; Stahmer et al., 2011; Stahmer et al., 2017). Parents perceived that the intervention increased their ability to notice their child's communication cues, strengths, and abilities to communicate as well as developing the skills to facilitate their child's learning of communication (Bailey et al., 2006). They considered the intervention to have a positive impact on their children and increased instances of child-initiated communication and parental responsivity to sustain engagement in mutual attention through play (Green et al, 2013). Parents noted that the most useful strategy they learned was to 'follow their child's lead', which is also in line with previous qualitative findings (Stahmer et al., 2017). Parents perceived positive outcomes for themselves and for their children, both behaviourally and emotionally. This corroborates findings from previous parent-mediated interventions that showed parents perceived the intervention to be effective (Bradshaw, Steiner, Gengoux & Koegal, 2015) and result in improved child outcomes (Brown & Woods, 2015; Rogers et al, 2014; Shertz, 2013; Siller et al., 2013). Concrete observable changes at the parent-child dyad has been shown to be a contributing factor to its effectiveness and this is supported by parents' perceptions of the intervention (Fukkink, 2008).

However, a dichotomy emerged in that some parents' expectations were not met by the end of PACT, particularly in relation to speech abilities. Furthermore, the ending of PACT received a mixed response. Parents who received a staggered ending and ongoing support perceived it effective, and those whose sessions ended abruptly with no further follow up perceived the intervention as negatively impacting on their child's ability to progress.

Affective Attitude and Self-Efficacy

The implementation style of the clinicians positively reinforced parents sense of self-efficacy in participating and using the skills taught during the intervention and adds to the literature base highlighting the importance of the strength of the relationship to encourage willingness to participate and influence self-efficacy (Feldstein & Glasgow, 2008; Dunst & Dempsey 2007). Parents believed that they had the skills and abilities to implement the intervention and they overcame barriers to engagement (Damschroeder et al., 2009). Some parents cited that they were able to carry out the intervention after PACT had ended and were encouraged to continue with home practice by the positive response of their children, thus increasing self-efficacy. However, some parents became discouraged during home practice when their child didn't respond positively towards their efforts, therefore, the interactions became an important factor in moderating self-efficacy (Trivette et al, 2010).

Despite initial apprehension towards being filmed playing with their children and watching the feedback, parents' affective attitude towards these elements of the programme were altered through exposure to the intervention. Within the first few sessions negative initial appraisals dissolved and made space for more positive affirmations through the process of habituation, with all parents expressing positivity towards watching their interaction and receiving feedback. Through discussion, parents were able to pay more attention to the parent-child interaction. This was facilitated by the nurturing, reflective and positive

relationship parents developed with their clinician. It is thought that video interactive guidance promotes empowerment by strengthening skills in interaction and communication and is dependent upon the quality of relationship between guider and client (Cross & Kennedy, 2011).

Parents reported overall positive perceptions towards their engagement with PACT and expressed that their children also enjoyed the sessions. There appeared to be a positive skew towards the intervention, whilst participants cited many reasons for positivity it is worth noting that interviews were conducted with those who chose to participate and completed the intervention. No children had a diagnosis of ASD when they began the intervention which may have provided participants with a source of support, encouragement and skills development whilst they awaited a definitive answer to their children's presenting difficulties, which likely contributed to the

positive affect towards the intervention. Negative affect was evident towards the perceived lack of ongoing support that some participants encountered and through expectations for enhanced verbal ability having not been met by the intervention. Parents whom were still awaiting diagnosis discussed feeling as though they were in 'limbo' and described a sense of abandonment, this may be due to the lack of available services for those without a diagnosis and the abrupt ending to the intervention.

Burden

Some parents perceived the intervention as effortless whilst other parents perceived engagement as more effortful at the beginning of the intervention. As they became more skilled in synchronous responding so too did their perceived ease of engaging in the intervention. Families cited employment, family circumstances and child factors as impacting on their ability to engage in home practice and struggled to find the time to

implement strategies, as noted by previous studies (Frueher et al., 2014). Parents who adopted a flexible approach to implementing the skills also appeared to be able to generalize the skills to everyday circumstances rather than focus on a rigid home practice timescale. Dunst & Trivette (2009) found that the more relevant the intervention is to the parents' context the more likely they are to adopt the intervention, for busy households this may be difficult to achieve without the flexibility to generalize skills to daily routines and external settings.

Clinical Implications

The findings in this study highlight some important considerations when implementing PACT within a clinical community setting. The information provided to parents at the beginning of the intervention could be bolstered with localized information regarding the service and links, include information about the research background and benefits to families and children. Expectations may not have been explicitly explored and discussed at the start of the intervention, leading to misconceptions of the expected outcome of PACT therapy. Joint planning at the beginning of intervention may serve multiple functions; making expectations clear and explicit, set the stage for active participation and allow concerns in relation to negative affect with regards to filming to be explored (Branson, 2015). This may potentially increase parental capacity for engagement and self-efficacy, particularly for those parents who decline the service following the initial session.

Previous literature advocates the role and strength of the clinical relationship as vital for intervention acceptability and implementation buy-in (Frueher et al., 2012; Stahmer et al., 2017). Interestingly, early intervention practitioners viewed collaboration as helping parents meet goals whereas parents valued listening and working together (Campbell, 2009). The strong, collaborative clinical relationship has been highlighted by parents as a mediating factor for increased self-efficacy and engagement with the intervention. They were praised

for their friendliness and positivity and balanced self-reflective practice with helpful suggestions when parents became stuck. If PACT is to be rolled out within routine clinical care, it is important that practitioners receive training and supervision in positive reflective practices that enhance collaboration and reduce didactic teaching.

Parents experienced a mixed level of success practicing strategies at home, applying them to daily routines and generalising them to external situations. Successful implementation of skills practice within daily routines is important and necessary for ongoing child language development and children are more able to generalize skills when interventions are integrated into everyday life, routines, activities and play (Dunst, 2001; Rogoff, 2003; Shreibman et al, 2015; Wetherby et al., 2014). Clinicians may benefit from spending time with families to consider how generalisable and adaptable skills are beyond the play scenarios enacted during the implementation of the intervention.

Furthermore, parental responsivity research suggests this is a dynamic skill changing in response to children's developmental stage and ability to initiate (Branstein et al., 2008) and studies have shown that when the parent coaching element has been ceased the child had no further gains (Brian, Smith, Zwaigenbaum, Roberts & Bryson, 2016). In a follow up mediation study to the initial PACT trial, change in child behaviour was due to increased parent synchronous behaviour via treatment delivery (Pickles, et al., 2015). This stresses the importance of the reflective feedback element of PACT. Following children across time to enhance gains made during the intervention may help to refresh parental skill and responsivity to their children's' communication cues. Indeed, some parents suggested that further follow up and refresher sessions would be beneficial.

Limitations

There are a number of limitations regarding this study. Firstly, despite numerous attempts to reach out to families who had initially received a PACT initial session and later declined, this study sample consisted of those who had engaged and completed the PACT intervention. As a result, this study may only include those who are motivated to engage in parent-mediated interventions and experienced fewer barriers to participation. Therefore, the views of why people may have chosen not to participate in PACT have not been represented within this study. Secondly, although parents endorsed PACT, citing the development of new skills and behavioural and emotional outcomes for both themselves and their children, this was not explicitly measured. Therefore, parents' views must be taken as anecdotal evidence of the outcomes of PACT. Thirdly, views were sought retrospectively, and parents may experience recall bias which could influence the accuracy of the details they provided. Lastly, participants in this study were a small convenience study within a rural area of Wales with a strong Welsh language heritage. There are likely be cultural differences in the way that PACT is implemented within Wales, therefore the findings cannot be generalised to other users of PACT from other cultural background.

Chapter 3

Reflective Paper

Contributions to Theory and Clinical Practice

The research presented in this thesis focused on exploring implementation and intervention fidelity factors in parent-mediated interventions (PMI) for children suspected or diagnosed with ASD. The literature review investigated how PMI research studies reported and measured elements of intervention fidelity and scored the methodological quality of their reporting practices. The empirical paper explored the acceptability of PMI with parents who had participated in Paediatric Autism Communication Therapy (PACT). This paper combines the findings together to report on 1) implications for future research 2) clinical implications and 3) personal reflections.

Implications for future research

Within recent years the prevalence rate of diagnosis for ASD has been steadily increasing. There are several purported reasons for this including the advancement of diagnostic measures and procedures, changes to the diagnostic criteria, increasing public and professional awareness and the screening of children with siblings already diagnosed (Matson & Kozlawski, 2011). This increases the demand on early intervention services within NHS and community services. Thus, requiring high quality research into robust and innovative service delivery models in order cater for the demand and complexity of services. There is a growing evidence base of the efficacy of PMI to increase access to services for young children with ASD (Neville et al., 2018; Oone et al., 2013). Findings from both the empirical paper and the literature review highlight the dearth of literature relating to implementation and intervention fidelity in PMI.

Understanding the link between intervention fidelity components and treatment outcomes

The PMI literature base clearly evidences the efficacy of PMI for children with ASD, yet the literature review showed there was a lack of reporting intervention fidelity components.

Despite the advances in implementation science literature, there is no consensus on how to measure intervention fidelity at the parent level (McConachie & Fletcher-Watson, 2014). Research studies lacked consistent data collection methods in relation to parent delivery to their child; dose, mastery of skill and especially mediating and moderating factors such as responsiveness (social validity, parental satisfaction, family wellbeing and stress and changes in parental confidence). Those that did collect data often utilised self-report measures to report on changes at the parent level, therefore were not blind to treatment conditions or group assignment raising questions of the validity of reporting. Furthermore, these measures were rarely linked to outcomes so the impact of parent fidelity could not be determined. Additionally, the literature base lacked reporting long-term follow up, essential to understand the long-term benefits of parent-mediated interventions. Studies showed that parents did not maintain outcomes at follow up, but children did (Pickles et al., 2015; Kasari et al., 2013). Without reporting fidelity at the parent level, it is impossible to determine optimum dose for parents to adequately learn and maintain the skills required for ongoing delivery to their children. Therefore, it is recommended that future studies concentrate on measuring and reporting dose and quality of delivery at the parent to child level in order to understand the links between parent delivery and child outcomes.

Individual characteristics, context and rates of attrition

Highlighted within the research there is a vast array of parental characteristics and contextual factors that may influence the generalisability of PMI (Trembarth et al., 2019). Both the literature review and the empirical paper highlighted potential individual characteristics that may mediate and moderate the impact of PMI for example higher parental insight was associated with improved outcomes for children (Siller et al., 2013). Kasari (2010) and colleagues found that parental self-report competence and skill implementation didn't predict outcomes, whereas clinician rated quality of interaction during sessions did. This suggests parents may over-report their competency and skill level to appease the clinician.

There were also anecdotal differences observed during the interviews between parents who wanted more directive support and those that enjoyed the exploratory nature of the PACT intervention, this may be in part to differences in baseline insight. These individual differences may impact on parents' ability to engage with the intervention and influence how the intervention is adjusted by clinicians to meet individual need which could account for the high attrition rates that were reported in the literature (albeit selectively). There are no studies which have examined how parent characteristics may impact treatment fidelity.

Some studies have shown that language gains are greater for children when the clinician and parent delivered the intervention in tandem. Parents appear to benefit from modelling, resulting in greater quality of skill enactment (Hampton, 2016). Studies that compare parent-mediated intervention to parent plus clinician mediated intervention may help to answer some of these questions and improve flexibility of the intervention to meet parents' needs, expanding knowledge of characteristics of families that do (or do not) respond to interventions.

However, attributing specific training practices (e.g. reflective feedback, modelling skills, self-observation) to high fidelity parental implementation of the intervention is difficult to assess (Barton, 2013). Examining the moderators and mediators of outcomes would require large sample sizes which are difficult to fund and coordinate. Nevertheless, these factors can have implications on the way in which interventions are delivered in practice. The literature lacks formal theories on the mechanisms underlying effectiveness, potential mediators and moderators that affect intervention delivery and how these interact with implementation context in both research and clinical settings (Vivanti et al., 2017).

Clinical Implications

Families in Wales are parenting their children within rural locations, the literature shows that parents in rural, compared to urban areas report barriers to engagement and lower treatment

gains (Hogsteen & Woodgate, 2013). Access to services may be limited due to transport issues, long waiting lists for diagnostic appointments and high staff attrition rates resulting in inconsistent service delivery. These issues were all highlighted as potential barriers to services during the interviews with parents and is supported by literature on rural ASD services (Murphy & Ruble, 2012; Hutton & Caron, 2005).

PMI studies reported that parental mastery of skill reached optimum level towards the end of intervention, after seven to eight sessions (Cassenheiser et al., 2013). The literature suggests that when parents implement the skills with higher frequency and quality the result is improved outcomes for their children. This has implications for services which are intending to implement low dose PMI in a clinical setting in order to maximise the potential of overstretched resources. Indeed, PACT is delivered in a local service at a low dose of six sessions and it may take parents longer than the length of intervention to gain the skills required to implement it with their children. Clinicians should consider the range of factors that may impact parent skill mastery and influence outcomes within their community.

Clinicians response to individual difference and the implementation of PMI in practice

To ensure the adoption and implementation within community settings we must look to implementation science to address the gaps (Vivanti et al, 2017). Clinicians often question the validity of research trials given the complexity of their caseload and heterogenous client group (Stahmer, Suhrheinrich, Reed & Schriebman, 2012). Part of my research process was dedicated to hearing the views of clinicians delivering PACT. I was unable to include the data within my research study because the ethical approval process was slow and hampered my progress. I conducted two focus groups; one with clinicians and one with two clinical psychologist service leads. The clinicians included an assistant psychologist, a speech and language therapist and a speech and language technician. I was struck by the overwhelming commitment that clinicians

showed towards the PACT intervention and the difficulties they endured in order to embed PACT into routine practice. The staff highlighted a range of issues they faced in attempting to encourage families to participate in home practice of the strategies and the reluctance of some staff members (not present at interview) to buy-in to the intervention. Issues raised include the substantial time commitment that the intervention requires (for both parents and staff), embedding the service into routine clinical care, lack of appropriate resources to carry out the intervention and reluctance on stakeholders to purchase the equipment. Differing perspectives towards the intervention that is intended to be adopted by the organisation can make the process of integration into routine clinical care more problematic (Damschroder et al., 2009). Clinicians may feel reluctant to try a new technique or feel unable to utilise training without appropriate supervision. Others may actively discourage team members from using the technique or deny parents the opportunity to participate with their reluctance to deliver the service. Gaining stakeholder perspectives in implementing new interventions is challenging. Clinicians may be faced with issues relating to organisational leadership, funding and resources. There may be a lack of commitment from staff and a need for supervision that makes it difficult to deliver the intervention (Stahmer et al., 2011; Green 2012). It is important to investigate factors such as the commitment from professionals and organisations, clinician skill and intention to embed the intervention effectively within the organisational culture (Vivanti et al., 2017).

During the interviews with parents I was struck by the broad range of characteristics that parents displayed, the differences in their reflective abilities and individual requests for more direction. Lack of knowledge with regard to family-level moderators may influence the ability to translate research to clinical practice (Wainer, Hepburn & McMahon Griffith, 2016). There is a need for interventions to be flexible in their methods of delivery to adapt to these individual differences. Joint planning at the beginning of the intervention phase would increase opportunity for clinicians and families to make informed decisions about their choice of treatment and the

adaptations that may be necessary for success (Branson, 2015). Adhering too rigidly to the intervention as described in the research could make it more difficult for parents to engage in the process. One strength identified in the PACT intervention was the ability of clinicians to build a positive relationship with parents, which is vital for the acceptability and parent buy-in (Freuler et al, 2012; Stahmer et al., 2017). There were a broad variety of interventions reviewed within literature review, for example, teach-model-coach-review whereas others utilised video feedback to help parents learn and reflect on how they were interacting or implementing the strategies, other models taught skills usually delivered by clinicians (e.g., P-ESDM). Utilising a community-based participatory research design to form a collaboration between researchers and community stakeholders would enable the development of research focusing on design, implementation and outcomes (Jones & Wells, 2007).

Diagnosis – the key to services?

One theme that emerged from the interviews that is important for services to be aware of was the perception that parents held towards diagnosis. Parents were at different stages in the diagnostic process and some believed that attending PACT helped them to circumnavigate the system by receiving a diagnosis more quickly, whilst others were still waiting or had an assessment appointment out of area. Those that had a diagnosis believed this had supported them to access services quickly whereas those that were waiting felt a considerable burden, with one parent commenting that they were still ‘*in limbo waiting for their life to start*’. This dichotomy seemed to impact on parental stress (BMA, 2019). Higher stress levels can impact on parent’s ability to participate effectively within the intervention (Kazdin & Mazurik, 1994; Osborne, McHugh, Sander, & Reed, 2008). Attending to parental wellbeing is as important as considering child’s needs, family systems perspective to factor into decision making and intervention (Head & Abbeduto, 2007).

COVID-19 and the impact on PMI

PMI are mainly delivered face to face with parents and children or delivered in a mixed approach with a combination of group-based intervention and 1:1 delivery. In rely on a variety of methods to engage the parents including modelling of skill, coaching, facilitative feedback and video-interactive guidance. Parents of children with ASD report higher levels of stress, greater emotional problems and more frequent arguments (Weiss, Wingsiong & Lunsky, 2014). It occurred to me whilst writing my thesis that the parents I met collecting data for my empirical paper gained support through external sources or PMI and may be at increased risk for isolation and an increase in stress (Weiss et al., 2014). Parents in the PACT intervention expressed a sense of loss when the support and relationship they built with their clinician came to an end. Furthermore, clinicians sited 'time, resources and long waiting lists' as reasons for shortening the recommended dose of PACT to parents. Turning towards the literature base on PMI delivery in telehealth may be one way that services can adapt and respond to the current crisis and continue to support parents' long term.

Technological advances have increased the ability of health service professionals to deliver services remotely for people with a diagnosis of anxiety and depression (Reger & Gahm, 2009; Spek et al., 2007). Telehealth has been used successfully within parent/caregiver education sessions (Wainer, 2015) and a systematic review of remote parent-mediated intervention training shows promising results for the future of delivering practices remotely to families (Parsons et al., 2017). Preliminary findings suggest that telehealth parent-training could improve social behavioural and communication skills for children with ASD. Greater effect sizes were seen for intervention outcomes that targeted parent's intervention fidelity skills (Parsons et al., 2017). Clinicians may wish to consider how they could adapt PACT for remote delivery to focus on maintaining parent fidelity to PACT intervention skills. This may ameliorate issues pertaining to intervention dose, clinician time and support through a crisis.

Personal Reflections

Reflections on the process

I first heard about the PACT project and potential research during our annual research fair. I was struck by how caring and considerate the project appeared to be. I had limited understanding of ASD, had an interest in neurological conditions and met with my research supervisors to discuss the project further. We began to design and develop a viable study, liaising between university and clinical team in order to develop something able to meet standards of doctorate whilst being a useful resource for the PACT team. This took a long time; the original project design would not have yielded enough statistical power with the number of participants and we wanted the research to be meaningful. We settled on an implementation study, the hope was that we could incorporate views of clinicians and participants to help uncover some of the facilitators and barriers to engagement. There was a lack of papers considering the responsiveness of participants to parent mediated interventions and clinicians were interested in how this intervention was received by parents when delivered within their own home. Carroll's (2007) definition of 'responsiveness' in the implementation literature is

Participant responsiveness measures how far participants respond to, or are engaged by, an intervention. It involves judgments by participants or recipients about the outcomes and relevance of an intervention. In this sense, what is termed "reaction evaluation" in the evaluation literature may be considered an important part of any evaluation of an intervention

This formed the basis of my search for a theoretical framework that matched the clinicians desire for understanding how their participants perceive the intervention and evaluated the reaction of participants to the intervention. The dimensions of Sekohl's (2017) theory of acceptability appeared to match Carroll's definition of 'responsiveness' in that it provided a

framework with which to consider the cognitive and affective attitudes of participants towards the intervention. I also considered whether the integrated framework behaviour change model, COM-B and the behaviour change wheel could be applied to the research question (Michie, Stralen & West, 2011). This model is used widely in health promotion and postulates that behaviour will occur when the person concerned has the capability and opportunity to engage in the behaviour and is motivated to enact that behaviour than any other (Michie et al., 2011). It was felt that whilst this model is helpful for considering the motivation of participants to engage in the intervention that was not the focus of the research and may miss important information relating to self-efficacy and affective attitudes which are also important factors to consider when evaluating how an intervention is received by participants. Ultimately the decision was a pragmatic one based on the needs of the service and available models.

In order for the project to be successful I needed to build links with differing clinicians pulling together perspectives of different specialisms including qualitative research and implementation science. Neither of which myself, nor my research supervisor, had a great deal of experience in. I gained skills in planning, organising and developing research ideas and was pleasantly surprised by my ability to draw teams together.

The delay in ethical approval on the one hand gave me time to familiarise myself with the literature and on the other produced hesitancy to start my literature review. I have never undertaken a literature review before and I wanted to make sure I was clear on the process before starting, and that I wouldn't need to do a different one if my project was rejected. In hindsight, starting the process much earlier would have been advantageous given the covid-19 effect. Nevertheless, I needed to develop the understanding and confidence to do it first. I believe I have developed in my abilities to synthesise a large and complicated body of literature.

I was humbled by the experience of listening to parents tell their stories of participating in PACT and enthused by the relationship they described with their clinician. It drew me to reflect on my own role as a clinician and the impact I have with those I work with. I was so determined to represent the voice of parents I struggled to let go of codes that I discussed with supervisors may be relevant to service delivery but not in the context of acceptability. Parents discussed the impact of not having a diagnosis on their family wellbeing and the sense of being left waiting in limbo as access to services heavily depended on a diagnosis. Whilst this is important for clinicians delivering PMI to know in relation to continuation of care it didn't fit with acceptability of the intervention and I had to let it go. I developed skills in qualitative interviewing, undertaking staff focus groups, managing emotional responses and encouraging space for clinicians to reflect. The feedback I received from clinicians in terms of the usefulness of the reflective space inspired me to consider the importance of group reflective practice.

Reflections on writing during a pandemic

It's less about 'how can I work from home' and more about 'how can we keep being happy at home while I'm working?'

The dawning of the new age of living in sanitary conditions coincided with the process of writing up my Thesis. Not only was the world experiencing collective trauma, I had my own brewing, our vulnerability only too obvious. I was already on the back foot due to a delay in receiving ethical approval highlighting issues within the university system. My son is 14, he is asthmatic and was considered within the high-risk group, he was anxious and afraid after the media coverage hammered home the respiratory problems people with a diagnosis of covid-19 were experiencing. I was told that this is the perfect time to write your thesis, you can't go out anyway, so I began the process with one simple question "how *can* I keep working from home?". I had to find a new way of studying, a new way of supporting my family, a new way to arrange

our living space so we could all work together on our respective projects. The process wasn't smooth, tension ran high, my partner is not used to children and we were forced together whilst still trying to find a rhythm in our relationships. My role in the home changed and expanded from mum to include peacekeeper, teacher, clinician and doctoral student; ultimately blurring the boundaries of who I was and when. This lack of separation left me ridden with guilt, 'I'm not being the mum I'd like to be', 'I'm not the effective and team focused clinician that I wished I was', 'I'm not giving enough to my thesis'. I needed to reconcile the guilt in order to focus on getting work done, accepting my feelings as a normal reaction to an abnormal situation that is difficult to process. Lockdown was difficult for my son and I learned to let go of expectations of keeping up with my perfectionist standards in order to make the home a happy place for people to live whilst I was working. I asked for help, something before embarking on the doctorate I would have struggled to do. What I learned was whether it was family-related, work-related or thesis-related the goal wasn't to keep up and do it perfectly but to do it in a way that helped us all to feel happy and accomplished, to value the small steps we take with as much pride and joy as the big steps. Principles from ACT and CFT helped me to find peace. I accepted the situation as it was and let go of preconceived ideas to enable me to look upon life and limited productivity with kindness, compassion and a non-critical stance. Ultimately, this is the best I could do in the circumstances and I'm comfortable with that.

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*denotes studies included for review

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Table 1. *Parent, Child and Intervention Characteristics*

PARENT GENDER	AGE OF CHILD	GENDER OF CHILD	SOCIAL ECONOMIC STATUS (by postcode)	AMOUNT OF PACT SESSION RECEIVED	ANY FOLLOW UP SESSIONS	STAGE OF PACT ON COMPLETION	REASON FOR ENDING PACT SESSIONS	LENGTH OF INTERVENTION (MONTHS)
Female	4	male	50% least deprived area	12	Had MIT as follow up	2	Had a good number of sessions	7
Female	3	male	30-50% most deprived area	11	No	1	Had a good number of sessions	10
Female	4	male	10% most deprived area	11	No	3	Had a good number of sessions	6
Female	11	Male	30-50% most deprived area	13	No	1	Had a good number of sessions	9
Female	3	female	50% least deprived area	6	No	5	Good progress made in 6 sessions	5
Female	3	male	50% least deprived area	18	Yes	5	Had full 18 session dose	12
Female	7	male	50% least deprived area	6	No	6	Good progress made in 6 sessions	3
Male	2	male	30-50% most deprived area	11	No	2	Had a good number of sessions	8

Table 2: Description of Themes

PACT is deemed an acceptable and worthwhile community clinical intervention	
<p>1. <i>'It's like climbing the stairs: A Collaborative Learning Journey'</i></p>	<p>Through participation in PACT parents develop their understanding of barriers and facilitators of successful communication with their child and develop skills necessary for successful communication, considering the outcomes for both themselves and their children and the resulting emotional and relational connection that exists through this journey together. The clinical relationship is key to facilitating this process and increasing the self-efficacy of parents to engage in the intervention.</p>
<p>2. <i>'I can't see another way of doing it: Components, Structure and Effectiveness'</i></p>	<p>This theme captures participants perceptions of the most salient element of PACT and describes parents' views of the components and structure of the intervention, barriers and facilitators to engagement and their overall experience of participating in the PACT intervention.</p>

Appendices

Appendix 1: Search strategy

CINAHL search strategy 18th February 2020

Limiters applied to each search are as follows:

- Peer Reviewed
- Age Groups: Infant, newborn birth-1month; Infant, 1-23 months; Child, pre-school 2-5 years
- Language: English
- Published Date: January 2010 – February 2020

#	Query	Results
S7	S5 and S6	632
S6	S3 OR S4	68694
S5	S1 AND S2	1284
S4	“feasibility studies” OR “evaluation studies” OR implementation OR evaluation OR fidelity OR adherence OR dose OR delivery OR responsiveness OR differentiation OR quality OR process OR dosage OR completeness OR compliance OR adaptation OR feasibility OR satisfaction OR adoption OR “quality improvement”	65723
S3	“empirically supported treatment*” OR “evidence based practice*” OR “evidence based treatment*” OR “evidence based intervention” OR “best practice*” OR innovation* OR guideline*	7677
S2	ASD OR autism* OR “autistic spectrum condition” OR “autistic spectrum disorder”	4279
S1	“parent mediated” OR caregiver* OR “Caregiver mediated” OR “parent-based” OR “parent-implemented” OR “parent directed” OR “parent intervention” OR “early intervention” OR “behavioral intervention” OR “parent training” OR “communication intervention” OR “early communication intervention”	9747

PubMed search strategy 17th February 2020

#	Query	Results
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#6	#5 and limiters year 2010-2020	259
#5	#3 OR #4	613,315
#5	#1 AND #2	925
#4	“feasibility studies” OR “evaluation studies” OR implementation OR evaluation OR fidelity OR adherence OR dose OR delivery OR responsiveness OR differentiation OR quality OR process OR dosage OR completeness OR compliance OR adaptation OR feasibility OR satisfaction OR adoption OR “quality improvement”	7601776
#3	“empirically supported treatment*” OR “evidence based practice*” OR “evidence based treatment*” OR “evidence based intervention” OR “best practice*” OR innovation* OR guideline*	698072
#2	“parent mediated” OR caregiver* OR “Caregiver mediated” OR “parent-based” OR “parent-implemented” OR “parent directed” OR “parent intervention” OR “parent training”	76034
#1	(ASD OR autis* OR "autistic spectrum disorder" OR "autistic spectrum condition" OR "autistic disorder")	20429

PsycINFO search strategy 18th February 2020

#	Query	Results
S6	(S1 and S2) and (S3 OR S4) And limiters: 1)date published 01.01.2010 to 31.01.2020 2) peer reviewed	978
S5	(S1 AND S2) AND (S3 OR S4)	1405

S4	“feasibility studies” OR “evaluation studies” OR implementation OR evaluation OR fidelity OR adherence OR dose OR delivery OR responsiveness OR differentiation OR quality OR process OR dosage OR completeness OR compliance OR adaptation OR feasibility OR satisfaction OR adoption OR “quality improvement”	126932
S3	“empirically supported treatment*” OR “evidence based practice*” OR “evidence based treatment*” OR “evidence based intervention” OR “best practice*” OR innovation* OR guideline*	9495
S2	ASD OR autism* OR “autistic spectrum condition” OR “autistic spectrum disorder”	28969
S1	“parent mediated” OR caregiver* OR “Caregiver mediated” OR “parent-based” OR “parent-implemented” OR “parent directed” OR “parent intervention” OR “early intervention” OR “behavioral intervention” OR “parent training” OR “communication intervention” OR “early communication intervention”	19654

ERIC search strategy 18th February 2020

Limiters set for each search are as follows:

- Document type: Journal article; article
- Language: English
- Peer reviewed
- Publication date: 1.01.10 – 31.01.2020

#	Query	Results
S7	S5 AND S6	384
S6	S3 OR S4	138205
S5	S1 AND S2	774

S4	“feasibility studies” OR “evaluation studies” OR implementation OR evaluation OR fidelity OR adherence OR dose OR delivery OR responsiveness OR differentiation OR quality OR process OR dosage OR completeness OR compliance OR adaptation OR feasibility OR satisfaction OR adoption OR “quality improvement”	128407
S3	“empirically supported treatment*” OR “evidence based practice*” OR “evidence based treatment*” OR “evidence based intervention” OR “best practice*” OR innovation* OR guideline*	22000
S2	ASD OR autism* OR “autistic spectrum condition” OR “autistic spectrum disorder”	7780
S1	“parent mediated” OR caregiver* OR “Caregiver mediated” OR “parent-based” OR “parent-implemented” OR “parent directed” OR “parent intervention” OR “early intervention” OR “behavioral intervention” OR “parent training” OR “communication intervention” OR “early communication intervention”	4984

Hand search of journal’s 19th February 2020:

Autism	1
Autism & Developmental Language Impairments	21
Autism Research	5
Journal of Autism and Developmental Disorders	19

Appendix 1: Data extraction Table

Study	Programme			Process evaluation					
	Author & year of publication Programme Country of delivery	Programme characteristics (dose of parent training, delivery format)	Sample size (TX, CT) Age Implementer qualifications Parent implemented home practice	Theoretical framework	Evaluated fidelity components	Definition fidelity component	Data collection Method and timing	Subject of evaluation	Summary of the results of the fidelity component
<p>Solomon et al., 2014</p> <p>Play and Language for autistic youngsters (PLAY)</p> <p>America</p> <p>Home</p> <p>1:1 plus modelling</p>	<p>36hr: 3h monthly sessions for 1 year Self directed 2hr DVD training, orientation materials, 1:1 home based, modelling 15-30mins, coaching, feedback, written video analysis</p>	<p>N=128 (64, 64) 49.9 (32-60 mnth)</p> <p>6 PLAY consultants (1 OT, 2SLT, 3 special educators) 2-5yrs experience as PLAY consultants – received 4 days training to certification plus 12-18mth supervision plus submitting 20 video write-ups Families encouraged to engage their child in 15-20 minute play sessions and throughout day for 2 hours/day.</p>		<p>Dose</p> <p>Dose</p> <p>Adherence</p>	<p>Hours /sessions Mean number of visits</p> <p>time parent spent using PLAY</p> <p>Consultant fidelity to treatment</p>	<p>Parent completed monthly log of PLAY hours</p> <p>Two study supervisors, trained to use projects fidelity manual rated random sample of consultant videos and write ups</p>	<p>Clinician</p> <p>Parent</p> <p>Clinician</p>	<p>3 hour x 12 visits mean number of visits = 10.52 SD= 3.01</p> <p>M= 621.90 hours (SD=273.64hr)</p> <p>Completed 610 visits, submitted 138 videos and write-ups for review (23%). 22 submissions per clinician. 97% met criteria. Corrective feedback given for those that did not meet criteria</p>	<p>No</p> <p>No</p> <p>No</p>
<p>Carter et al 2011</p> <p>America</p> <p>Hanen More Than Words (HMTW)</p> <p>Centre and in-home</p> <p>Group & Individual</p>	<p>Group-Based PE, 1:1 parent-child sessions with therapist coaching, child therapy and parent coaching, video feedback</p>	<p>N= 62 (32, 30) M=51, F=11 20.25 SD 2.6 (15-25) Group and individual sessions provided by speech/language pathologist certified in HMTW</p> <p>Clinician training not reported</p>		<p>Responsiveness</p> <p>DOSE</p>	<p>Consumer satisfaction Survey. Rating of group leader, cohesion and support within treatment group</p> <p>8 group sessions with parents only. 3 in home individual</p>	<p>Questionnaire</p>	<p>Clinician and group climate</p> <p>Clinician</p>	<p>Consumer satisfaction high mean rating 5.48/6 on group experience and 3.46/4 on group leader experience</p> <p>5 completed in fewer than 9/11 combined sessions</p>	

				Quality	<p>sessions</p> <p>Coded for parent responsivity Parent-child free play procedure (PCFP)</p>	<p>Video recorded play session</p> <p>3x time points: T1,T2 (5 months after T1, T3 9 months after T1)</p> <p>Reliability blind, independent coding random 20%</p>	<p>Parent</p>	<p>Moderate Increased responsivity t1-t2 d= .55 t(32) = 2.88 p=.007</p> <p>Moderate decrease responsivity t2-t3 d= -.44 t(38) = -2.4 p= .02</p> <p>ICC on proportion of codable intervals T1= .46, T2= .84 T3= .75</p>	<p>YES – effects of intervention on change in parental responsivity t1-t2 (t(1,31)=1.8 p=.08) and t1-t3 (t(1,35) = 1.8, p= .09) not significant but effect sizes large .71 and .50 for both time points</p>
				Adherence (FOTI measure included 'quality of teaching style' e.g. quality measure for practitioner but no information)	<p>Fidelity of treatment implementation (FOT) adherence to Hanen recommended content</p>	<p>Self-report Checklist developed for the study</p> <p>97% of group session</p> <p>78% of individual session.</p> <p>Second rater group 23% individual 34.5%</p>	<p>Clinician</p>	<p>Inter-observer occurrence agreement .89 (SD=.047)</p> <p>Self-report HMTW implemented with 88% (SD=4.7) of intended elements in group and 89.9% (SD=7.9) in individual</p> <p>Mean item by item Reliability observed 92% (SD=10) for group and 92% (SD=11) for individual</p>	
<p>Kasari et al 2015 America JASPER (joint attention symbolic play, engagement and regulation)</p> <p>Home 1:1</p>	<p>10hr 2 30min sessions per week for 10 weeks</p> <p>1:1 active coaching and feedback manualised parent-mediated</p> <p>Parents taught to use strategies in structured sequence</p>	<p>N=86 (43, 43) Age Mean 31.5 (22-36)</p> <p>Post doctoral clinical psychologist supervised clinicians weekly</p> <p>Therapists PhD candidates in Human development and Psychology. 3/8 therapists BA level therapists, in JASPER arm.</p> <p>Therapists required to demonstrate 90%</p>		DOSE	<p>Jasper parent mediated model – 1hr per week for 10 weeks (2 sessions of 30 minutes per week)</p>		Interventionists		
				Adherence	<p>Treatment integrity fidelity rating</p>	<p>JASPER specific fidelity rating observation of 20% of sessions observed through one-way window</p>	<p>Clinician</p>	<p>91.4% (75-100%)</p>	

		fidelity on JASPER specific measure of fidelity 2-6 months of training.							
Kasari et al 2014 America JASPER Home 1:1	Caregiver mediated manualised intervention establishing dyadic engagement during 3 routines at home (play and everyday activities) active coaching, modelling, prompting. Weekly written materials	N=112 (60, 52) 41.9 (24-60) Trained clinicians established 80% fidelity before beginning treatment		DOSE	24h 2 1hr sessions a week for 12 weeks		Clinician	Attrition was high (35% by follow up) 90% of sessions completed	
				Adherence	Fidelity of intervention for each child	Monthly Method not stated	Each Clinician	Averaged 76% range 0.41-0.99 Therapist fell below 80% site coordinator gave weekly feedback on sessions	
				Responsiveness	Extent to which caregivers are using strategies each week	Questionnaire weekly (stated as diary) 4 questions address caregiver adherence (really this is responsiveness) 2 address competence (also responsiveness)	Parent	Rated use of strategies high (but I don't believe the questionnaire looks at rate of implementation) mean 1.3 (low score=little difficulty caring out intervention)	
				Quality	Caregivers quality of fidelity (comfort, confidence, enthusiasm, accuracy)	Questionnaire 5pt likert scale Weekly rated by clinician	Parent	Range 3-5 mean 4.28 (SD, 0.50). High adherence as rated by clinicians	
Casenhiser et al 2011 Canada DIR/Floortime Clinic 1:1	Child therapy and parent coaching, video feedback 3hrs a day recommended parent interaction	N=51 (25,26) 42.5 (24-59) Interventiosist licensed SLT or OT's 3 weeks intensive hands-on training from DIR faculty members. Continuous training at DIR institute. Meet weekly with DIR faculty member who oversaw therapy, provide instruction and consulted on cases		DOSE	2hr week 1 year Every 8 weeks met with therapist to discuss progress and review videotaped play session		Clinician		
				Dose	Hours spent in therapeutic intraction	Time log	Parent	Average 25hrs week interaction	
				Quality	Parent fidelity to treatment	Pre/Post MEHRIT fidelity scale (aimed to	Parent	Pre 1.5 (SD=-.12)average score. Post	YES: post-treatment performance as potential predictors of

						measure fidelity clinicians)			change in child outcomes
Pajareya & Nopmaneejumrulers 2011 DIR/Floortime Group & home 1:1 Thailand	Lecture explaining intervention components, training in observation of cues, follow child's lead, implement techniques, modelling skills, coaching, observation of play and feedback, manual based on affect based language curriculum (ABLC, Greenspan and Lewis, 2005).	N=32 (16, 16) 28:4 M:F 56.6 (24-72) Degree in rehabilitation medicine, trained in DIR/Floortime DVD training, manuals, books and practiced technique for 2 years before study started		DOSE Dose		One day training workshop, 3hr DVD lecture. 1.5 hr (unclear how many sessions) Required to carry out floortime for minimum 20hrs a week Weekly log to estimate average weekly hours spent doing floortime	Clinician Parent	15.2hrs average a week	YES: Parents who added home based DIR/Floortime™ intervention >10hrs (n=9) made greater gains in FEAS than parents who added intervention less than 10hrs week (n=6) non-significant difference
Poslawsky et al 2015 The Netherlands VIPP-AUTI (video feedback intervention to promote positive parenting adapted to autism) Clinic based group 1:1 home	Detailed manual. 1:1 home based training, video feedback, discussion, clinic-based PE group sessions,	N=78 (40, 38) 42.2 (16-61) Bachelor/masters degrees (nursing, social work, psychology) >3 years work experience Brief training of interveners. Weekly supervision, feedback sessions of all visits with researchers during intervention phase.		Dose Adherence Responsiveness	Treatment Treatment fidelity Assess treatment satisfaction	12 weeks. 5 home visits 60-90mins 2 weekly intervals. 20% of cases checked for fidelity by reviewing film fragments and preparation for home visits Follow up only Client satisfaction questionnaire (CSQ-8)	Clinician Clinician Clinician	All parents reported satisfied or very satisfied M24.6 SD=4.5. No group difference in satisfaction	
Roberts et al 2011 Australia Building Blocks 1:1 home based Modelling clinician to child	Direct modelling, constructive feedback on education management, discussion of family issues: Individualised program (speech,	N=56 (27, 28) Transdisciplinary team – teachers, speech pathologists, OT's, psychologists		Dose		40hrs - 2hr fortnightly sessions over 40 weeks (20 sessions). Visits made to pre-school or day care settings to observe child,	Clinician		

	sensory, social skills)					provide strategies to staff and support generalisation of skills			
				Adherence	Treatment fidelity checks to establish core domains outlined in the program were addressed	Throughout & +- End of treatment file review – programme based pre and post assessment checks, written individual plans, record of reviews, final evaluations for each child using program proformas	Clinician	High level of treatment fidelity. All CB groups for children and parents observed by a team member were conducted as outlined in building blocks manual	
				Quality	Parental perception of competence	2 time points – baseline and follow up	Parent	No significant change for home-based group, variable outcomes.	
Siller et al 2013 America Focused Playtime Intervention 1:1 home based modelling	Manualised treatment manual Capacity building approach. 2 parts to session; 1 st 30-60 min. Parent and child free play 10 mins, clinician introduction to topic then alternate with parent for 15-45mins, modelling strategies, feedback on parent play, comment on child responses. 2 nd part 30-60mins with parent only intervention topic elaborated through workbook, video feedback, review of	N=70 M=64 F=6 Delivered by trained graduates and post-doctoral students in developmental psychology and counselling		Dose	12 weekly in home training sessions, 1 session per week for 90mins. Fidelity		Clinician		
				Adherence	Not stated or defined	All intervention sessions Videotaped observation and fidelity checklist. 2 sessions per child chosen at random and coded using checklist	Clinician	Inter observer reliability based on 20 videotaped sessions, excellent agreement (ICC=.85) 77 sessions(2 intervention topics selected at random) 88.3% fidelity score above 80% (M=89.6% SD=9.0)	
				Quality	Responsive Parental communication	Baseline and exit, 3 visits: 2 in research lab, 1 at home.	Parent (maternal verbal behaviours)	20% of videotaped interactions (85-99 videos) coded by independent observers	Yes – parental gains in behaviours on children’s expressive language

	homework					Observation of video 1 st marked verbal utterances. Second coder decided if it was synchronised with child attention. Coded 2 mins of video with computer system		range of agreement 86%-91%. Significant main effect of treatment group allocation on gains in maternal synchronisation for t1 to t2 (t(51)=2.12, p<.05. No effect of gains in parental parent on children's expressive language. Treatment effect non-significant for mothers who were not insightful at baseline.	
Tonge et al 2014 Australia PEBM Centre based 1:1 centre based & group	Individual sessions skills based and action oriented, workbooks, modelling, video feedback, rehearsal, home practice. Manulaised based education and behaviour management skills training. Alternate group and individual sessions	N-107 30-60m Intervention group (N=70) Delivered by special educators or psychologists. To maintain treatment integrity therapist received training in each condition, received ongoing supervision nad training, therapist rotated across treatment conditions		Dose Adherence	Treatment integrity and intervention adherence	20 weeks 10 x 90 minute small group sessions alternated with 10x 60 minute individual sessions 10% sample of group therapy session videotaped for content review	Clinician Clinician	Didn't publish how much exposure parents received	
Gengoux et al 2019 America Pivotal response treatment package (PRT-P) Home based – parent training plus clinician delivered	Parent training and clinician delivered Parent training provided by Masters level clinicians supervised by first author. In-home treatment was provided by bachelors level clinicians. Weekly	N=48 (24, 24) 24-60m		Dose		24 weeks: 12 week intensive phase 60m parent teaching plus 10hr clinician to child 12 week maintenance phase 60m parent teaching plus 5hrs clinician	Parent and clinician	All families received all 15 parent training sessions. Children scheduled to receive 180hrs received average 160hrs (range 141-180 hours)	

	supervision			Quality	Parent fidelity of PRT implementation	to child Baseline, week 12 and week 24. joint scored structured laboratory observations videos between clinician and parent 6 PRT variables. Percentage of parents meeting 80% fidelity.	Parent	Parents with a score of at least 80% were considered to have met fidelity. Inter-rater agreement 87% k22 was calculated for chance agreement. Baseline no parent met fidelity. Week 24, 21 of 23 parents (91%) met fidelity.	
				Responsiveness	Retention rate		Clinician	96% over 24 weeks suggests strong acceptability of the treatment.	
Kasari et al 2014 America Focused playtime intervention (FPI)	45 min interactive play between parent and child, Clinician demonstrated strategies, feedback on parents use of strategies. Videotaped interactions. 45mins parent only workbook, video feedback, conventional teaching, review of weekly homework	N=66 (32, 34) mean age 22.37m SD 3.8m Trained clinicians		Dose		12 weeks 1 session per week 90mins per session	Clinician		Yes. Number of sessions not associated with any outcomes measures except significant positive correlation between the amount of response of joint attention and number of sessions in FPI treatment group
In home			Adherence	Treatment fidelity	Monitored on random sample of 25% of intervention sessions	Clinician	Average 96% range 72%-100%		
1:1 parent education and coaching model			Quality	Parent responsiveness	Entry, Exit, follow up. Measure the proportion of times the parent responded to the child within a 10min window	Parent	Inter-rater reliability .83 Significant treatment effect with FPI group greater improvement from treatment to end (F(1,89)=7.32 p=0.0008 not maintained at follow up, not significantly better than control). Any amount shown at baseline significant treatment effect start to end of treatment and significant increase in amount of responsiveness		

								maintained at follow up.	
Kasari et al 2010 America Joint Attention Home 1:1	Sessions included coaching caregiver and child engaging in play routines, responsive and facilitative interaction methods, applied behaviour analysis. Direct instruction, modelling, guided practice, feedback, handouts	N=42 (19,19) 21-36m M age=30.82 29 male 9 female Graduate students in educational psychology experienced with children with autism 4 clinicians worked with 8-9 families each. Training included 2 pilot subjects with supervision prior to beginning the study, group weekly supervision		Quality	Performance of quality of strategies learned during the intervention session	Caregiver quality of involvement scale: 5pt likert scale, 18 item. clinician rating end of each intervention session (n=24)	Parent	High fidelity at end of treatment period average score 3.37 (SD = 0.32) range 2.56-3.94)	Yes. Relationship between caregiver quality of involvement, adherence to treatment/competence, and treatment outcomes.
				Dose		8 week 24 sessions 45mins (3x per week) 30 minute direct instruction, last 10 minutes practice			Higher caregiver quality of involvement scores significantly predicted increased joint engagement scores at post treatment after controlling for pre-treatment scores.
				Responsiveness	Parent adherence to treatment and competence	Weekly (n=8) Self-report adherence-to-treatment and competence measure 5pt likert scale	Parent	Parents report uniformly high adherence M=3.97, SD = 0.65 and competence M=4.35, SD = .053	Caregiver involvement not related to the duration of object engagement or the unengaged/other category in the caregiver-child dyad at posttreatment, not did it predict increases in play or joint attention skills.
				Quality	Caregivers Fidelity adhering to treatment	Videotapes pre&post treatment 4pt likert scale on how well they demonstrated each objective or aspect of the treatment protocol	Parent	Average total quality of intervention cornbachs alpha .86 Independent coders inter-rater reliability 20% of tapes 0.89 range 0.68-0.98	
				Adherence	Clinician fidelity to treatment	Videotaped session pre and post, 4pt checklist	Clinician	20% of each participants sessions were rated interaclass correlation coefficient 0.86 range 0.74-0.99	

<p>Brian et al 2017 Canada Social ABC's (founded on PRT principles)</p> <p>Home 1:1</p>	<p>Manualised program, delivered by caregivers 1:1 didactic sessions guided by manual, parent-child practice and live coaching, primarily in the home but also local park, coaching, learn through context of play as well as meals, bath time, diaper changing)</p>	<p>N=63 16-30m 5 coaches, bachelor level degrees, training process described elsewhere</p>		<p>Adherence</p> <p>Dose</p> <p>Quality – measure of mastery</p> <p>Responsiveness</p>	<p>Fidelity implementing and parent coaching</p> <p>Intervention</p> <p>Parent implementatio n fidelity</p> <p>Parent's perceived self- efficacy & parent satisfaction</p>	<p>Not reported</p> <p>12 weeks 1.5hr home visits, tapering intensity week 1:3visits; week 2:2 visits, weeks 3-8:1 visit/week; week 10 and 12 1 booster visit/wee; week 9 and 11 check in phone call 3 time points, BL, post training, follow up.</p> <p>Video's coded for 10 x 1 minute intervals (2 per time point)</p> <p>BL & Fup 21 item 5 point likert scale.</p> <p>7 item questionnaire at follow up</p>	<p>Clinician</p> <p>Parent</p> <p>Parent</p> <p>Clinician & parent</p>	<p>Not reported</p> <p>Interrater reliability 20% of video segments coded by second rater blind to group allocation and time point very high M=86%; range 80-96% Parents in treatment condition increased from 48% to 87% and maintained at 83% at f- up. 67% of parents met fidelity at post treatment and 83% at follow up. No condition x time interaction. Parents in treatment condition reported significant improvement from BL (M=59.61, SD 7.22) -F-UP M=64, SD 8.78), p=.009 Paretns in treatment condition rated very favourably (M=32.80, SD=3.08, of a possible 35)</p>	<p>Yes. Parent gains in fidelity (use of social ABC's significantly contributed to the prediction of increased responsiveness (R²=.5s, P<.001).</p> <p>Parent education level did not predict PT fidelity (R² =.009, P=.46)</p>
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Green et al 2015 England Adapted video interaction to promote positive parenting (iBASIS-VIPP) Home intervention 1:1	Video feedback to help understand and adapt to their infants individual communication style. Interpretation of infant behaviour, recognising intentions, sensitive responding	N=54 (28,26) 7-10m Therapists graduate speech and language therapist and psychologists supervised		DOSE		6-12 sessions according to need in discussion with family	Clinician	All families 6 core sessions M=9.5/12 SD 1.6, range 6-11.	
				Adherence	Therapist fidelity to the manual	Video recorded Assessed in 23 sessions from 15 participants, randomly selected 21 item pass or fail measure	Clinician	Double coded Mean fidelity score was 19.4 passed items per session (93%, range 15-21) only 1 session not meeting 80% fidelity threshold	
				Quality	Sensitive responsiveness and caregiver non-directiveness	2x time points BI & 5 months treatment. 6min videotaped free play in research setting	Parent	Within-trial double coding 38% of trial recordings high inter-rater agreement range r=0.64 to 0.75 (p<0.001) Increased care-giver non-directiveness (0.81, 95% 0.28, 1.52)	
Bearss et al 2015 America Behavioural problems Centre based & home Individual & parent-child coaching	Parent training (11 core, 2 optional, 2 telephone boosters, 2 home visits). Manualised training with verbatim scripts and instructions for therapists. Direct instruction, video examples, practice activities, rehearsal(role-play). Parents applied new techniques to specific behaviours. Comprehensive supplementary information of components.	n-180 M=158, F=22 36m-83m M=4.7years SD 1.1 years). Training and supervision very detailed in supplementary information. Therapists were trained to 80% reliability. Therapist with masters level or more, weekly supervision, monthly cross-site teleconferences to ensure integrity of study interventions.		Dose	24 weeks. 1 core sessions 60-90mins 2 optional sessions 1 home visit and up to 6 parent-child coaching sessions over 16 weeks. 1 home visit and 2 booster sessions		Inerventionist	Parents attended 92% (901/979) of core parent training sessions	
				Adherence	Treatment integrity	Checklist. 10% sample randomly selected, video-recorded parent training and parent education sessions	Clinician	Excellent fidelity M=96.7% SD 8.3 for parent training and 97.2% SD=6.4 for parent education.	
				Responsivity	Attrition		Clinician	11.2% (10/89; 3/10 parents discontinued treatment but completed assessments	

<p>Rogers et al 2018 America Parent implemented early start Denver model (P-ESDM) Clinic 1:1 sessions</p>	<p>Coaching, home visits to aid generalisability. Manualised training plus. Materials according to parent preference, Motivational interviewing</p>	<p>N=45 12-30months Therapist training in MI and weekly peer supervision. Highly experienced ESDM-certified professional/faculty : 2 psychologists, a speech/language therapist, 3 behaviour. Several years experience. Videoconferenced monthly to review videos, code and check agreement, provide peer supervision, guard against site drift. Separate assessment team, met and maintained assessment fidelity and inter-rater reliability standards.</p>		<p>DOSE</p> <p>ADHERENCE</p> <p>Quality</p> <p>Responsiveness</p>	<p>Fidelity</p> <p>Mastery of skills taught</p> <p>Social validity</p>	<p>12 weeks 1.hhr clinic based parent coaching weekly plus weekly 1.5 hr home visit</p> <p>Videotape each session for coding therapist.</p> <p>Every 4 weeks, ESDM fidelity rating system. coded videos observed parent mastery of treatment skills in home and clinic. EDSM Fidelity rating system 5pt likert measured parent change</p> <p>End of treatment Parent satisfaction measure and parent-therapist working alliance scale</p> <p>Self-report Weekly motivation (MI) to focus parent</p>	<p>Clinician</p> <p>Clinician</p> <p>Home setting videoed to see what skills had generalised. Parent fidelity rated monthly. Parent change rated every 4 weeks.</p> <p>Parents & Clinician</p> <p>Parent</p>	<p>11/240allocated to P-ESDM declined 25% or more intervention hours at UCD site. PESDM++ 7 declined 25% or more intervention hours (6UCD, 1 UW) 19 parents</p> <p>Clinicians met fidelity of implementation standards 85% or greater on consecutive measurements. Fidelity examined repeatedly across trial slippage resulted in retraining and re-assessment.</p> <p>10% of videos rated for agreement. Total scores range 14-60 higher scores = more usage of skills. Significant interaction effect of treatment groupo x time $F(1,166)=7.90, p=.0056$ greater improvement (bL, M=3.40 ET 3.80). Inter rater reliability 0.47 only fair agreement 80 video clips of 29 children.</p> <p>Intervention evaluation form for parents (unpublished). 27/30 parents completed. Parents highly satisfied. 50% scoring all items 5. No effect of treatment group on mean score of group. Medium effect favouring the PEDSM++ group.</p>	<p>YES: significant association detected on PATH CC scores additional 2.6% change in checklist scores by end of treatment for every 0.45 point change in fidelity score. Children of parents who showed improvement over time on fidelity scores showed greater development gain over time than did parents who did not show fidelity over time.</p>
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Rogers et al 2012 America Early start Denver model (ESDM) Clinic Centre & home Individual parent plus parent coaching	Parent training curriculum, coaching intervention method, began with 5 min warm up period of parent child interaction. Verbal description and written material, modelling of skill. Discussion of what parent observed, parent practiced the technique in play, therapist provided coaching, encouragement and feedback. generalisability to other settings discussed at end. Self-instructional manual materials on target technique to review.	N=98 14-24months Highly experienced and credential therapists trained to fidelity		Quality Responsiveness Dose Adherence	Parent fidelity tool Response of family to therapist 12 consecutive session. 1 hr in length. Fidelity	P-ESDM parent fidelity tool. Questionnaire 13 parent behaviours. Video recorded at 2 time points. Observation of 10 min parent-child interaction. End of 12 weeks Trained to fidelity monitored quarterly during study. Therapist fidelity measure.	Parent Parent rated on clinician Clinician Clinician	Total score range 14-60. Parents were training in techniques until they reached 80% fidelity or higher. Groups equivalent at T1. T2 pre-test showed large effect size for treatment group (.57) Measured at end of intervention P-ESDM group reported significant stronger working alliance with primary therapist than community group (M=5.23, SD=1.1) P=.06 Good internal consistency among scale items. Average score with child = M=4.47 (SD= .24) / 5 Coaching interactions with parent: M=3.62 (SD = .25) / 4	YES. Relationship between parent behaviour and child symptoms and development examined. Relationship between fidelity and child performance. No significant relationship between parent change scores on fidelity measure during 12 week.
Dawson et al 2010 America ESDM Home Child intervention & parent coaching	Detailed intervention manual and curriculum. Parents received parent training in specific techniques semi-monthly. ESDM techniques include interpersonal exchange, positive affect, shared engagement, individualised plan, generalised through	N-48 (24, 21) 18-30months Evaluated by experienced examiners naïve to intervention. 1 year after onset or 2 years after onset or 48mths. Intervention trained therapists. Supervised by graduate-level, trained lead therapist with	Therapist trained to competence, completed course work, passing tests, mastering the intervention demonstrating 80% maximum score on fidelity instrument. Maintained fidelity.	Dose Parent Adherence		2 year intervention. 2hr session, twice daily, 5 days week for 2 years. 20hrs week ESDM intervention from clinicians, parent training and parent delivery 5 or more hours per week	Clinician Clinician Parent Clinician	Retention 100%. Mean intervention hours 15.2 (SD=1.4). Parents reported spending average 16.3hrs week SD=6.2 using ESDM strategies Trained to 85% fidelity	

	everyday activities. Parents choose from curriculum (bottom up). Ongoing consultation with clinical psychologist, SLT, developmental behavioural paediatrician.	minimum 5 years experience. Delivered by therapist who hold baccalaureate degree, received 2 months training and met weekly with lead therapist.			objectives and strategies.	Observation of intervention bi-weekly by lead therapist and 3 months by SaLT pathologist.		and maintained ongoing fidelity. Only rate for training given, not for adherence to treatment.	
Shertz et al 2017 America Joint attention mediated learning (JAML) Home based 1:1	Manualised treatment. Facilitate parent learning and confidence to mediate engagement. Facilitative non-prescriptive approach to leverage parent's expertise and knowledge. Intervention guidance materials. Parents review weekly activity logs, engaged in play, recorded session then watched with clinician. Guided reflection, positive examples, questioning probes. Video examples and written material of mediated learning principles.	N=144 (73, 71) 16-30mths. Intervention co-ordinator		Dose Adherence Quality Responsiveness	Fidelity of protocol for implementation Implementation fidelity Social Validity	32 weeks, 1 hr week. Parents expected to participate in play based interaction for 30mins daily All sessions recorded. 25% sessions randomly selected rated by independent assessor. 12 item 3pt checklist. Administered immediately following each session. Observation of parent-child recordings and logbook of daily activities Post intervention 18 item parent report questionnaire perceived acceptability of intervention.	Parent Clinician Parent Clinician	High level obtained (M+2.96, SD=0.03 R=2.85-3.00) M=2.74, SD=0.17 R=2.06-2.95. Inter-rater agreement for both parent and clinician 25% High interobserver agreement for clinician M=99%, R50-100%. Parent 93% R=53-100%. High acceptability Table of all scores reported.	
Turner-Brown et al 2016 America Clinic and home	Manualised. Session divided into 5 activities. Didactic discussion with	N=49 (32, 17) Licensed clinical social workers with experience in		Dose		24 sessions, 90 minute each. In home = 20, parent group at	Clinician	Reported 100% attendance 24/31 completed group 19/20 home visits	

<p>Family Implemented TEACHH for toddlers (FITT)</p> <p>Home 1:1 and modelling & clinic group</p>	<p>coach and parent, play based activities on Table, floor, routine based activities, planning for implementation between sessions. Practice reflection and feedback</p>	<p>autism. Initial training with study investigators related to domains and strategies tagged in FITT</p>		<p>Adherence</p> <p>Quality</p> <p>Responsiveness</p>	<p>Fidelity</p> <p>Parent implementation</p> <p>Social validity</p>	<p>clinic = 4. Parent attendance reported.</p> <p>FITT form checklist for each session</p> <p>Therapist rated fidelity at each session. 10 item checklist 7pt scale.</p> <p>End of intervention parent feedback form. satisfaction Goals.</p>	<p>Clinician</p> <p>Parents</p> <p>Parents & Clinician</p>	<p>FITT fidelity form each session by clinician. Forms. Quite high 94% R=64-100% inter rater reliability for live coding of sessions 20% 94% R=68-100%</p> <p>Rated high 83% SD=13 majority 70-96% range</p> <p>Reported satisfaction on all domains. Reported in Table format</p>	
<p>Watson et al 2017 America Adapted Response Teaching (ART)</p> <p>Home 1:1 modelling</p>	<p>Introduction to Art, assess child's pivotal behaviours profile, explored family routines to provide context of ART, coaching strategies, rationale for targeting behaviours, responsive strategies. Family action plan co-produced to integrate strategies between sessions</p>	<p>N=87 (45, 42) 6 professionals experienced in child development, ASD and EI (e.g. teachers and therapists).</p>	<p>As below</p> <p>IFC adapted from Mahoney & MacDonald, 2007</p>	<p>Dose</p> <p>Quality</p> <p>Adherence</p>	<p>Fidelity</p> <p>Implementation fidelity to assess extent to which clinicians engaged parents in ART component</p>	<p>30 in-home sessions plus 6 additional contacts (email/phone) across 6 months</p> <p>Parent implementation rating form. questionnaire administered by clinician each session</p> <p>Observation of video recorded sessions, monthly ART 25 item implementation checklist rated by trained research assistants</p>	<p>Clinician</p> <p>Parent</p> <p>Clinician</p>	<p>Mean 24.9 (SD=5.2 R=12-32) in home sessions. 2.4 SD 3.6 R=0-15 other contacts.</p> <p>M=.77 SD=.15 Moderate adherence to ART</p> <p>Inter-rater reliability 34 tapes (13%). 157 (14.7% rated, Mean 0.87 SD=0.9 (good)</p>	

Appendix 2. Validity and *quality assessment* Table

Paper	Criterion	1	2	3	4	5	6	Validity score	Quality % H/M/L
Bearss et al 2015	Dose	-	+	+	+	+	-	4	66 M
	Adherence	NA	+	-	+	+	-	3	60 : M
	Responsiveness	-	-	-	+	+	-	2	33 : L
Brian et al 2017	Adherence	NA	+	-	-	-	-	1	20 : L
	Dose	-	+	-	+	+	-	3	50 : M
	Quality	-	+	+	+	+	+	5	83 : H
	Responsiveness	+	+	+	+	+	-	5	83: H
Carter et al 2011	Responsiveness	+	+	-	+	-	-	3	50 : M
	Dose	-	+	+	+	-	-	3	50 : M
	Quality	-	+	+	+	+	+	5	83: H
	Adherence	NA	+	+	+	-	-	3	60 : M
Casenheiser et al 2011	Dose	+	+	-	-	-	-	2	33 : L
	Quality	-	+	-	+	+	+	4	66 : M

Dawson et al 2010	Dose	+	+	+	+	-	-	4	66 : M
	Responsiveness	-	+	-	+	-	-	2	33 : L
	Adherence	NA	+	+	-	+	-	3	60 : M
Gengoux et al 2019	Dose	+	+	+	+	+	-	5	83: H
	Quality	-	+	+	+	+	-	4	66 : M
	Responsiveness	-	+	-	-	+	-	2	33 : L
Green et al 2010	Dose	+	+	NA	+	+	-	5	83: H
	Adherence	NA	+	+	+	+	-	4	80 : H
Green et al 2015	Dose	-	+	+	+	+	-	4	66: M
	Adherence	NA	+	+	+	+	-	4	80 : H
	Quality	-	+	+	+	+	-	4	66 : M
Kasari et al 2010	Responsiveness	-	+	-	+	+	+	4	66 : M
	Quality	+	+	+	+	+	+	6	100: H
	Dose	-	+	-	+	+	-	3	50 : M
	Adherence	NA	+	-	+	+	-	3	60 : M
Kasari et al 2014	Dose	-	+	-	+	-	+	3	50 : M
	Adherence	NA	+	-	-	+	-	2	40 : L
	Quality	-	+	+	+	+	-	4	66 : M
Kasari et al 2014	Dose	-	+	+	-	+	-	3	50 : M
	Adherence	NA	+	-	-	+	-	2	40 : L

	Quality	-	+	+	+	+	-	4	66 : M
	Responsiveness	-	+	-	+	+	-	3	50 : M
Kasari et al 2015	Dose	-	+	+	+	-	-	3	50 : M
	Adherence	NA	+	-	-	+	-	2	40 : L
Pajareya & Nopmaneejumruslers 2011	Dose	+	+	+	-	+	+	5	83: H
Poslawsky et al 2015	Dose	-	+	-	+	-	-	2	33 : L
	Adherence	NA	+	+	-	+	-	3	60 : M
	Responsiveness	-	+	-	-	-	-	1	17 : L
Roberts et al 2011	Dose	-	+	-	+	-	-	2	33 : L
	Adherence	NA	+	+	+	+	-	4	80 : H
	Quality	-	+	-	-	+	-	2	33 : L
Rogers et al 2012	Quality	-	+	-	+	+	+	4	66 : M
	Responsiveness	-	+	-	+	-	-	2	33 : L
	Dose	-	+	-	+	-	-	2	33 : L
	Adherence	NA	+	-	+	+	-	3	60 : M
Rogers et al 2018	Dose	-	+	+	+	+	-	4	66 : M
	Responsiveness	+	+	+	+	+	-	4	66 : M
	Adherence	NA	+	-	+	+	-	3	60 : M
	Quality	-	+	+	+	+	+	5	83: H

Shertz et al 2017	Dose	+	+	-	+	-	-	3	50 : M
	Adherence	NA	+	+	-	+	-	3	60 : M
	Quality	-	+	+	+	+	-	4	66 : M
	Responsiveness	-	+	-	+	-	-	2	33 : L
Siller et al 2013	Dose	-	+	-	+	-	-	2	33 : L
	Adherence	NA	-	+	-	+	-	2	40 : L
	Quality	-	+	+	+	+	+	5	83: H
Solomon et al., 2014	Dose	+	+	+	+	+	-	4	66 : M
	Adherence	NA	+	+	+	+	-	4	80 : M
Tonge et al 2014	Dose	-	+	-	+	-	-	2	33 : L
	Adherence	NA	+	-	-	+	-	2	40 : L
Turner-Brown et al 2016	Dose	-	-	+	+	+	-	3	50 : M
	Adherence	NA	+	+	+	+	-	4	80 : M
	Quality	-	+	-	-	+	-	2	33 : L
	Responsiveness	+	+	-	+	-	-	3	50 : M
Watson et al 2017	Dose	-	+	+	+	-	-	3	50 : M
	Adherence	NA	+	+	+	+	-	4	80 : M
	Quality	-	+	-	+	+	-	3	50 : M

1.Rating of criteria: + = yes, - = no NA = Not applicable

Criteria:

1. Level of evaluation; positive if the fidelity component was evaluated on two or more levels (i.e. parent, clinician, child), negative if the fidelity component was evaluated on only one level (i.e. parent, clinician, child) *.
2. Operationalisation of fidelity component; positive if the fidelity component was defined or operationalised, negative if only the name of the fidelity component was provided and not further defined or operationalised.
3. Data collection methods; positive if two or more techniques for data collection were used (triangulation), negative if only one technique for data collection was used. **
4. Quantitative fidelity measures; positive if measurement of the fidelity component was performed with adequately described methods, negative if measurements of the fidelity component was not performed with adequately described methods **.
5. Frequency of data collection; positive if the fidelity component was measured on more than 1 occasion (e.g. pre, during after delivery), negative if the fidelity component was measured on only 1 occasion.
6. Relation fidelity component and programme outcome assessed; positive if tested whether the fidelity component was related to programme outcomes, negative if not tested whether the fidelity component was related to programme outcomes.

* Does not apply to adherence, as it is not possible to evaluate on two or more levels – i.e. only on clinician level.

** adequate = sufficient information to be able to repeat the study.

Appendix 3: Additional information pertaining to the validity and quality scoring of fidelity components

Adherence quality scores:

1. NA because adherence is only measured at the clinician level because parent adherence is related to skill acquisition and mastery and therefore, quality of the intervention delivery not adherence to it.
2. Name given and explanation of what/why
3. Scored positive if Inter-rater reliability measure of adherence is reported
4. Adequate described measures for replicability
 - Measures described
 - Time point described
 - Model specified
 - Explanation of what is being measured
5. Positive if specified how they have measured across time points
6. If clinician adherence is related to outcomes

Quality, quality scores:

1. Positive if quality is measured for parent and clinician: outcome score of parent mastery of skill, questionnaire measure of parental satisfaction with clinician or programme, parental measure of self-efficacy,
2. Name given to quality score (e.g., adherence, quality)
3. Positive if inter-rater reliability or more than one method used (e.g., questionnaire rating both parent skill and clinician skill)
4. Positive if adequate information relating to the content and scoring of measure
5. Positive if measure used at different time points
6. Positive If parent or clinician mastery or skill is related to child outcomes

Responsiveness

1. Positive if measured for parent and clinician
2. Positive if explanation given of the component
3. Positive if inter-rater reliability or more than one measure used
4. Positive if measure of responsiveness was described by a model, content or full explanation
5. Positive if measured at different tim
6. Positive if responsiveness related to treatment outcomes

Dose

1. Positive if measured at the parent / Clinician or child level
2. Named and operationalised
3. Positive if number if both intention plus reported number of sessions
4. Positive if fully described in enough detail (e.g. length and duration) or linked to research or manualised with full description of how to find the information to replicate
5. If reported number of sessions attended this will automatically be positive for dose as the , negative if this information is missing
6. Positive if dosage linked to results

Appendix 4: Interview transcript read through and notes

Interview 6

1 Interviewer exchanges small talk, introduces the interview, discusses confidentiality and begins
 2 recording, interviewee had started talking so transcript starts from when the recording started

3 6: I still do some of the stuff now because we were encouraged to keep doing it Home Practice

4 I: what sort of things have you kept doing

5 6: Um well we still try and like set aside like you know a bit of time each day um we used to do when flexibility
 6 we did pact it was aimed to do 30 minutes a day whether it was 3 10 minute intervals or whatever so
 7 we still try and you know have a bit of time each day um to do the type of things we would do at - TIME
 8 PACT so like not no toys (.) bubbles funny faces singing and things like that yeah

9 I: and how did you find fitting in that 30 minutes a day Time, external pressures

10 6: um huh when I first started it was difficult because I was working now that I don't work um you
 11 know its cos I'm with [child] all the time it's quite its quite you know it's not hard at all. Having Cop

12 I: how did you manage to fit it in and what were the main barriers and difficulties when you were barriers
 13 working * Acceptability of home practice - adaptation

14 6: um sometimes in the (main barriers were [child] if you know for getting him to want to do things)
 15 um sometimes you can't um I just used to well I still do we don't necessarily get 30 minutes every
 16 day but we you know I'll try and do small small break it down into like little bit in the morning um
 17 unfortunately [child] isn't a morning person so we tend to do more of it in the evening bit of time Childs
 18 after he has had a shower and he's got his pyjamas on and things like that so I find it easy I found it limited
 19 easier to split it down into shorter cos you know you wouldn't get [child] to sit there for half an hour attention
 20 and do things you know that just isn't going to happen with him at the moment so just breaking it
 21 down into smaller chunks that made it a lot easier yeah

22 I: more manageable

23 6: yeah, yeah

24 I: so when you were working what were the main difficulties for you in terms of

25 6: um probably um I'd have to do it in the evening and it was um trying to you know when you come
 26 home from work you make you've got everything else to do the last thing you want to do but yeah
 27 that was the trying to find time you know when you were when I was working so it was tended to be
 28 done like later on at night um you know but as I say it's a lot easier now because I'm not at work
 29 I: and do you see that there is a benefit to doing the home practice

lasting legacy

Competing Demands

Barriers to implementing Skills

Childs lead

Home Practice

Competing Priorities

Time FACTOR

* PACT as Learning

BACT TO BASICS

Interview 6

30 6: Um yeah definitely I think um sometimes with what helped me with pact what I got out of it was
 31 um you forget sometimes that it's the basic simplest things that actually make a difference I think
 32 sometimes when you you know you when you realise that your child does have a you know issues
 33 and that you think that the answer gonna be really complicated and hard and sometimes it just it
 34 was good just to remind us that do you know what it is the basic little things that you can do at
 35 home that you don't need things for you know that actually um you forget I think I just forgotten
 36 how important play was to a child you know and it just reminded us and you know still now think
 37 you know it is the basic little things that you know can make the big difference

Childs difficulties seem complex = complex answer =

Parent self efficacy?

IMPACT OF PACT

Recognition of parent skills to child?

38 I: and what were those basic things
 39 6: as I say just to just to remind yourself that playing and interaction is such an important you know
 40 part of of a child's development (-)

* Intervention: easy to understand? : Big impact?

41 I: and going back to when you were kind of first introduced to pact what was your understanding of
 42 the aims of the pact intervention and the sort of things that you would be doing

Acceptable

Parents understanding explanation of PACT

43 6: um at first obviously when they explained that it was sort of like playing and things like that I was
 44 a bit like 'oh how's this going to make a difference' but no as time went on and and we did it you
 45 know you could tell [child] you know he made you could keep his attention for longer so there was a
 46 definite benefit to it um and again you know it just reiterated that you know sometimes it is the
 47 basic little things like play you know you don't have to have all these fancy things to you know and it
 48 and that is an important part of communication just going back to basics really

Scepticism

Parents see the value of PACT

Parent skills

* Temporary elements to change

Parents learning elements of PACT

49 I: and right at the very beginning what was the sort of information that you were given from the
 50 team about PACT

51 6: um the information I was given that it was basically they'd used it with kids with with you know
 52 with autistic kids and they'd found um that it had helped um so they had you know they had
 53 information research that kids had benefited from it so it was something that obviously I wanted to
 54 you know anything that would help [child] I mean he's still not talking now but you know he's he
 55 responds to his name now um he'll make better eye contact he's getting better um you know he's
 56 more focused on you than he used to be so I think for [child] it's definitely helped yeah

Parent Understand Why PACT

Reasons to do PACT

Open to anything

child initiated joint attention

57 I: and in terms of how much information the team gave you did you feel that was enough or too
 58 much what

Parents see Benefits of PACT for child

still not talking now - expectations PACT would help talk? disappointment of non-verbal?

Parents see clinician as honest information
 PACT can't do miracles! Parents couldn't
 miracle?

Interview 6

59 6: um thinking back no it was it was fine yeah I mean they didn't make any false promises or
 60 anything like that you know it wasn't a magic magic answer but yeah it just gave us reminded us of
 61 the basic skills that are important when yer you know when yer trying to communicate with [child]

62 I: and what was the um your reasons for carrying on with PACT after you'd had that introduction
 63 session *Professional advice increased likelihood of participating*

Parent effort to try

64 6: I mean [clinical] just advised us that it you know that it would be beneficial so like I say we don't
 65 necessarily do it every day but we try and still do a little bit of that the skills that we've learnt you
 66 know try and sit down with him and just have one to one without you know all the toys which
 67 sometimes you can't do sometimes he doesn't you know he doesn't want to do it but we you know
 68 we we we try a lot more it its now that we realise how important the basics are we do try and focus
 69 on them more

*skills learned
 Parents view child barrier to practice*

Recognition of IMPACT of skills Effort

70 I: can you give me a sort of breakdown of what sort of things you did in a typical PACT session when
 71 you were working with [clinician]

Content of PACT session

Acceptability of Content of PACT sessions + Parent understanding

72 6: um one of the things [child] used to do was he liked bubbles so we'd get the bubbles out um and
 73 we'd do um you know try and get him to sort of you know anticipation and wait for me and
 74 encourage me to blow the bubbles and just um you know things like that um we used to do tickle
 75 um and peak a boo with a blanket and things like that we used to do yeah so I think all things that
 76 [child] enjoyed *recognising child's likes + dislikes.*

77 I: and how did you find the structure of the sessions
 78 6: um I mean yeah they were fine they you know it was aimed at [child] so they were you know easy
 79 to follow and you know there was no problem with them at all

Acceptability of structure - Aimed at child

- Emotional experience of PACT.

IMPACT of Videoing Self-conscious

80 I: and what did you think about being videoed how was that for you
 81 6: um that was a bit (laughs) um I don't like having my photo taken you know I'm a bit like that but
 82 no I mean it was to help [child] at the end of the day so um yeah it's not nice looking back at yourself
 83 on a video camera but um yeah it was to benefit [child] so there was no real issue with that

Emotional IMPACT of video

benefits to children outweigh self-conscious exposure

84 I: did it take you a while to get used to it or did you
 85 6: no not really um I think the first few sessions yeah it was a bit you felt that you were a bit like 'oh
 86 well I've got to do something magnificent here I need to perform for the camera' but then well after
 87 a few sessions you just forgot it was there to be honest with you and you just you know went just

*Self-conscious awareness
 - Social image
 - Self concept*

1 time less self-conscious over time.

Appendix 5. Example initial coding of transcript

<p>Interviewer: what do you think were the main differences for [child] and for you as a family through doing the pact</p> <p>I think her behaviour improved hugely because in the beginning she would throw the biggest and I think it's taken a lot of training for family members as well because you know older generation would see how she behaved as um they thought she was an angry child difficult child um awkward child you know because she wasn't able to communicate.....</p> <p>... she used to have huge tantrums screaming fits and things like that and you know mostly arguments with her sister over toys but they've hugely reduced you know</p> <p>...because my grandparents for instance I'm lucky to still have them have gone 'gosh hasn't she blossomed' and you know she's changed completely changed as a child um you know because she used to be screaming or um really difficult and its hard for them in their 80's to deal with that wasn't it um but yeah she's slowed down she's communicating a lot better and yeah she's a lot happier as well she's always been a very happy child but when she's not been understood these big tantrums yeah distress response is what we used to call it come out yeah.</p> <p>...when we look back now and the huge tantrums we couldn't go anywhere really we'd avoid shops we'd avoid restaurants or anything like that because um she'd have meltdowns and um yeah so now it's easier you still have difficulties and you know 'oh it's going to be one of those days' but it's so much easier you know</p> <p>...she's able to say and she'll try to say and she might not be very clear in her speech but she's trying and if you don't understand her she will be you know um she'll really try to get us to understand she'll take you and make you look and things like that and she'll try and say what it is in the way she thinks the words should be said yeah lots</p>	<p>PACT positive benefits to child (behaviour improved)</p> <p>PACT positive impact on wider family</p> <p>Older generation view behaviour as 'difficult and awkward' don't see behaviour as communication</p> <p>Increased communication = decreased stress response</p> <p>PACT positive impact on family relations</p> <p>Positive impact on family relations</p> <p>PACT facilitates changes in the child – emotional (happier) and behavioural (slowed down, improved communication)</p> <p>Parents see positive behaviour change</p> <p>Misunderstood increases likelihood of tantrums</p> <p>Older generation less tolerant?</p> <p>Social isolation due to child behaviour (embarrassment, not wanting to upset child?)</p> <p>Social support easier now communication is improved</p> <p>PACT improves child communication efforts</p> <p>Child increased behaviour for communication – uses sounds and direction to help parents understand?</p>
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Appendix 6. Example of combining codes

Participants endorsement of PACT		
INTERVIEW	LINE	EXTRACT
12		<p>“but without impact you know that really did help yeah”</p> <p>“I think it’s a really really good project and I think that it should be there for the long run”</p> <p>“I can’t see how it wouldn’t help”</p>
13	<p>204-207</p> <p>325</p> <p>357</p> <p>533</p> <p>569</p> <p>572-575</p>	<p>“if somebody asked me ‘o if you’ve never had pact would you do it again I’d definitely and I’d definitely recommend it to other parents as well you know if they have a child who has no interest in you know um relationships or wanting to be alone and not taking an interest in toys I’d definitely recommend pact to them”</p> <p>“it did make a difference didn’t it yeah no there’s nothing I would change about it really”</p> <p>“I’d definitely recommend it and do it again yeah”</p> <p>“I was happy with the way it was run”</p> <p>“it really does help and it works so I definitely recommend it”</p> <p>“I think it’s important that pact carries on because I think it makes a lot of difference especially to other autistic children who’ll be growing up and you know it’s made a massive difference with [a] so I think it’s very important for them to have it and that the access is there for them to have it and the support for the parents as well yeah”</p>
14	<p>30</p> <p>85</p> <p>95-96</p> <p>373-374</p>	<p>“the actual sessions worked well”</p> <p>“it was done mainly though play so he obviously got enjoyment out of that and it was good to see”</p> <p>“the sessions themselves yeah there was benefit to them”</p> <p>“we never came away and thought ‘oh didn’t like that”</p>
15	<p>55</p> <p>113-114</p> <p>134-135</p> <p>239-240</p> <p>245-247</p>	<p>“they made me feel good”</p> <p>“so, it’s through the pact sessions that he’s done well so more than happy I would do it again I would in a heartbeat I would do it again”</p> <p>“I liked everything about it”</p> <p>“they were really good I was more than happy with them I’d do them all over again if I had to cos they just help”</p> <p>“I’ve got nothing negative to say about it I was happy the way that it didn’t just help us it helped the entire family and the entire family I was able to do what I learned in pact sessions to teach the rest of my family”</p>
16	<p>45-46</p> <p>55-56</p> <p>150-151</p> <p>343</p> <p>484-485</p> <p>494</p> <p>597</p>	<p>“there was a definite benefit to it”</p> <p>“I think for [child] it’s definitely helped”</p> <p>“we you know that having the pact has has been really really helpful for us”</p> <p>“I don’t think there’s nothing negative I can say about it no”</p> <p>“it really helped us um I recommend it to anyone that can have it I would definitely do it”</p> <p>“as I say we found it really helpful”</p> <p>“we’ve had a really positive response”</p>
17	<p>170-174</p> <p>325-328</p> <p>454-455</p>	<p>“obviously a lot of autistic children can be very difficult to engage with and communicate with then it would be a very effective therapy you know... in that respect it’s a yeah I would say a very effective therapy”</p> <p>“I can see how it would work probably better for a pre-school child ...yeah I could see how it would be more beneficial”</p> <p>“I can see how the therapy would work better for pre-school child”</p>
18	<p>232-233</p> <p>267-269</p>	<p>“without PACT I don’t think I think we’d still be struggling now at this stage”</p>

<p>797 813 824</p>		<p>“I loved it yeah, I loved every minute of it cos it was so educational for me as well it was brilliant for {child} wasn’t it but for me as a parent you saw the good things that you did and the not so good”</p> <p>“There is nothing negative to say”</p> <p>“I can’t fault it I can’t fault them cos it made me well in a way it made me a better parent for it yeah, well a lot better parent actually”</p> <p>“our experience has been nothing but positive...there’s nothing you can say that it didn’t help or there was no negatives, it was really good”</p>
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Appendix 7 HRA ethics approval



Dr Mary-Anne Pasteur
Principal Clinical Psychologist
BCUHB
Child Development Centre,
Holyhead Road,
Bangor
LL57 2EE

29 November 2019

Dear Dr Pasteur

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title: Paediatric Autism Communication Therapy (PACT):
from a randomised controlled trial to a community
clinical setting. The Parent Perspective

IRAS project ID: 270383

Protocol number: LSRP

REC reference: 19/LO/1817

Sponsor Bangor University

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the “Information to support study set up” section towards the end of this letter.

1 How should I work with participating NHS/HSC organisations in Northern Ireland

and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report

(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

2 How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

3 What are my notification responsibilities during the study?

The standard conditions document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

4 Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **270383**. Please quote this on all correspondence.

Yours sincerely

Isobel Lyle

HRA Approvals Manager

Email: hra.approval@nhs.net

Copy to: Mr Huw Ellis



Participant Information Sheet

Paediatric Autism Communication Therapy (PACT): from a randomised controlled trial to a community clinical setting. The Parent Perspective

Research Team:

Lindsay Jackson: Trainee Clinical Psychologist
Dr. Mary-Anne Pasteur: Clinical Psychologist

We would like to invite you to take part in a research study undertaken by Lindsay Jackson, Trainee Clinical Psychologist in part of a Doctorate in Clinical Psychology. This study seeks to understand the service user perspective of receiving the PACT intervention. This information sheet gives you more information about the study; please read it carefully before deciding whether you would like to take part. One of the researchers will be happy to go through this sheet with you and answer any questions you may have.

The project has been approved by the Bangor University Psychology Research Ethics Committee and the NHS Research Ethics Committee, London-Queen Square.

What is the purpose of the study?

Research has shown that the PACT intervention helps parents and carers to strengthen the communication with their child. This is the first time PACT has been delivered in a community clinical setting and little is known about how parents and carers view receiving PACT. This study aims to hear your views about how you found the PACT sessions, what got in the way of you getting the most out of the sessions and what made it work. We are also interested in finding out why you chose to either take part in PACT sessions or choose not to continue. The study aims to give a voice to parents and carers who were offered PACT sessions so that clinicians may make improvements to service delivery.

Who is carrying out the research?

Lindsay Jackson is a Trainee Clinical Psychologist on the North Wales Clinical Psychology Doctorate and is undertaking this research study as part of her training as a clinical psychologist at Bangor University. Dr Mary-Anne Pasteur, Senior Clinical Psychologist is a PACT clinician and will be supervising the research.

Why have I been invited?

You have been invited because you are someone who has either participated in PACT sessions or have been invited to receive PACT sessions and chosen not to participate.

Do I have to take part?

No. Taking part is completely voluntary. We ask that you read this leaflet carefully before you decide. Please ask a member of the research team about anything that you are unsure of. If you decide not

to take part, you do not need to give a reason; choosing not to take part will not affect any services you receive in any way.

What will happen if I do take part?

You will be asked to meet with a researcher and answer questions regarding your experience of attending PACT sessions. This will be an interview that will be audio recorded. The researcher will then listen to your interview and try to summarise the important themes that you talked about. Because your views are really important to us, we will send you a copy of the summary (either by mail or encrypted email, whichever you prefer) and ask you to read through the summary to see if we have got it right. We will ask you if you have any suggestions to add to what we have come up with. This could be done via email, telephone call, or face-to-face, whichever suits you best.

What will the interview be about?

The interviewer will be asking you to tell us about your opinion of PACT, particularly regarding what parts of the intervention you found difficult/easy or helpful/unhelpful and why you decided to attend sessions (or not). The interview will be semi-structured, I will ask you some questions about the PACT sessions and you will have the opportunity to give your opinion about the PACT sessions.

The interviews will be conducted in English, we are very sorry that the researcher does not have the ability to conduct the interviews in any other language and we do not have access to an interpretation service.

What is the time commitment?

Interview: You will meet with the researcher for an interview which is expected to take between 1 and 1½ hours. There will be opportunities to take breaks as needed.

The follow-up could be very brief if you are happy with how the researcher has analysed your interview or could take longer if you feel that they haven't quite got it right. This is expected to be between 30mins to an hour and is dependent upon what changes you'd like to make.

Where will the interview take place?

The interview will be at a mutually agreed location. This could be at a clinic near your home where you are comfortable to attend, or your home if childcare is difficult to arrange.

Will my involvement with LD services or any other service I am attending be affected?

No, you will continue receiving the same service.

What are possible benefits of taking part?

You will be helping the IMPACT team to better understand the experience of parents receiving PACT sessions. This will help them with planning services in the future to ensure that parents receive the best possible treatment for their child.

You will also receive a gift voucher of £15 at the start of the interview for contributing your time in taking part. Should you decide at any point to stop the interview or withdraw from the study, you WILL NOT be asked to return the gift voucher.

What are possible disadvantages of taking part?

This study involves asking you about your experiences of receiving PACT, the impact it may have had on your family and relationships and your decisions to either attend or not attend. This may involve talking about difficult times or problems that you encountered which could result in uncomfortable emotions arising.

You will also be required to set aside some time to be interviewed.

Will my information be kept confidential?

Yes.

Any information collected about you during this research study will be kept strictly confidential. At the beginning of the research, you will be assigned a random number, which will be your unique identification number throughout the study. The information about you can only be identified by this unique identification number known only to the researchers. Your research data (i.e. the transcript of your interview) will be collected by the researcher. This data will not be in any way linked to your personal details (e.g. name, address etc.). Information will be treated in confidence however should any concerns about the safety or wellbeing of you or your child it might be necessary to report the matter to an appropriate professional.

If, at any time during the study, you disclose any incidents where you, someone you know or professionals have acted in an unethical or abusive way, the researcher has a **statutory (i.e. legal) requirement** to breach confidentiality. This means that the researcher cannot keep this information confidential and is required to report this information to the appropriate responsible person or authority. Whenever practicable, the researcher will inform you that they will be breaching confidentiality by disclosing the information you have provided. The researcher can disclose this information without your explicit consent, if it is deemed in your best interest, the interest of the child or children in your care or the best interest of the public, to do so.

What will happen to the results of the study?

The data will be written up in the form of a doctoral thesis, a copy of which will be available from Bangor University Library. The data will be used to inform service delivery and improve outcomes for parents and carers attending PACT.

The data may also be used for academic research publications (for instance, articles in Clinical Psychology magazines, or conference presentations); you will not be identifiable. If you want to know more about the results of the research you can speak to the research team.

Who will have access to information about me?

Your details are confidential. Your name is only recorded for consent purposes, and at the beginning of the study you will be assigned a random study number. Additional measures of confidentiality will be in place, including keeping any data you have supplied, including your consent form, in a locked filing cabinet. Any computer data will be stored safely on a password-protected NHS or Bangor University computer. All data will be retained by the research team for a minimum of 5 years, after which they will be safely and securely disposed of, in line with NHS policies. Anonymised data is stored for 5 years for a number of reasons; firstly, transparency of information ensures published results are related to the data collected. Secondly, storing data to reproduce the study measures if the results could be reproduced or repeated in the same way. Thirdly, storing data provides an audit trail of the procedures and methods used in carrying out the study. The audio-recording of your interview will be destroyed once the principal researcher (Lindsay Jackson) has completed her training and been awarded her doctorate. Only the research team will have access to the transcripts and audio-recordings.

What if I want to withdraw from the study?

You can withdraw from the interview at any time, and you do not need to give an explanation. You also have the right to ask that any data you have supplied up to that point be withdrawn/destroyed. However, after the information from the interview you gave has been analysed and the follow-up

discussion regarding this analysis has taken place, it will no longer be possible to withdraw your data from the research. Up until the follow-up discussion has taken place and the analysis has been agreed between yourself and the researcher, you can ask to have your data destroyed. You will be informed when this point has been reached and asked to confirm that you are still happy for your data to be used. Please feel free to discuss this further with a member of the research team.

You have the right to decline answering particular questions during the interview if you are uncomfortable.

What if something goes wrong?

If you have any concerns, you can contact any member of the research team, using the contact details at the bottom of the information sheet. You are urged to contact your GP should you be concerned about your mental wellbeing. Further places of support will also be available should you require it.

If you remain unhappy about the research, the response to any concerns you may have raised, and/or wish to raise a complaint about any aspect of the research, please contact **Huw Ellis, Psychology Manager on 01248 38 3229.**

How do I find out more or volunteer to take part in the research study?

If you would like to find out more, or take part in the study, please complete the attached form and either post it in the stamped addressed envelope provided or hand in to your PACT clinician. If the PACT clinician does not hear from you they may contact you by telephone to arrange an appointment at your convenience. Once you have given consent, the researcher will arrange a convenient time and place for the interview to take place. Completing the below form does not mean that you have consented to take part in the research or commit you to doing so. You can change your mind at any time.

For further information, please contact:

Name:	Lindsay Jackson, Trainee Clinical Psychologist		
Address:	North Wales Clinical Psychology Sessions (NWCPP) School of Psychology, Brigantia Building, Bangor University, Bangor, Gwynedd, North Wales LL57 2DG		
Phone:	01248 388365	Email:	sepa83@bangor.ac.uk

Name:	Dr.Mary-Anne Pasteur, Consultant Clinical Psychologist Child Development Centre Holyhead Road Bangor LL57 2EE		
Address:	Child development Centre,		

Phone:	03000852602	Email:	<u>Mary-</u> Anne.Pasteur@wales.nhs.uk
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Thank you for taking the time to read this information sheet.

Lindsay Jackson
North Wales Clinical Psychology Sessions (NWCPP)
School of Psychology,
Brigantia Building,
Bangor University,
Bangor,
Gwynedd,
North Wales
LL57 2DG

I am interested in taking part in the research project described above. I would like to share my views and experiences of PACT sessions.

What are your contact details?

Name: _____

Landline: _____

Mobile 1: _____

Mobile 2: _____

Email: _____

What is the best way to contact you? _____

What is the best time to contact you? _____

Is there a time when it is not good to contact you? _____

(You will only be contacted between the hours of 9.00am – 5.00pm Monday – Friday unless you specifically request to be contacted outside those hours)

By returning this form you are under No Obligation to take part in the research if you do not wish to. If you decide to take part in the research, you can change your mind at any time.

Please return this form to your PACT clinician or in the stamped address envelope provided.

General Data Protection Regulation: GDPR

Bangor University is the sponsor for this study based in North Wales. The researcher will be using

information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Bangor University will keep information for the purpose of the study for 5 years after the study is completed. This information will be held by Bangor University and BCUHB. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting the research team.

BCUHB will keep your name, and contact details confidential and will not pass this information to Bangor University. BCUHB will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from Bangor University] and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Bangor University will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name, or contact details.

BCUHB will collect information from you and your medical records for this research study in accordance with our instructions. BCUHB will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study.

Where this information could identify you, the information will be held securely with strict arrangements about who can access the information. The information will only be used for the purpose of health and care research, or to contact you about future opportunities to participate in research. It will not be used to make decisions about future services available to you, such as insurance. Where there is a risk that you can be identified your data will only be used in research that has been independently reviewed by an ethics committee.

PARTICIPANT CONSENT FORM

Paediatric Autism Communication Therapy (PACT): from a randomised controlled trial to a community clinical setting. The Parent Perspective

Please initial each box if you agree with the statement

- 1 I confirm that I have read and understand the information sheet dated 18.11.2019 for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered to my satisfaction.
- 2 I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my medical care or legal rights being affected.
- 3 I understand that I can contact my GP, speak to a PACT clinician or discuss with the research team if I become concerned about emotional wellbeing during the interview.
- 4 I understand that data collected about me during this study will be anonymised (i.e. it will be made anonymous) before it is submitted for publication.
- 5 I agree to being audio recorded when I am interviewed
- 6 I agree to anonymous quotations of what I have said being used in publications

PTO

7 I consent to my anonymised transcript being stored for 5 years after the student receives their Doctorate in Clinical Psychology.

8 I agree to take part in this study.

.....
Name of Participant Date Signature

.....
Researcher Date Signature

DEBRIEFING INFORMATION

Paediatric Autism Communication Therapy (PACT), from a randomised controlled trial to a community setting. The Parent Perspective

Thank you for taking the time to participate in this research study by sharing your views of the PACT intervention. Your generosity and willingness to participate in this study is greatly appreciated. The purpose of the present study is to assess how acceptable PACT is in a community setting and the questions I asked you were designed to give you the opportunity to share your experiences of either receiving PACT or choosing not to receive PACT. These experiences will be valuable in understanding how PACT is received by parent's and carers and will help to shape the delivery of the PACT intervention for future parents and carers.

Sometimes people may find answering questions about their experiences distressing. If this is the case and you would like to speak to someone about your thoughts, please contact your current clinician if you have one, your GP or a trusted member of your support network.

Following transcription of your interview if you would like the opportunity to review our meeting I will contact you to ensure I have accurately captured what you have told me and check that you are happy with it. You will also be offered the opportunity to receive the final analysis written up in journal format. This could be sent via email, post or in person if you would prefer. Please let the researcher know if you would like to receive further information and your preferred method of receiving it.

If you have any concerns or complaints about this study, or the conduct of individuals conducting this study, then please contact College Manager, School of Psychology, Bangor University, Bangor, Gwynedd LL57 2AS or e-mail huw.ellis@bangor.ac.uk

If you are interested in the origins of PACT, you may wish to read the following reference:

Green, J., Charman, T., McConachie, H., Aldred, C., Slonims, V., Howlin, P., ... PACT Consortium (2010). Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial. *Lancet (London, England)*, 375(9732), 2152–2160. doi:10.1016/S0140-6736(10)60587-9

Thesis Word Count

Acknowledgement and Dedication:	543
Thesis Abstract:	266
Chapter 1	
Word count without tables and figures:	7228
Tables and figures:	1564
Chapter 2	
Word count without tables and figures:	8971
Tables and figures:	336
Chapter 3	
Word count:	3221
References word count:	3706
Appendices:	11341
Word count:	66
Total word count: (excluding abstract, tables, figures and references, title pages, dedication)	19420
Overall thesis word count:	37960