

Activating Parents in Early Intervention: The role of relationship in functional and family gains

by

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Thesis

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Abstract

Including parents of children with a disability in early intervention programs has been widely advocated by multiple health professional disciplines. Within these interventions a substantial body of research supports the positive influence of the parent-child relationship on developmental outcomes. Programs that upskill parents, reflect family context and focus on increased participation in broader community and social settings are now considered best practice. Such programs have good face validity, with recent studies showing parents strongly endorsing the sharing of skills and strategies, allowing them to extend the child's learning to multiple situations including within the family and wider community. Despite this evidence, successful widespread implementation of relationally-based programs has been difficult to achieve. Working directly with parents can include challenges beyond simply introducing strategies and having them apply these outside therapy sessions. It requires therapists to work in a context where parents may be struggling with feelings of incompetence and experiencing high levels of individual and relational stress that are often associated with parenting a child with a disability. Developing therapy goals that reflect family imperatives can also present challenges as therapists and parents may be driven by objectives derived from developmental checklists rather than contextual, family-prioritised goals. This thesis investigated the efficacy of a manualised program designed by the candidate (PCRI-EI; parent child relationally informed – early intervention) in addressing these challenges in an early childhood development clinic that delivers multidisciplinary services to children with disabilities. A preliminary case study showed promising changes for the family, in reduced stress and improved sense of competency for the parents, as well as positive impacts on functional outcomes for the child. Parents reported improvements in family engagement in community activities as well as in their own ability to more broadly understand their child's challenges. A subsequent qualitative study investigated the

experience of therapists as they made the transition to a relationally-based practice. Feedback from therapists indicated the systematic approach embedded in the protocol combined with reflective supervision built their competence and confidence in working collaboratively with families. At the same time, they reported being better able to generate therapeutic goals that preferenced family context and priorities over therapist-driven developmental aims. Changes in parents' stress, psychological well-being and sense of competence, was investigated in a third study. Findings showed notable reductions in stress levels over time particularly those generated by parents' conceptualisation of their child as difficult. Increased parental wellbeing and sense of competency were also reported. These changes were consistent across diagnostic categories. The final component of the thesis investigated impacts of PCRI-EI on the child's functional capacity. Significant and marked increases in functioning were observed across time. The gains did not differ by diagnosis and parental feedback indicated family context was prioritised and valued. These improvements were generalised throughout social, community and educational settings. Taken together these findings indicate that through the combination of a manualised therapy model and ongoing reflective supervision, PCRI-EI supports the implementation of relationally-based, family-centred practices. PCRI-EI appears to provide the *how-to* component. The absence of which seems to have inhibited the widespread adoption of such programs in early intervention. Given the exploratory nature of the thesis these conclusions require further investigation. Nonetheless, they suggest successfully engaging parents in early intervention requires a systematic approach embedded in the practices of the organisation. The role of the therapist in supporting parents build the skills to work in this context is critical. Achieving that change in therapists' capacity involves a similarly methodical approach that integrates professional development, reflective supervision and an appreciation of the professional identity challenges the changed way of working may present. This combination of factors does not appear to have been addressed in

previous investigations around establishing relationally-based practices in early childhood interventions.

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This paper HAS NOT been submitted for an award by another research degree candidate (Co-Author), either at CQUniversity or elsewhere.

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In conducting the study, I was responsible for conception and design, analysis and interpretation, drafting and production. This publication was written by me. I formed the research question, collated the literature, analysed the data and interpreted the results. [70% contributed by Candidate]

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My first co-author, Professor Kevin Ronan, contributed to conception, design, analysis and interpretation and reviewed and edited drafts. [15%].

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CHAPTER 1: Activating parents in early intervention: The role of relationship in functional and family gains

The scientific examination of early childhood development is “a treasure that should be returned to babies and their families as a gift from science” (Fraiberg, 1980, p.3, as cited in Weatherston, 2007).

According to recent figures from the Australian Institute of Welfare (AIHW, 2020), in 2018 an estimated 4.5% of children aged between 0- and 14-years had a profound or severe disability; defined as having core activity limitation and schooling restrictions. These core limitations are categorised as one, or a combination of, intellectual, sensory, communication, psychosocial, physical, or acquired (e.g., brain injury) disabilities. When this broad population data is considered at the level of an individual family, the challenges of having a child with a disability is compelling, impacting many aspects of family functioning and well-being.

To illustrate, for most families when a child is born their arrival is met with excitement and the expectation of wellbeing. This presumption is filled with hopes and dreams as well as the unconscious anticipation of normative development. In most cases, these expectancies are met. A healthy infant starts to grow and quickly develops relationships, language capacity, cognitive skills, and physical competencies. For other families, once they are past the counting of fingers and toes, there is a different reality. One that brings another experience, shrouded in confusion, ambivalence, considerable distress, a sense of incompetence and, at times, loss of hope. As Kalmanson (2009) poignantly describes it:

Something intangible awaits in the shadows of development, only becoming palpable by perplexing the parents when unconscious expectations about the quality of connection with their infant begins to feel like unrequited love (p. 40).

These shadows of development are ultimately categorised in diagnostic terms including Global Developmental Delay, Intellectual Disability, Autism Spectrum Disorder, Down Syndrome, and Cerebral Palsy to name a few. Additionally, there are the children who have suffered trauma at birth or have rare genetic syndromes. In these cases, parents search for reasons and histories trying to make sense of the very different experience to the one that they had imagined. They also must manage the high levels of stress both individual and relational that having a child with a disability can bring (Hayes & Watson, 2013). The implications of relational stress (within the parent-child relationship) are important to highlight. Without an appreciation of the impacts of the child's developmental difficulties on behaviour, parents often begin to experience their child as difficult. Consequently, their responses to the perceived difficult behaviour can become punitive, which prompts increasing difficult behaviour (Greenberg et al., 2006; Neece et al., 2012). This cycle becomes self-perpetuating, substantially impacting the already compromised developmental trajectory of the child as well as increasing stress levels and disrupting many aspects of family life (Robinson & Neece, 2015). Equally troubling are findings that higher levels of parental stress are associated with poorer outcomes in early intervention programs for children with a developmental disability as well as in parental skills enhancement training (Davis & Neece, 2017).

After time and multiple consultations with various professionals, these families arrive at a point where treatment becomes the imperative, with early intervention seen as the best option (Guralnick, 2017). Early intervention programs have been found to moderate the impacts of the child's disability, expanding parents' skills, and providing a foundation for the child's longer-term development, health, and well-being (Sukkar et al., 2017). It is to those programs that parents or care-givers shift their hopes for their child, themselves, and their wider family.

Historically, early interventions to develop capacity in children with disabilities were addressed within discipline boundaries e.g., speech pathology, occupational therapy, and physiotherapy (King et al., 2009). Described as a functional diagnostic model (Matthews & Rix, 2013), treatment was therapist driven and focused on goals and activities that increased capacity. This approach often strongly influenced parenting and early family experiences (Rix & Paige-Smith, 2008). It also increased stress for parents who reported feeling that the interventions were imposed and that their parenting skills were being constantly assessed (Matthews & Rix, 2013). Recent evidence has suggested that these clinically informed, evidence-based practices may not be as effective when applied without considering the wider social and relational influences in child development (Barfoot et al., 2017). This questioning has resulted in a paradigm shift to a philosophy and practice of relationship-focused interventions where the parent-child relationship is considered a fundamental component in the delivery of therapy and integral to successful outcomes (Barfoot et al., 2015; Salisbury & Copeland, 2013). However, despite endorsement of such an approach across disciplines (Hughes-Scholes & Gavidia-Payne, 2019; Pretis, 2011), successful implementation of relationally-based programs has proved difficult (Campbell et al., 2009). Systematically developing allied health therapists' capacity, either through education, professional development, or mentoring, to engage relationally with parents and families appears fundamental to the successful implementation of such programs (Campbell et al., 2009).

The purpose of this thesis is to investigate the effectiveness of a program that was specifically developed to integrate the parent-child relationship into the delivery of therapy in early childhood development settings. The intent of the intervention was to systematically embed into practice the essential features of relationally-based, early childhood interventions for families of children with disabilities. As well as addressing the potentially disrupted attachments, these elements included shifting the focus of treatment from the child alone to

the broader family context where developmental goals were collaboratively established. Parents were included in the delivery of therapy to expand their skills, so they were able to apply them in broader family and community settings. This partnership with parents also offered support and education intended to reduce parental stress and enhance psychological well-being and sense of competency.

Creating this therapeutic partnership was dependent on therapists being able to transition to a relationally-based model of practice. Regular reflective supervision between the senior psychologist (program developer) and the allied health therapists provided the mentoring support needed to build therapists' confidence and competency working this way. These practices were aggregated under the umbrella term parent child relationally informed – early intervention (PCRI-EI).

In this chapter the literature guiding the thesis is reviewed. Firstly, the importance of the parent-child relationship in development is discussed. This section also includes a description of the challenges and alternate methods of developing that relationship when the child has a disability. Following this, programs that have been successful in repairing parent-child relationships in typically developing populations are introduced to understand what they might contribute to a disability setting. An overall summary including the unique challenges of implementing a relationally-based program in an early childhood development setting completes the review. The rationale for this thesis is then explained and overall aims outlined.

The parent-child relationship

Attachment theory and its developmental consequences, which include communication, emotional regulation, language, and cognition, has illuminated the role and impacts of the parent-child relationship across the lifespan (Bowlby, 1969, 1973, 1980). In establishing a secure parent-child relationship, while the role of the parent is central, the

development of the relationship is conceptualised as a both-way process with parent and child taking an active part (Bowlby). A key aspect of which is the child providing cues, which the parent reads and responds to (Barfoot et al., 2017). Whittingham (2016) suggests the metaphor of a control system, where the child controls the type and intensity of their cues, and the parent attunes and responds accordingly. This system is thought to facilitate a calm-alert state integral in optimising learning and development (Barfoot, 2017). It also establishes a secure base from which the child can safely and confidently explore the world; a notion that remains a fundamental component of attachment theory (Ainsworth, 1963; Bowlby, 1988). These cues and responses then create a template that manifests across the lifespan (Weatherston, 2007).

More recently, Bowlby's early theory and research has been expanded to include concepts such as reflective functioning (Fonagy, et al., 2002; Shai & Belsky, 2011), mentalising (Slade, 2005) and insightfulness (Oppenheim, et al., 2012). In addition, links between attachment and normative developmental gains (e.g., cognitive, language, social and emotional) have been the subject of a broadening research base to include children who have atypical developmental trajectories (Oppenheim et al., 2012).

Reflective Functioning

Reflective functioning (Fonagy et al., 1991) is the capacity to understand behaviour as being representative of underlying mental states and intentions. When applied to the relationship between parent and child, the theory emphasises the critical contribution of the parent's capacity to reflect on the child's internal experience in establishing a secure attachment and facilitating other developmental outcomes (Slade, 2005). Parental reflective capacity develops from early simple imitation of facial expressions, gestures and vocalisations into a complex, dynamic understanding of minds through which the child develops (Soderstrom & Skarderud, 2009). Keeping the child in mind through looks,

gestures, verbal responses, tone, and words, brings a reality to the child's inner experience (Fonagy et al., 2002). Doing so promotes a growing capacity in the child to take ownership of their internal state and sense of self. By keeping the child in mind in a reflective sense, the sensitive, responsive caregiver helps them understand what it is like to be with another person and how to act in social contexts, a skill that can be difficult for atypically developing children to acquire (Soderstrom & Skarderud, 2009). It also develops the secure base, which as previously noted is a cardinal feature of attachment theory (Bowlby, 1988).

Mentalising

Looking to utilise its therapeutic potential, Slade (2009) introduced mentalising to the parents of a child with a diagnosis of autism spectrum disorder (ASD). She described the challenges of mentalising the internal motives of a child for whom connecting with the world can be confusing and at times frightening. This results in a situation that is made even more difficult when the child's cues are not easily recognised or understood by the parent. Something Slade described as requiring parents to “mentalise the unmentalisable” (p.7). She elaborated, noting that like all children, the child with Autism is critically dependent on the relationship for survival. Beyond basic needs, the child also requires their parents to help them learn to negotiate the world. This includes creating a stable, safe place (secure base) from which the child can extend themselves and navigate the challenges of development (fundamental in early intervention settings).

Complicating matters further, the parents of a child with a disability are required to make sense of cues and signals that are at times incomprehensible, appear as happenstance or are labelled as being a part of the diagnosis. In addition, parents must do this in a context short of the expected shared joys and delights of mutuality and reciprocity that are available in typically developing situations. At the same time, they need to be able to manage high levels of stress, feelings of incompetence and a profound sense of loss (Robinson & Neece,

2015; Slade, 2009). Considering the difficulty of developing reflective skills in this context, Slade noted that other conceptualisations of reflective functioning might provide answers on how to help parents do that.

Insightfulness

One such perspective has been termed insightfulness (Oppenheim et al., 2012). Building on the concepts contained in reflective functioning and mentalising, Oppenheim and colleagues (2002) were interested in assessing parents' ability to notice the child's cues, match and respond sensitively while considering the needs and developmental capacity of the child. To do that they developed the Insightfulness Assessment (IA; Oppenheim & Koren-Karie, 2009). The idea being that by creating an empirical assessment of insightfulness, they could investigate parent-child interactions in real-time rather than via a reflective narrative. It would also provide the opportunity to examine the presumed impact of attachment on the parent-child relationship across settings and between diagnostic groups of children (i.e., within typical and atypical developmental trajectories).

The assessment relies on the use of video review of interactions between parent and child. Parents are asked a series of questions, which are scored and classified into one of four categories. The first category indicates the capacity for insightfulness (positive insightfulness). The remaining three categories represent a lack of insightfulness described in different ways (one-sided, disengaged, or mixed). For a detailed explanation of the protocol please see Oppenheim and Koren-Karie (2001, 2016). Of interest for this thesis is that as well as applying IA in typically developing contexts and looking at outcomes for the child, Oppenheim and colleagues (2009) applied it with atypically developing children. For example, in studies of mothers with children with autism spectrum disorder (ASD), insightful mothers were more responsive and sensitive in their interactions with their children, and their children were more likely to be securely attached than those whose mothers fell into one of

the non-insightful categories. Similar outcomes were obtained for children with Intellectual Disabilities (Feniger-Shaal & Oppenheim, 2013). Taken together these findings point to the possibility that building insightfulness (and the associated high levels of responsiveness and sensitivity) in parents of children with a disability may prove valuable in a developmental context (Baker et al., 2010). These studies offer further support to the contention that it is possible for children with disabilities to form a secure attachment. However, this still requires parents to be able to recognise and respond to cueing systems that can be difficult to comprehend. That said, helping parents who may be low in insightfulness build that capacity remains challenging. Particularly when established barriers to developing insightfulness are worry and anger (Oppenheim et al., 2002) both of which are often present in parents of a child with a disability (Robinson & Neece, 2015).

Given the fact that over time typical parent-child interactions shift from nonverbal to verbal interactions, Koren-Karie and colleagues (2003) also included parent-child dialogues in their investigations of insightfulness. The assumption being that if in infancy the interactions between parent and child established a secure base, the language used by both parties in later life (called emotionally matched dialogues) would continue to reflect that secure base. Transcripts of dialogues were analysed and classified as either emotionally matched (a secure base) or as one of three unmatched categories (excessive, flat, or inconsistent), which showed a lack of a secure base. As expected, children who were securely attached as an infant were more likely to engage in emotionally matched dialogues when they were older. Turning their attention to high-risk dyads (difficult behaviour and high levels of emotional dysregulation in the child, high stress levels in parents), the authors argued that children in that situation had difficulty engaging in matched dialogue in later life because of the disruptions in their attachments during infancy. This prompted the question as to whether the ability to create matched dialogues could be increased through intervention. Oppenheim

and Koren-Karie (2009) tested this hypothesis by working with parents and children considered high risk because of behavioural and emotional issues in the children and multiple situational stressors for parents.

Parents and children both received therapy. For the child it was an attachment-based intervention designed to enhance their feelings of security and help with emotional regulation. For parents, it involved talking to therapists about parenting strategies to support the child. The findings showed a significant increase in matched dialogue in the dyads, resulting in a reduction in the difficult behaviours displayed by the children. Acknowledging uncertainty as to which aspect of the therapy precipitated the changes (i.e., parent- or child-focused therapy), the study indicates parents and children can learn language-based skills that may change the attachment style that developed early in life. The findings also suggest working with parents by taking a mental health/skills development approach has merit and impact.

Parent Embodied Mentalising

In their efforts to integrate mentalising skills into therapy, Shai and Belsky (2011) argued that the way reflective capacity is currently considered (language based) fell short of capturing the full range of mentalising opportunities that exist in the parent-child relationship. Addressing this perceived shortfall, they introduced the idea of parental embodied mentalising (PEM). PEM is defined as the parent's ability to notice, interpret, and respond to the child's internal mental states based on the child's whole of body movement (i.e., their kinaesthetic cues). By using matching physical responses, parents connect and respond to the cue using the child's kinaesthetic language – a non-verbal facsimile of the matched dialogue proposed by Oppenheim et al. (2009). Extending this hypothesis, Shai and Belsky (2011) contend that when both parties are engaged in this body-movement based communication the impact can be substantial. When the parent responds to the body movements of the child, the

internal intentions (of the child) are recognised. This is not a simple matter of copying. It involves a complementary, sensitive physically-generated response by the parent to the various kinaesthetically expressed mental states of the child. By recognising the non-verbal movements as cues that reflect internal experiences, and by responding with similar movement, it appears parents can more effectively regulate their child and instill a sense of safety (secure base) from which the child can explore.

A simple example in our clinic involves interactions between a mother and her young, non-verbal child with a diagnosis of ASD. In play-based sessions the child had an array of non-verbal responses which seemed to be contextually bound. When the child was enjoying the play, they would put one hand under their chin and wiggle their fingers. Mum was encouraged to copy the movement. At the same time, she said “you are having fun”. Over the next several sessions as well as making the movement more frequently, the child began to look at Mum as she imitated the movement. Unexpectedly, the child began to produce other hand movements, which Mum similarly copied and named. As Mum became more skilled at identifying what the hand movements represented, she began to identify early signs of distress and was able to regulate her child before the distress overwhelmed. She summarised the personal impact of this experience simply saying – “I now know he needs me”.

Shai and Belsky (2011) differentiate between high and low levels of PEM. A parent high in PEM better understands that their child’s actions are motivated by mental states and are meaningful. Consequently, the child develops a sense that they can actively communicate their ideas and intentions to others who can and will respond, promoting more secure attachment and exploration. In contrast, when a parent is low in PEM, the child would have less of these experiences leading to compromises in their sense of agency and connectedness. The resultant attachment pattern would be characterised as insecure.

The authors illustrated the difference between high and low PEM using the example of a child's response to being tickled. As the tickling continues, the child slightly moves away and brings their arms across their stomach. A mother high in PEM would recognise this movement as an expression of displeasure and change her response perhaps by moving back. A mother low in PEM would miss this subtle signal and not be responsive (e.g., continue to tickle) possibly creating distress for the child (Shai & Belsky, 2011).

In sum, PEM posits the idea that a secure attachment, and the developmental capacity it brings, can also be facilitated through a kinaesthetic mentalising process, where body cues and signals provide an agenda for a corresponding sensitive response. This is particularly valuable when developing parents' relational skills in a disability context where language is often compromised and where the child may be relying on non-verbal mechanisms to communicate their internal experiences.

Active imitation

Taking a similar view and influenced by the work of Daniel Stern (1977), Ephraim (1986) developed active imitation, a technique for working with people who have severe learning, communication, and behavioural difficulties. The process involves interacting using body language to build up meaningful conversations. Ephraim further developed the practice based on his frustration with the then prevalent methods of working with people with learning and communication disabilities. Nind and Hewitt (1994) integrated these techniques into the curriculum of a school for children with profound disabilities and behavioural difficulties. They termed it intensive interaction (Caldwell, 2006) and in this context it was extensively used with children (Nind & Hewitt, 1994, 1998, 2001).

Caldwell (2006) described this approach as one of learning the language of the other and responding to what has meaning for them in that context. She cited her own and others' experience of connecting with their communication partner as promoting change. To

illustrate this experience, she described the case of Bill who was deaf, blind, and engaging in very challenging behaviour to the point where it was difficult for staff to care for him:

Bill constantly licks his lips, moving his tongue round and round. This is the way he talks to himself, his brain/body language. He will not let me touch his hands, so I make a circular movement on the top of his foot. After a minute or two he starts to laugh, so loudly that staff come running from all over the house. They have never heard him laugh before. We join in his pleasure, for although he cannot hear me laugh, he can feel me shaking in accord with his laughter. I continue drawing movements on his foot, which reflect his tongue movement (p. 281).

Caldwell (2003, 2005) argued this process provides a reference point that is recognisable. This reference point can help promote connection and personal meaning including the development of a secure base from which to explore. However, imitation as an empathic form of feedback needs to be contingent and personal to elicit a sense of connection and agency (Shay & Belsky, 2011). This idea of imitation promoting agency is predicated on the notion that the brain, which generated the original stimulus is in a sense recognising its own signals, prompted by the matched responsiveness of the other (Caldwell, 2006). Active imitation is aimed at shifting the attention of the individual from their (previous) internal orientation to the person imitating thereby generating an outward interest in the world of the other and beyond. Using a case study with a 23-year-old man with a diagnosis of autism spectrum disorder (ASD), profound learning disabilities and severe epilepsy, Caldwell detailed her use of intensive interaction with him:

It is day two now. Gabriel is flicking string. I use a similar length, which to begin with, he grabs from me. I continue with more string. Gradually he becomes less possessive. He begins to shake his and then to turn and see if I shake mine, answering him in a way that has meaning for his brain. His face becomes calmer, and he begins

to look around at his surroundings in a way we have not seen before, as if seeing them as they are without confusion. He becomes more and more focused on what has become our interaction, smiling to himself, and referring back to me with his gaze (p. 280).

Another observed outcome of intensive interaction is the “reduction of stress rooted in sensory confusion” (Caldwell, 2006, p.280), which she hypothesises as characteristic of people with ASD. This reduced level of stress allows the person with ASD to manage experiences that would be normally difficult or even impossible for them to do in their usual context. Thereby opening the opportunity for them to extend their participation into a bigger world outside of themselves. In terms of research, Caldwell’s (2005) findings indicate that this process can produce body language changes and increased eye contact and shared attention. Sensory hypersensitivities often experienced by people with ASD have also been found to decrease, ultimately opening the way for increased participation in a variety of activities.

When taken together, the insights from PEM and active imitation illuminate a different pathway to the development of reflective capacity when language development is compromised, and the cuing system is difficult to comprehend. For parents of a child with a disability this is a frequent experience (Slade, 2009). By developing the capacity to appreciate that a child can represent their internal experiences using their body, parents learn to generate a different set of sensitive non-verbal responses hypothesised to create the secure base fundamental in producing positive developmental outcomes (Barfoot et al., 2017).

Improving disrupted attachments: Programs for typically developing children

Mismatches between cues and responses from parents are also argued to impact attachment processes in typically developing dyads (Marvin et al., 2002; Oppenheim et al., 2012). Consequently, programs developed to address attachment difficulties in this context

may offer an insight into promoting attachment and secure base within disability populations. The next section references two programs where building the skills of the parent in repairing disrupted attachments is the focus of the intervention.

Circle of security – a parent-led intervention

Parent-led interventions are designed to improve parent-child communication, particularly in the parent's ability to read and respond to the child's cues (Pickles et al., 2016). In such circumstances, the parent must bring an active, conscious, learned orientation to their own child's unique cues to help the child develop a secure base. Equipping parents with these skills extends the opportunity for learning beyond therapy rooms to many settings (Rocha et al., 2007).

Exploring the idea of a parent-led intervention within a typically developing dyad, Marvin et al., (2002) developed a group treatment protocol called circle of security (COS: Marvin et al., 2002) to provide parent education and therapy that is informed by attachment theory. Conducted over twenty weeks in small groups of six and using videotapes to review interactions, this individualised program has five overarching goals:

- (1) to create a holding environment or secure base from which the parents can explore their parenting.
- (2) to provide the parents with a user-friendly map of attachment theory that is called the circle of security.
- (3) to help parents develop their observational skills, especially as these apply to reading and responding to their children's (often subtle and misleading) cues.
- (4) to develop a process of reflective dialogue – a skill that the parent can then use internally; this process is seen as the central dynamic for change.
- (5) to support the parents' empathic shift from a defensive process to empathy for their children (p.116).

Their target high-risk population comprised parents or care-givers of toddlers aged one to four years who were classified as having disordered attachments. Given the severity of negative outcomes associated with a disordered pattern of attachment (Moss et al., 2005; Sroufe et al., 2005), intervention success was defined as achieving a shift in pattern from disordered to ordered (secure or insecure) as opposed to a shift from insecure to secure attachment.

In terms of the intervention itself, integral to success was the identification of the unique pattern of attachment-caregiving interactions that the authors suggest can appear like a reciprocal dance that involves both parent and child (Marvin et al., 2002). When these distinct patterns are identified, the intervention is individualised using a method called the “creation of the linchpin issue” (p.1020). The linchpin issue is described as the most problematic pattern of attachment behaviour identified within the dyad. When successfully addressed it is expected to have substantial positive impact on the child’s attachment. This is done by working on this problematic pattern with the parents using specific techniques and actionable concepts (Marvin et al., 2002). In other words, the program adopts a skills-development based approach.

At the time of their initial project study, analysis of 75 dyads who had completed the program showed a significant shift from disordered attachment patterns to ordered attachment. The number of children classified as secure also increased and there was a concurrent decrease in the number of caregivers classified as disordered (Marvin et al., 2002). In summary, the intervention operationalised the complexities of attachment theory and reflective functioning and condensed them into meaningful and actionable concepts that parents were able to apply with their children across multiple settings.

Despite the success of COS in promoting more effective parenting and positive outcomes for the child, there is no published evidence of it having been applied in early

intervention settings for children with a disability. However, there appears to be scope for this given the attention paid to the importance of cue reading in the formation of more functional attachments. Nevertheless, the question remains as to whether the unique constellation of challenges surrounding the parent-child relationship in a disability population requires a different application of the attachment research to achieve similar ends.

Watch, Wait, Wonder – an intervention predicated on following the child’s lead

Another example of an intervention that has successfully operationalised the intricacies of attachments within a dyad is the watch, wait, wonder (WWW; Muir, 1992) program. Described as an infant-lead intervention, WWW requires the parent to follow the child’s spontaneous activity much like a therapist follows the lead of their client. In so doing the focus shifts to the initiatives of the child rather than those of the parent or the therapist (Cohen et al., 1999). Tucker (2006) added the use of video of the parent interacting with the child to the protocol, assisting them to identify (and consolidate) helpful responses with the child through video feedback. At the same time, the video review provided a vehicle for the therapist to suggest other potentially helpful responses in the specific context. Going through the video also helped the parent to identify and catalogue cues more easily. Discussions with the therapist broadened the parent’s thinking about the meaning of these cues and how to respond in ways that reflected the child’s intentions. In this way, the parent became an observer of the child’s activities, gaining an insight into their inner world and its influence on behaviour. Put simply, their reflective functioning skills grew. In addition, the parent became the expert; a more knowledgeable and capable observer of their child, no longer relying on the therapist. In turn this allowed them to apply the skills across settings (Tucker, 2006).

Like the COS protocol, WWW is attachment-based and brings the complexities of reflective capacity and sensitive, responsive cue reading to an actionable form, which parents can learn, execute, and generalise. It also introduces them to their child as an active

participant within the relationship. Similar to COS, WWW does not appear to have been extensively used within the disability context.

Summary

Secure attachment is the product of a both-way relationship between a child and a sensitive caregiver who can recognise and respond to the cuing system actively generated by the child (Tronick & Beeghly, 2011). The consequential secure base is considered fundamental to key aspects of learning and development, whether social-emotional, cognitive, physical, or communicative (Klebanov & Travis, 2014). For parents of children with a disability, to achieve the secure base there is a requirement to tune into difficult to read cues, which can be non-verbal, are often missed and/or are difficult to interpret. In addition, for these parents the capacity for sensitive responding can be compromised for many, varied reasons. These include high levels of distress, diagnostic uncertainty, acceptance of their child's difficulties, individual and relational stress, and mental health issues that are often associated with having a child with a disability (Robinson & Neece, 2015).

When cues are recognised and sensitive responses generated, secure attachments can develop. This level of attunement requires active, supported observing and cataloguing by parents of the unique cues of their child and the generation of responses that are initially outside the parent's current repertoire. In normally developing populations of children, programs like COS and WWW have demonstrated these skills can be learned. The work of Oppenheim et al. (2002) shows it is also possible for parents of high-risk children to acquire skills that promote reflective capacity. In addition, the notion of matched dialogues presents an interesting possibility around the use of language in generating sensitive responses in the face of difficult to understand cuing systems and compromised language. However, unlike typically developing contexts where the repaired relationship is the goal, in disability settings there is a somewhat different focus.

It needs to be remembered that the primary focus in early childhood development clinics is to optimise the child's functional capacity. Parents want their children to communicate, walk, develop play skills, participate in school and community activities, and become reasonably capable in the skills of daily living. In turn, allied health therapists are trained to apply best practice therapy to achieve these developmental goals. Despite the evidence showing these goals are more effectively acquired in the context of a well attuned parent-child relationship, achieving that while addressing the developmental priorities of the child requires a different approach to those employed solely to promote a more secure attachment. As well as integrating relational aspects into developmentally specific therapies, such a program needs to equip allied health therapists with the skills to manage those dual imperatives.

Organisation of the thesis

Background

The current practice-based study is set in an early childhood development clinic in the Northern Territory of Australia. A Non-Government Organisation, the remit of the service is to provide services to families of children aged 0- to 6-years who have significant developmental disabilities. It employs a multi-disciplinary team including occupational therapists, physiotherapists, psychologists, and speech pathologists. Historically the service employed a therapist-lead model of practice, however as part of ongoing service development the decision was taken to shift focus to a relationally-oriented approach. This was based on emerging evidence and therapists' experience of working with families presenting with high levels of stress and distress, concerns about parental competency and a strong sense of disconnection from their child. There was also increasing anecdotal evidence that, for these families, their lives were becoming smaller and restricted because of the challenges of being in the community with their child.

The treatment manual

Informed by attachment theory and contemporary perspectives on attachment and its impact on early childhood development detailed previously, a manualised program that operationalised and simplified these theories was developed by the lead researcher (at the time the senior psychologist in the service). The manual provided therapists with a flexible, phase-based structure to help them integrate relationally-based practices with functionally oriented (skills development) therapy. It also included scripts to help them understand and manage the sometimes-difficult issues that present when working relationally. The phase-based approach recognised parents' different skill levels, provided competency markers to identify progress and examples of helpful responses to build parental skills. In sum, the program introduced different techniques for therapists to build on parental strengths, thereby expanding response repertoires as well as enhancing parents' capacity to see the world through their child's eyes. All of which are linked to developing a secure base for the child (Oppenheim et al., 2012) and in promoting the calm-alert state that is strongly associated with optimising developmental gains (Barfoot et al., 2017b). The manual also included scripts and strategies on how to work with parents in developing treatment plans that reflect family priorities, a fundamental feature of family-centred practices (Dunst, 2014).

Research questions

Guided by the research around the development of relational skills, what constitutes best practice in family-centred early intervention and the challenges implementing those principles, the decision was taken to focus the research questions on three areas. Given the central role of the therapist in achieving the shift to this new practice, the first question was whether the combination of the manualised approach and reflective supervision developed therapists' capacity and confidence in working relationally with parents and in a family-centred way. If this shift in practice for therapists was successfully achieved, it was

hypothesised that there would be a consequential reduction in stress levels and an increased sense of competency for parents in the program; both of which are associated with improved outcomes behaviourally and therapeutically. This (impact on parents) was the subject of the second research question. Finally, with this relationally-based foundation and partnership with parents in place, it would be expected that the functional capacity of the child would increase and reflect family priorities over developmental checklists. This was the third research question included in the thesis. In sum, the aims of the thesis are:

1. Understand the effectiveness of PCRI-EI in building therapists' capacity, skills, and confidence in transitioning to a relationally-based model of practice.
2. Investigate the impact of PCRI-EI on parental stress levels, psychological well-being and sense of competency.
3. Explore whether the relational foundation promoted by PCRI-EI supports the attainment of functional gains by including and upskilling parents and prioritising family context.

Four chapters (chapters 2 – 5) address the aims of the thesis, each chapter presents a paper that has been published in an international, peer reviewed, journal. The order they are organised does not match the order of publication due to the vagaries of journal submission.

An initial case study that included four families is presented in Chapter 2. This paper outlines the theoretical underpinnings of PCRI-EI, practice processes and measures as well as the phase-based approach contained in the treatment manual. Changes within the family context, in reduced stress and improved sense of competency for the parents, as well as positive impacts on functional outcomes for the child are described.

The first aim of the thesis is considered in the study outlined in Chapter 3, which retrospectively investigated the experience of therapists as they made the transition to a relationally-based practice. Initially providing a background history of the challenges in

implementing relationally-based programs, this study investigated the effectiveness of PCRI-EI in building therapists' skills in making the shift from a therapist-lead practice to one which reflects the principles of relationally-based interventions. Chapter 4 addresses the second aim of the thesis, this study examined the impact of PCRI-EI on parental stress, psychological wellbeing, and sense of competence.

The final aim, investigating the utility of PCRI-EI on increasing the child's functional capacity, was the focus of the study described in Chapter 5. This study investigated changes in capacity of the child across time, including parents' perspective on how those changes reflected and impacted the family context and their participation in community settings.

Concluding the thesis, Chapter 6 offers an overall reflection of the findings of the combined studies. It also details how PCRI-EI is being implemented in settings beyond those with a developmental orientation e.g., working with parents and children in mental health settings. Limitations, future directions, and recommendations are also discussed.

References

- Ainsworth M. D. (1963). The development of infant-mother interaction among the Ganda. In Foss, B. M. (Ed.), *Determinants of infant behavior* (67-112). Wiley.
- Australian Institute of Health and Welfare (2020). Australia's children. Cat. no. CWS 69. Canberra: AIHW. <https://doi.org/10.25816/5ebca4d0fa7dd>
- Baker, J. K., Messinger, D. S., Lyons, K. K., & Grantz, C. J. (2010). A pilot study of maternal sensitivity in the context of emergent autism. *Journal of Autism and Developmental Disorders*, 40, 988 – 999. <https://doi.org/10.1007/s10803-010-0948-4>.
- Barfoot, J., Meredith, P., Ziviana, J. & Whittingham, K. (2015). Relationship-based parenting to support developmental outcomes for a young child with cerebral palsy: A practice application. *British Journal of Occupational Therapy*, 78(10), 640-643. <https://doi.org/10.1177%2F0308022615583304>
- Barfoot, J., Meredith, P., Ziviana, J., & Whittingham, K. (2017a). Relationship-based approaches in early childhood intervention: Are these applicable to paediatric occupational therapy under the NDIS? *Australian Occupational Therapy Journal*, 64, 273-276. <https://doi.org/10.1111/1440-1630.12343>
- Barfoot, J., Meredith, P., Ziviana, J., & Whittingham, K. (2017b). Parent-child interactions and children with cerebral palsy: An exploratory study investigating emotional availability, functional ability, and parent distress. *Child: Care, Health and Development*, 43, 812-822. <https://doi.org/10.1111/cch.12493>
- Bowlby, J. (1969). *Attachment and loss*. Vol. 1: Attachment. Basic Books.
- Bowlby, J. (1973). *Attachment and loss*. Vol. 2: Attachment. Basic Books.

- Bowlby, J. (1980). *Attachment and loss*. Vol. 3: Attachment. Basic Books.
- Bowlby, J. (1988). *A secure base: Parent-child attachment and healthy human development*. Basic Books.
- Caldwell, P. (2003). *Learning the Language*. Pavilion Publishing.
- Caldwell, P. (2005). *Creative conversations: Communicating with people with profound and multiple learning disabilities*. Pavilion Publishing.
- Caldwell, P. (2006). Speaking the other's language: Imitation as a gateway to relationship. *Infant and Child Development*, 15, 275-282. <https://doi.org/10.1002/icd.456>
- Campbell, P. H., Chiarello, L., Wilcox, M., & Milbourne, S. (2009). Preparing therapists as effective practitioners in early intervention. *Infants and Young Children*, 22, 21-31. <https://doi.org/10.1097/01.IYC.000034334.26904.92>
- Cohen, N. J., Muir, E., Lojkasek, M., Muir, R., Parker, C. J., Barwick, M., & Brown, M. (1999). Watch, wait, and wonder: Testing the effectiveness of a new approach to Mother-Infant Psychotherapy, *Infant Mental Health Journal*, 20, 429-451. [https://psycnet.apa.org/doi/10.1002/\(SICI\)1097-0355\(199924\)20:4%3C429::AID-IMHJ5%3E3.0.CO;2-Q](https://psycnet.apa.org/doi/10.1002/(SICI)1097-0355(199924)20:4%3C429::AID-IMHJ5%3E3.0.CO;2-Q)
- Davis, A.L., & Neece, C.L. (2017). An examination of specific child behavior problems as predictors of parenting stress among families of children with pervasive developmental disorders. *Journal of Mental Health Research in Intellectual Disabilities*, 10, 163-177. <https://doi.org/10.1080/19315864.2016.127698>
- Ephraim, G. (1986). A brief introduction to augmented mothering. *Playtrack pamphlet*. Harpebury Hospital School, Radlet Herts.
- Feniger-Shaal, R., & Oppenheim, D. (2013). Resolution of the diagnosis and maternal sensitivity among mothers of children with intellectual disability. *Research in Developmental Disabilities*, 34, 306-313. <https://doi.org/10.1016/j.ridd.2012.08.007>

- Fonagy, P., Gergely, G., Jurist, E., & Target, M. (2002). *Affect Regulation, mentalization and the development of the self*. Karmac.
- Fonagy, P., Steele, M., Moran, G., & Higgins, A. (1991). The capacity for understanding mental states: The reflective self in parent and child and its significance for security in attachment. *Infant Mental Health Journal*, 13, 200-216. [https://doi.org/10.1002/1097-0355\(199123\)12:3<201::AID-IMHJ2280120307>3.0;2-7](https://doi.org/10.1002/1097-0355(199123)12:3<201::AID-IMHJ2280120307>3.0;2-7)
- Greenberg, J. S., Seltzer, M. M., Hong, J., & Orsmond, G. I. (2006). Bidirectional effects of expressed emotion and behavior problems and symptoms in adolescents and adults with autism. *American Journal on Mental Retardation*, 114, 229-249. [https://doi.org/10.1352/0895-8017\(2006\)111\(229:BEOEEA\)2.0.CO;2](https://doi.org/10.1352/0895-8017(2006)111(229:BEOEEA)2.0.CO;2)
- Guralnick, M. J. (2017). Early intervention for children with intellectual disabilities: An update. *Journal of Applied Research in Intellectual Disabilities* 30, 211-229. <https://doi.org/10.1111/jar.1223>
- Hayes, S. & Watson, S. (2012). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of autism and developmental disorders*, 43, 629-642. 10. 10.1007/s10803-012-1604-y.
- Hughes-Scholes, C. H., & Gavidia-Payne, S. (2019) Early Childhood Intervention Program Quality: Examining Family-centred Practice, Parental Self-Efficacy and Child and Family Outcomes. *Early Childhood Education Journal* 47, 719–729. <https://doi.org/10.1007/s10643-019-00961-5>
- Kalmanson, B. (2009). Echoes in the nursery: Insights for treatment of early signs of autism in a baby sibling. *Journal of Infant, Child and Adolescent Psychotherapy*, 8, 40-48. <https://doi.org/10.1080/15289160802683427>

- King, G., Strahan, D., Tucker, M., Duwyn, B., Desserud, S., & Shillington, M. (2009). The application of a transdisciplinary model for early intervention services. *Infants and Young Children, 22*, 211-223.
<https://doi.org/10.1097/iy.06013e3181abe1c3>
- Klebanov, M. S., & Travis, A. D. (2014). *The critical role of parenting in human development*. Taylor & Francis.
- Marvin, R., Cooper, G., Hoffman, K., & Powell, B. (2002). The circle of security project: Attachment-based intervention with care-giver-preschool child dyads. *Attachment & Human Development, 4*, 107-224. <https://doi.org/10.1080/14616730210131635>
- Matthews, A., & Rix, J. (2013). Early intervention: parental involvement, child agency and participation in creative play. *Early Years, 33*, 239-251.
<https://doi.org/10.1080/09575146.2013.766151>
- Moss, E., Cyr, C., Bureau, J. F., Tarabusly, G. M., & Dubois-Comtois, K. (2005). Stability of attachment during the preschool period. *Developmental Psychology, 41*, 773-783. <https://doi.org/10.1037/0012-1649.41.5.773>
- Muir, E. (1992). Watching, waiting, and wondering: Applying psychoanalytic principles to mother-infant intervention. *Infant Mental Health Journal, 13*, 319-328. [https://psychnet.apa.org/doi/10.1002/1097-0355\(199224\)13:4%3C319::AID-IMHJ2280130307%3E3.0.CO;2-2](https://psychnet.apa.org/doi/10.1002/1097-0355(199224)13:4%3C319::AID-IMHJ2280130307%3E3.0.CO;2-2)
- Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behavior problems: A transactional relationship across time. *American Journal on Intellectual and Developmental Disabilities, 117*, 48-66. <https://doi.org/10.1352/1944-7558-117.1.48>
- Nind, M., & Hewitt, D. (1994). *Access to communication*. David Fulton Press.
- Nind, M., & Hewitt, D. (1998). *Interaction in action*. David Fulton Press.

- Nind, M., & Hewitt, D. (2001). *A practical guide to intensive interaction*. David Fulton Press.
- Oppenheim, D., & Koren-Karie, N. (2002). Mothers' insightfulness regarding their children's internal worlds: The capacity underlying secure child–mother attachment. *Infant Mental Health Journal*, 23, 593–605. <https://doi.org/10.1002/imhj.10035>
- Oppenheim, D., & Koren-Karie, N. (2016). Parents' insightfulness: The importance of keeping the inner world of the child in mind for parenting plan evaluations. In L. Drozd, M. Saini, & N. Olesen (Eds.), *Parenting plan evaluations: Applied research for the family court*, (2nd ed., 47–59). Oxford University Press.
- Oppenheim, D., Koren-Karie, N., Dolev, S., & Yirmiya, N. (2009). Maternal Insightfulness and resolution of the diagnosis are associated with secure attachments in preschoolers with autism spectrum disorders. *Child Development*, 80, 519-527. <https://doi.org/10.1111/j.1467-8624.2009.01276.x>
- Oppenheim, D., Koren-Karie, N., Dolev, S., & Yirmiya, N. (2012). Maternal sensitivity mediates the link between Insightfulness/resolution and mother-child attachment: The case of children with autism spectrum disorder. *Attachment and Human Development*, 14, 567-584. <https://doi.org/10.1080/14617734.2012.727256>
- Oppenheim, D., Koren-Karie, N., & Sagi, A. (2001). Mother's empathic understanding of their preschoolers' internal experience: Relations with early attachment. *International Journal of Behavioral Development*, 25, 16-26. <https://doi.org/10.1080/01650250042000096>
- Pickles, A., Le Couteur, A., Leadbitter, K., Salomone, E., Cole-Fletcher, R., Tobin, H., Grammar, I., Lowry, J., Vamvakas, G., Byford, S., Aldred, C., Slonims, V., McConachie, H., Howlin, P., Parr, J. R., Charman, T., & Green, J. (2016). Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial. *The Lancet*, 10059,

- 2501-2509. [https://doi.org/10.1016/S0140-6736\(16\)31229-6](https://doi.org/10.1016/S0140-6736(16)31229-6).
- Pretis, M. (2011). Meeting the needs of parents in early childhood intervention: The educational partnership with parents – good practice and challenges. *Journal of Policy and Practice in Intellectual Disabilities*, 8, 73-76.
<https://doi.org/10.1111/j.1741-1130.2011.00292.x>
- Rix, J., Paige-Smith, A., & Jones, H. (2008). “Until the cows came home” Issues for early intervention activities. Parental perspectives on the early years learning of their children with Down Syndrome. *International Journal of Contemporary Issues in Early Childhood* 9, 66–79. <https://doi.org/10.2304/2Fciec.2008.9.1.66>
- Robinson, M., & Neece, C.L. (2015). Marital satisfaction, parental stress, and child behavior problems among parents of children with developmental delays. *Journal of Mental Health Research and Intellectual Disabilities*, 8, 23-46.
<https://doi.org/10.1080/19315864.2014.994247>
- Rocha, M. L., Schreibman, L., & Stahmer, A. C. (2007). Effectiveness of training parents to teach joint attention in children with autism. *Journal of Early Intervention*, 29, 154-172. <https://psycnet.apa.org/doi/10.1177/105381510702900207>
- Salisbury, C. L., & Copeland, C. G. (2013). Progress of infants/toddlers with severe disabilities: Perceived and measured change. *Topics in Early Childhood Special Education*, 33, 68 – 77. <https://doi.org/10.1177/0271121412474104>
- Shai, D., & Belsky, J. (2011). When words just won’t do: Introducing parental embodied mentalising. *Child Development Perspectives*, 5, 173-180.
<https://doi.org/10.1111/j.1750-8606.2011.00181.x>
- Slade, A. (2005). Parental reflective functioning: An Introduction. *Attachment and Human Development*, 7, 269-281. <https://doi.org/10.1080/14616730500245906>

- Slade, A. (2009). Mentalising the unmentalisable: Parenting children on the spectrum. *Journal of Infant, Child and Adolescent Psychotherapy*, 8, 7-21.
<https://doi.org/10.1080/15289160802683054>
- Soderstrom, K., & Skarderud, F. (2009). Minding the baby: Mentalization-based treatment in families with parental substance abuse use disorder: Theoretical framework. *Nordic Psychology*, 61, 47-65. <https://psycnet.apa.org/doi/10.1027/1901-2276.61.3.47>
- Sroufe, L. A., Egeland, B., Carlson, E. A., & Collins, W. A. (2005). *The development of the person: The Minnesota Study of Risk and Adaptation from birth to adulthood*. Guilford Press.
- Stern, D. N. (1977). *The first relationship*. Harvard University Press.
- Sukkar, H., Dunst, C. J., & Kirkby, J. (2017). *Early Childhood Intervention*. Routledge,
<https://doi.org/10.4324/9781315688442>
- Tronick, E., & Beeghly, M. (2011). Infants' meaning-making and the development of mental health problems. *American Psychologist*, 66, 107-119.
<https://doi.org/10.1037/a0021631>
- Tucker, J. (2006). Using video to enhance the learning in a first attempt at 'Watch, Wait, and Wonder'. *Infant observation*, 9, 125-138.
<https://doi.org/10.1080/13698030600810359>
- Weatherston, D. (2007). Returning the treasure to babies: Infant mental health and early headstart. *Infant Mental Health Journal*, 28, 246-251.
<https://doi.org/10.1002/imhj.20132>
- Whittingham, K. (2016). Mindfulness and transformative parenting. In E. Shonin, W. V. Gordon, & M. Griffiths (Eds). *Mindfulness and other Buddhist-derived approaches in mental health and addiction* (pp. 363-390). Springer.

CHAPTER 2: Case study

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It is presented as it was published, except for changes to support consistent chapter formatting throughout the thesis.

Manuscript title: Activating Parents in Early Intervention: Preliminary findings from an empirical case study.

Clarification: As noted above the chapter is presented as it was published. However, following examination, suggestions were made to clarify certain elements of this chapter and to enhance overall readability of the thesis. Following are extracts from Chapter 4 that were recommended by the examiners.

The first is relevant to page 33 of the chapter which describes the current intervention:

The Current Intervention

PCRI-EI combines constructs and programs such as: (a) Insightfulness, described as the ability to appreciate motives underpinning the child's behavior, to hold a more complex view of the child, accepting challenging behavior, and a willingness to integrate new information about the child (Oppenheim et al., 2012); (b) Reflective Functioning, the capacity to understand behavior in the context of underlying mental states and intentions (Fonagy et al., 2002); (c) Parent Embodied Mentalizing, defined as the parent's capacity to "implicitly conceive, comprehend, and extrapolate the infant's mental states from the infant's whole-body movement, and adjust their own kinaesthetic patterns accordingly" (Shai & Belsky, 2011, p.173); (d) Active Imitation, described as interacting with body language through imitation to build up meaningful conversations (Ephraim, 1986); (e) Intensive Interaction, which involves learning the language of the communication partner in all its forms and responding to whatever has meaning for them, the experience of which creates

personal meaning and lends itself to the development of a secure base from which to explore (Caldwell, 2006; Nind & Hewitt, 1998, 2001) and; (f) Circle of Security, a program to address disordered attachment patterns within the parent-child dyad (Marvin et al., 2002). It also reflects considerations from Functional Contextualism (Hayes et al., 1999) and recent developments on parents' mindfulness and self-regulation, believed to have knock-on effects impacting a child's acquisition of developmental skills and ability to self-regulate (Singh et al., 2007).

The second clarification is relevant to page 36 of the chapter which describes the measures:

Parenting Stress Index – Short Form 4th Edition (PSI-4-SF: Abidin, 2012). The PSI assesses parents' perceived sources of stress in the parent-child system. The short form comprises 36 items across three subscales; (1) Parental Distress (PD), which reflects a parent's perception of child-rearing confidence, conflict within the parental relationship, social support and restrictions on other aspects of their life; (2) Parent Child Dysfunction Interaction (P-CDI), which captures the parent's perception that the child does not meet expectations and interactions within the dyad are not reinforcing and; (3) Difficult Child (DC), which measures the parent's view of the child's behavior; specifically temperament, oppositionality and demandingness. Abidin (2012) suggests an overall percentile score equal to or above the 85th percentile as being indicative of clinically significant distress for the parent. Items are rated on a 5-point scale from strongly agree to strongly disagree and have a correlation of .87 with the long form, which has demonstrated the following reliability coefficients, Child Domain .89, Parent Domain, .93 and Total Stress .95 (Abidin & Wilfong, 1989). Reliability coefficients for this study were .91 in the PSI overall, .78 in the PD subscale, .92 on the P-CDI subscale and .91 on the DC subscale.

Parenting Sense of Competence Scale (PSOC: Johnston & Mash, 1989) contains 17 items, rated on a 6-point Likert scale from strongly agree to strongly disagree. Acceptable

levels of internal consistency (range 0.75 – 0.88) have been validated for the PSOC (Gilmore & Cuskelly, 2009). Reliability analysis for this study revealed a Chronbach Alpha of .91.

Abstract

The parent child relationally informed – early intervention (PCRI – EI) was developed from the clinical application of attachment theory. The premise is to expand the responsiveness of parents and clinicians working with children who have developmental delays. It was evaluated via four single case studies (children aged 18-months to 6 years) using an AB(A) design including baseline assessment and evaluation across 12-week therapy blocks. Parents provided session-by-session feedback. A battery of measures was used pre- and post-treatment. An independent evaluator assessed fidelity. Functional gains were reported. Parental stress, parent/child relational stress and difficult child rating decreased. Parental sense of competence increased; there were slight gains in well-being measures. Results suggest PCRI-EI is a promising intervention for engaging parents in therapy and achieving positive outcomes.

Attachment theory and its developmental consequences, which include communication, language and cognition, has illuminated the role and impacts of the parent-child relationship in typically developing contexts (Bowlby, 1969, 1973, 1980). Many early intervention programs e.g., circle of security (Marvin et al., 2002) and watch, wait, wonder (Muir, 1992) address disrupted attachments, recalibrating developmental trajectories for certain at-risk populations. However, where the developmental capacities of the child are compromised, research is lacking (Whittingham et al., 2011). For example, when a child has Cerebral Palsy, a complex neurological condition that compromises all aspects of functioning, few programs address the attachment challenges experienced by both parent and child. Though there is no treatment research to date, there is an emerging literature illuminating the ability of these children to form attachments, including what may be required of parents to facilitate attachment and the carry-over impacts (Slade, 2009).

A key aspect of an attuned relationship is the child providing cues, which the parent reads and responds to (Barfoot et al., 2017a). Whittingham (2016) suggests the metaphor of a control system, where the child controls the type and intensity of the responses, and the parent attunes and responds accordingly. This system is thought to facilitate a calm-alert state integral in optimising learning and development. For the parents of a child with developmental delays, they are required to undertake this in the presence of a cueing system that may seem incomprehensible, appear as happenstance, or as epiphenomena of a diagnosis. Furthermore, parents must bond in a context short of the expected joys and delights of mutuality and reciprocity (Kalmanson, 2009).

Moreover, given the compromises in their child's development and cueing systems, parents have to manage their own distress, loss, grief, and sense of incompetence (Slade, 2009). That said, when the child is more regulated, targeted developmental strategies to address developmental needs appear more effective (Barfoot et al., 2017a).

The Current Intervention

The parent child relationally informed – early intervention (PCRI-EI) was developed from findings evaluating attachment theory in clinical work with children. PCRI-EI includes constructs such as insightfulness (Oppenheim et al., 2012), reflective functioning (Fonagy et al., 2002), parent embodied mentalising (PEM; Shai & Belsky, 2011), active imitation (Ephraim, 1986) and intensive interaction (Caldwell, 2006; Nind & Hewitt, 1998, 2001) as well as findings from circle of security (COS; Marvin et al., 2002). It also incorporates considerations from functional contextualism (Hayes et al., 2012) and recent developments on parent's mindfulness and self-regulation, believed to have knock-on effects impacting a child's acquisition of developmental skills and ability to self-regulate (Singh et al., 2007). These models and practices have come from significant scientific enquiry, which produced reliable and clinically significant insights and treatment-related outcomes across a range of presentations (Soderstrom & Skarderud, 2009; Oppenheim et al., 2009; Sanfuji et al., 2009).

The premise of the program is to operationalise and simplify these theories to expand the responsiveness of parents and clinicians. The intervention is fundamentally relational because it relies on parents remaining sensitive and responsive to the child's experiences in meeting developmental demands. These include cognitive and sensory processing challenges, anxiety, affective, fear-based responses, physiological arousal and resistance to sometimes painful physical requests (e.g., sustained stretching of a muscle). Further, this occurs in a context where the child's communication is often limited to subtle, non-verbal, idiosyncratic cueing.

Whilst relational, the program does not view a changed relationship as the outcome. Instead, as an instrumental outcome, it becomes the foundation for facilitating further functional change. For example, a parent reflecting to a child with Cerebral Palsy that things are difficult when their body is not doing what they want relies on reflective capacity

(Fonagy et al., 2002), meaning making (Tronick & Beeghly, 2011) and an attuned response (Weatherston, 2007). This attuned response is then thought to facilitate the child's ability to persist in the task in frequency, duration, and/or intensity/effort terms. For example, the parent might say: "You are getting frustrated because your body is not doing what you want, you can do it". In doing so, this encourages task persistence, resilience and the optimal calm-alert state.

Alternatively, another child, who is learning to stand in a functionally appropriate way, may respond more positively to a parent who is attuned to the preference for playing versus ongoing requests to stand. For example, when playing with a doll house positioned where the child needs to stand to access it, the parent might say: "This is fun, we can get dolly into her bedroom". Thus, the parent understands how the functional goal – standing – is not all that important to a child and instead appreciates playing with the parent is more motivating. Consequently, the child is more likely to engage in a functionally-oriented play activity (standing) rather than a set of positioning requests. Whilst the examples given reference children with a diagnosis of Cerebral Palsy, the process (i.e., attuned responses using child-specific language) can be applied to many diagnoses and challenges, including cognitive, affective and sensory reactions to developmental, task and contextual demands.

The model maintains a distinctive core philosophy: Collaboration between the family and the service that acknowledges potential differences in views about a child and their developmental difficulties. One that respects and is geared towards parent goals, while at the same time observing evidence-based principles. In doing so, PCRI-EI emphasises expanding parents' response repertoires in the context of illuminating, referencing and respecting the child's experiences. At the same time there is an appreciation of the therapeutic value of addressing directly the many challenges families of these children face.

Running parallel with this family/child orientation is a similar consideration for therapist's development. This includes incorporating relational and reflective capacity, considering the child's experience, and having compassion for the parent; all of which are thought to impact the therapeutic alliance and efficacy of therapy. Reflective supervision supplements an induction and training process that includes a treatment manual. As a companion to training and an ongoing therapist tool, it contains case examples and scripts that are operationalised exemplars of the models and related techniques referenced to previously.

Consistent with a philosophy of collaboration, the model includes session-by-session feedback, ongoing tracking of goals and bi-annual parent wellbeing measures. These cover (1) parental stress, using the Parental Stress Indicator-Short Form (PSI-SF; Abidin, 2012); (2) Parental Sense of Competency (PSOC; Johnston & Mash, 1989); (3) mental health, using the Kessler Psychological Distress Scale (K6; Kessler et al., 2002); (4) adapted measures of parental insight and (5) level of community involvement. Including measures of stress and competency reflects research reporting high levels of stress in parents of children with a disability (Hoffman et al., 2009) and the negative impact of stress on parenting responses and developmental outcomes (Neece et al., 2012).

From a practice perspective, the intent is to engage and empower the family by providing a measurable in-session voice, to quantify developmental gains in a way that melds the parental goals with those that are clinically indicated while paying attention to parent wellbeing. In a practical sense the measures facilitate movement from anecdotes to objectively based outcomes; something that can be difficult to sustain in practice-based settings.

In sum, PCRI-EI incorporates features of well-established and empirically-supported theoretical and treatment models that consider the challenges and impacts on development of

a well attuned parent-child relationship, including in a disability context. It does this whilst maintaining a core focus on a collaborative relationship between families and a service with an allegiance to combining rigorous evidence-based practice with a family-oriented flexible practice-based evidence philosophy. That is, the practice-based model and accompanying evidence, seeks ongoing feedback, measures outcomes that are generated collaboratively and emphasise parent empowerment, wellbeing, and capacity as a key component of the therapy itself. Reflective supervision allows therapists to develop skills in working with parents. It also extends therapists' response repertoires to consider context as well as affective, cognitive, sensory and physiological arousal experiences of all members of the family. Thus, a primary outcome (the better attuned relationship) is a platform aimed at promoting increased efficacy of extant, evidence-based practices.

Empirical Case Study Rationale and Aims

As part of a broader group comparison, investigating PCRI-EI within an early childhood developmental service, the purpose of this study was to present a pilot evaluation via four single case studies, comprised of children with four separate diagnoses. It used a simple, practitioner friendly AB(A) design including a baseline assessment and ongoing goal tracking over 6 sessions in 12-week treatment blocks. Parents provided session-by-session feedback regarding treatment satisfaction, the approach and their therapist. Additionally, a battery of parent and family wellbeing measures was used pre- and post-treatment. To monitor treatment fidelity, an independent evaluator conducted an out of session assessment. Ethics approval was secured from Central Queensland University Human Research Ethics Committee, HREC approval number H15/09-202.

Method

Participants

Participants were referred through sources including the Public Hospital, General Practitioners, Paediatricians, Community Health Nurses, Allied Health Professionals and the government health service. In this study, as described below, participants ($n=4$) comprised clients with different diagnoses. They were from the first group who agreed to participate in the research and were referred through the Government Allied Health Team ($n = 2$), the Public Hospital (PH; $n = 1$) and a paediatrician ($n = 1$).

The children were aged between 18 months and 6 years, met eligibility criteria and included: a 5-year-old male diagnosed with Autism Spectrum Disorder (ASD); a 6-year-old male diagnosed with Cerebral Palsy (CP); an 18-month-old male diagnosed with Down Syndrome (DS); and a 3-year-old female diagnosed with Global Developmental Delay (GDD). The child with ASD was from an Asian/Caucasian background, English was the primary language; the remainder were from Caucasian backgrounds. Therapy was provided at a community-based early childhood development service. Informed consent was necessary for participation.

Because the service is comprised of a multidisciplinary team, this study included occupational therapists, a physiotherapist, speech pathologists and a psychologist. All were trained in the manualised model. Fortnightly supervision with a senior psychologist (lead author and program developer) was provided to ensure treatment fidelity, facilitate professional development and maintain client's best interests. Joint sessions with the psychologist were undertaken during the first three months to expedite fidelity and practically demonstrate the material.

Assessments and Measures

Initial assessment was undertaken using the Griffiths Mental Development Scales (GMDS; Griffiths, 1984) or the Bayley Scales of Infant and Toddler Development (Bayley

III; Bayley 2006), both standardised measures of children's development. The choice of assessment was indicated by the age of the child.

Therapy outcome measures based on Subjective Units of Discomfort Scale (SUDS; Stanley & Averill, 1998) were collected using a pre-post methodology across 12-week therapy blocks. Goals were agreed upon during the pretreatment phase with parents rating where their child was functioning. At the end of the block, goals were reviewed and the difference in scores calculated. The satisfaction measure was administered at the end of each session and included items on adherence to agreed goals, therapist fit, parent's experience, treatment approach and overall session satisfaction. Fidelity was assessed using a measure administered by an independent assessor.

A parent pack was also completed. It comprised a pre-post-follow-up battery of reliable, valid measures that have demonstrated treatment sensitivity. The pack also includes measures of parent's self-reflected changes in responsiveness, perceptions of their child's behaviours and a rating of community engagement. Ultimately these measures will be administered 6-monthly as part of the ongoing monitoring of parent well-being. Because families participating in this study joined the service prior to the introduction of the outcome measures, they have been treated as pre- and post- measures in this context with the post measure administered six months after the pre-measure.

Parent Sense of Competence Scale (PSOC: Johnston & Mash, 1989) contains 17 items, rated on a 6-point Likert scale from strongly agree to strongly disagree. Acceptable levels of internal consistency (range 0.75 – 0.88) have been validated for the PSOC (Gilmore & Cuskelly, 2008).

Parenting Stress Index – Short Form (PSI-SF: Abidin, 2012). The PSI assesses parent's perceived sources of stress from the child and those related to parenting. The short form comprises 36 items, rated on a 5-point scale and has a correlation of .87 with the long

form, which has demonstrated the following reliability coefficients, Child Domain .89, Parent Domain, .93 and Total Stress .95 (Abidin & Wilfong, 1989). Abidin (1997) suggests a clinical threshold score of being equal to or above the 90th percentile in the total score.

The Kessler Psychological Distress scale (K6: Kessler et al., 2002), a six-item short dimensional instrument, measured levels of mental health in the previous four weeks. The scales have been shown to have sound psychometric properties (Kessler et al., 2002).

Goal Tracking Form (GTF: Ronan, 2009). The GTF uses a visual analogue scale on a 10cm line. Parents mark the line between Never Happens and Always Happens indicating their assessment of functioning. The measure follows the principles of the SUDS and is particularly useful in the service model because of ease of administration by clinicians and parents (e.g., Ronan et al., 2016; 2018).

Session Rating Scale V 3.0 (SRS: Miller et al., 2002). The SRS comprises 4 items covering relationship, goals and topics, approach, and overall rating. Scales are visual analogue rated between 0 and 10, with 10 indicating complete satisfaction. Duncan et al. (2003) found adequate test-retest and internal consistency reliability (co-efficient alphas of .64 and .88 respectively, N=420), and concurrent validity of .48, $p < .01$ against the Helping Alliance Questionnaire (HAQ-II; Luborsky et al., 1996).

Thoughts, feelings and behaviour measures. Two Likert scale-based items were designed specifically for the research. Informed by Oppenheim and colleagues (2009) on their insightfulness construct, they are intended to quantify parents' insight into the motives for their child's behaviour and being open to new and sometimes unexpected information about their child. Both are 5-point scales with parent's indicating agreement with the following statements: I have an idea of what thoughts and feelings my child is communicating through their behaviour, and I can see differences in the way my child

behaves in different situations and can adjust my responses as a result. Ratings ranged from 1 (Never) to 5 (All of the time).

The insightfulness assessment procedure used by Oppenheim and Koren-Karie (2013) is an extensive evaluation process of videotaping, reflection with parents, transcripts and ratings on 10 classification scales. This procedure could not be sustained in the current clinic setting. Consequently, the lead author developed more clinic-friendly measures to ascertain pre- and post- treatment responses to the key features. Reliability of the measure (i.e., item inter-correlation) across the first set of 48 participant families was found to be .71.

Community involvement measure. This Likert scale, specific to the study reflects a particular challenge of having a child with a disability, specifically spending time in community settings. Parents rate their satisfaction from 1 (Not at all) to 5 (All of the time) with the amount of time the family spends in the community and at home. The service has a philosophy that promotes the idea of life getting bigger, thereby capturing natural reinforcement opportunities for the child and family. An essential component of service delivery, this is a simple, practical way to measure such changes. Correlation between the two items of this measure across the first set of 48 participant families was found to be .60.

Treatment fidelity measure. Adapted from Ronan et al. (2012), the measure comprises 24 items reflecting the treatment manual's principles and practices. It rates integrity of delivery with respect to therapist stance, engagement and support, therapy skills and adherence to treatment imperatives. Item examples include: My key therapist really encourages me to be part of my child's therapy program; I feel my key therapist is helping me meet the goals I have for my child. Whilst the main purpose of this measure is to assess intervention adherence, it also communicates a family-centered philosophy and creates the opportunity for parents to provide feedback to someone independent of the service. It includes three questions: What do you find most helpful about the therapy? What do you find

least helpful about the therapy? Are there any comments or other feedback you would like to give? It was administered by an Occupational therapist completing her PhD at an interstate University. Alpha reliability of the original measure used with young people in complex family environments was .82 (Ronan et al., 2012). Here, alpha reliability across the first set of 22 participants was .98.

Procedures: Design, assessment and intervention

A single case, AB(A) design across four participant families was used in the study. The independent variable, the intervention, occurred at the centre.

Screening and assessment. The service observes a Transdisciplinary approach guided by three elements: (1) simultaneous, multi-discipline assessment of the child, which may or may not involve the parent, (2) ongoing interaction between disciplines to exchange knowledge and skills, and (3) role release, which occurs when disciplines release intervention strategies to other team members (King et al., 2009). Thus, all disciplines participated in the assessment.

Initially the child engages in free play. When they settle, the assessor transitions to formal testing. There are two components to the initial assessment. The first is to secure clinical information, the developmental and play profile, behavioural observations revealing the child's communication cues and the parents' key concerns. The second is introducing the model, providing the rationale and including parents as experts in their child and key members of the treatment planning. Feedback on the results is given once calculated.

Therapist development: Training and supervision. The program incorporates ongoing therapist development including manual-driven skill expansion, and fortnightly reflective supervision with a senior psychologist (program developer). Supervision promotes self-care, particularly salient in a context that contains grief and loss, significant stress and anxiety for parents and children. These sessions allow for questions around principles of the

approach, parental issues, child responses and the therapists own challenges in working in this context.

Therapy approach. Guided by the manual, the approach provides therapists with a flexible, phase-based structure and integrates key treatment principles with suggestions of accessible, child-friendly language to use. Given the complexity of the underpinning theories, consideration was given to operationalising and simplifying these theories to ensure they are accessible, both cognitively and affectively to maximise application and generalisation. Taking a phased approach, the manual is inherently flexible in its application, while still having main principles and practices by which to gauge fidelity. It recognises parent's different skill levels, provides competency markers to help therapists consider progress and examples of helpful responses to enhance parental skills. In sum, the program introduces different techniques to build on existing strengths, thereby expanding response repertoires of parents to consider their child's unique cuing system as well as enhancing their capacity to reflect on the child's experience over and above the diagnostic prognostications. All of which are linked to more positive outcomes for the child (Oppenheim et al., 2012) and in promoting the calm-alert state that is strongly associated with optimising developmental gains (Barfoot et al., 2017b).

The first session is for parents only. Its purpose is to clarify assessment outcomes, understand the parent's formulation, introduce the clinical formulation and set goals for therapy. Initially longer-term goals are discussed, e.g., what parents hope for their child when they reach their early 20s. This helps make sense of the therapy today in future-oriented terms. Then short-term therapy goals are agreed, including these examples: functional aspects (e.g., fine/gross motor skills, feeding, and activities of daily living), developmental imperatives (e.g., communication, problem solving, relationships, play, and school-readiness) and psychosocial factors (e.g., resilience, agency, self-regulation and independence). This

process can reveal the level of acceptance the parents have for their child's difficulties, key in developing the insightfulness described by Oppenheim and colleagues (2002). Details are summarised in a therapy plan given to parents. The pre-treatment parent pack is also completed.

As noted previously, PCRI-EI uses a phase-based approach (details below). Several sessions may be devoted to each phase; it may be only one. The manual contains markers of competence to help both parent and therapist decide on when to move to the next phase. When determining this, therapists maintain the perspective that skills continue to develop and build throughout therapy.

Phase one sets the foundations – observation, narration, waiting and following. the child's ideas. It establishes the collaborative nature of the work and reiterates goals. The therapist explains ongoing therapy protocols, including an outline of the session, session summary, and session rating forms. The session summary includes goals, observations from the session itself and homework. This protocol addresses in a practical skill-based sense developing parent's capacity and response repertoire. It also sets expectations for the relational aspect of the work. Parents are encouraged to play with the child; the therapist assumes role of collaborator and the play-based nature of the therapy begins.

The second phase introduces reflective capacity, cue reading and active imitation. It extends the parent's repertoire in reading and responding to their child's whole of body cueing, which has been shown to change perceptions of the child's internal state as well as their own sense of connectedness (Fraiberg, 1979; Shai & Belsky, 2011). A focus on both of these has demonstrated facilitative effects in producing attachment (Oppenheim & Koren-Kari, 2002). Video review with parents is often introduced in this phase to facilitate cue reading (Barfoot et al., 2017b).

The third phase focuses on affect regulation of parent and child. As well as working with parents on helping their child manage a range of contextual affective responses (e.g., frustration a child with a diagnosis of ASD may have when the parent introduces turn taking in play), this phase introduces parents to their own affective responses to the child's behaviours. This includes struggles with tasks and the ongoing impacts of grief, loss and confusion that can manifest in interactions between the parent and child, including in therapy and in the community.

The fourth phase involves reframing behaviour and appreciating contextual issues. It is intended to shift parents' thinking about their child's behaviour (including language) from a why are they doing this? perspective, to what are they telling me about their experience right now? Contextual thinking is introduced to help parents actively manage excursions into community settings while notions such as workability (Hayes et al., 1999) and helpful and unhelpful connecting behaviours are presented as alternate ways to describe behavioural responses.

The fifth and final phase is integration, relapse prevention, and generalising to settings outside the therapy. This includes consolidation of an overarching goal of therapy: to have parents rely more on their experience of their child in various contexts rather than on conceptualisations that may include biases such as diagnostic descriptions or worries about potential behavioural difficulties. Attention is paid to extending work from previous phases to help parents bed down, and express confidence in their changed responses being available and active in different environments. Importantly, an intervention theme of a fuller family life being a goal versus a day-to-day set of tasks and challenges focused on having a child with a disability is also reiterated. Furthermore, the changed response repertoire is reinforced through discussions that highlight and reinforce the parent's role in achieving functional goals.

Results

Intervention fidelity

Because the introduction of the measures was staggered to meet operational requirements, the 24-item fidelity measure was administered once as part of this pilot evaluation. The mean item score (range 1-5) was 4.64 ($SD = .33$), indicating a good level of fidelity. Investigation of lower item scores along with comments made by the administrator indicate one question, which focused on schooling options, was irrelevant. Several other questions needed clarification. Consequently, adjustments have been made for use in the larger group comparison study. There were a number of parent responses to the accompanying questions. These included:

- “They teach me and guide me on how to communicate with my son and how to speak his language so we can communicate with each other. They help me figure out what is happening when things get difficult”.
- “Reaffirms to me that I'm not getting it totally wrong. Makes me feel confident that I can help him. I was really struggling there for a while before starting. Our whole family can now connect with him”.

Treatment outcome: Goal tracking

Goals reflected parent imperatives and assessment results. For practical reasons goals were limited to four per treatment block. Figures 1-4 indicate GTF scores for participants across two 12-week treatment blocks. This data reflects a 20% improvement in parent-rated functional outcomes. Individual goal changes ranged from -5% to 55%. While these results overall are supportive, it is important to note they are pilot and single case-based, not group comparison-based. That said, the data presented in this study provide early evidence of what the intervention may be capable of achieving in functional, goal-based terms.

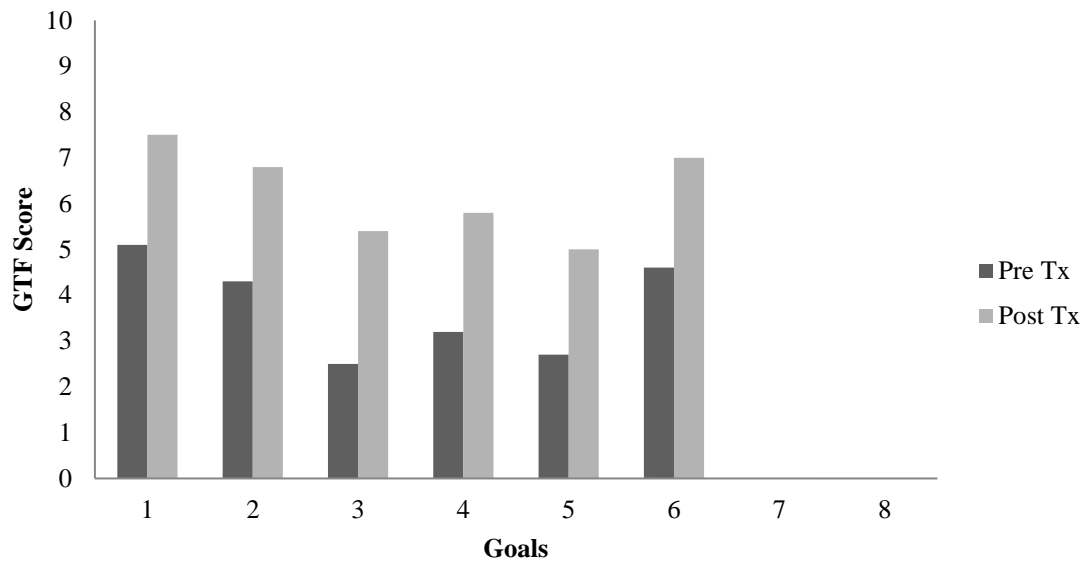


Figure 1. Goal scores for participant 1 from pre-treatment to 12-week post-treatment follow up interval.

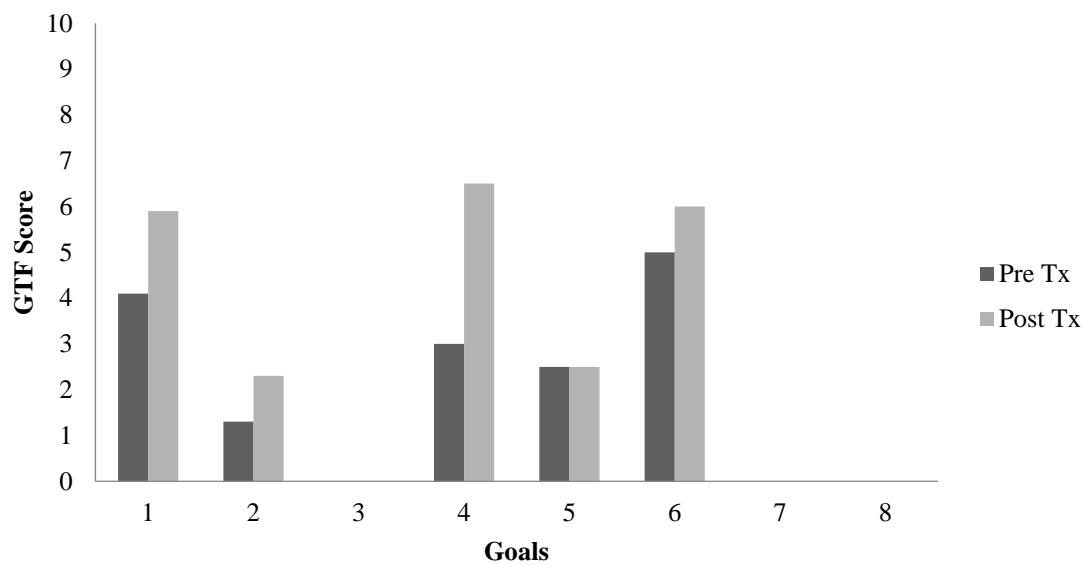


Figure 2. Goal scores for participant 2 from pre-treatment to 12-week post-treatment follow up interval.

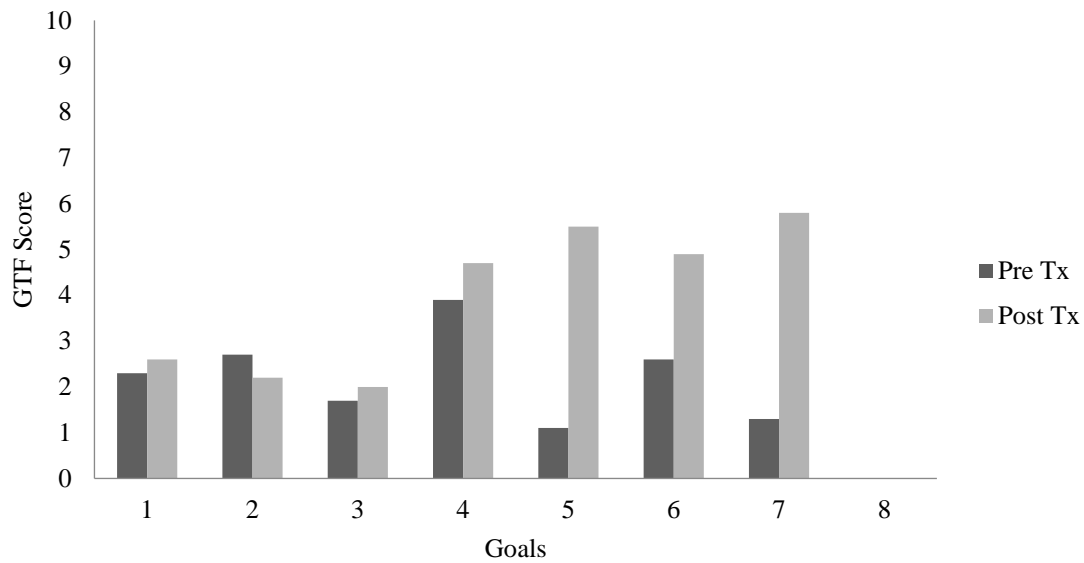


Figure 3. Goal scores for participant 3 from pre-treatment to 12-week post-treatment follow up interval.

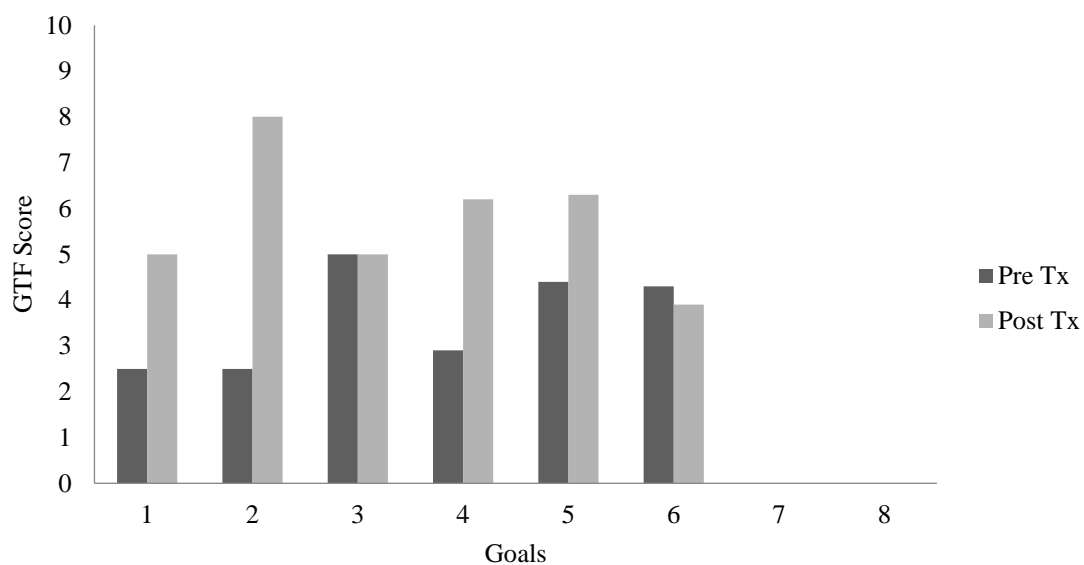


Figure 4. Goal scores for participant 4 from pre-treatment to 12-week post-treatment follow up interval.

Session satisfaction

SRS results averaged 9.3 (on a 0-10 scale) across time with the four items indicating participants developed a positive alliance with their therapists, agreed that goals were

addressed, endorsed that their input was considered, that the approach resonated and that they were satisfied with the program overall.

Instrumental outcomes: PSI, PSOC, K6, Thoughts and feelings, Interpreting behaviour and Community involvement.

Table 1 shows results for overall and individual parent-related and family factors across the PSI, PSOC, K6, Reflective aspects and Community Involvement. PSI scores are represented as percentiles. Across families the mean pretreatment percentile score for Overall Stress decreased from 53.5 to 39, Parental Distress from 57 to 50.5, Parent-Child Interaction Distress from 55 to 38 and the Difficult Child scale score from 46 to 32.5, indicating parents were on average experiencing reduced stress levels. There were modest gains on the K6, the mean score reduced from 13 to 12. The mean PSOC score increased from 70.5 to 78.8 indicating an increased sense of competency. On the measures developed for this study (and the service), scores on the Thoughts and Feeling item increased from 3.5 to 4.25, a similar gain was shown on the Interpreting Behaviour item (3.25 to 4). Finally, there was a modest increase in the scores on the Community Involvement measure (3.5 to 4) indicating parents were somewhat more satisfied with the community activities undertaken.

Table 1

Combined Mean Scores for PSI, PSOC, K6, Thoughts and Feelings, Interpreting Behaviour, & Community Involvement (n = 4)

Parenting and Community Involvement	Pre-TX	SD	Post-TX	SD
Total Stress (PSI)	53.5	29.0	39.0	24.2
Parent Distress	57.0	32.1	50.5	22.9
Parent/Child Interaction Distress	55.0	24.9	38.5	16.7

Difficult Child	46.0	36.8	32.5	32.1
PSOC	70.5	9.8	78.8	5.6
K6	13.0	3.0	11.0	2.0
Thoughts and Feelings	3.5	0.6	4.25	0.5
Interpreting Behaviour	3.25	1.0	4	0.8
Community Involvement	3.5	0.6	4	0

Parenting and Community

Pretreatment

Post treatment

Involvement

Individual PSI, PSOC, K6, Thoughts and Feelings, Interpreting Behaviour, & Community

Involvement for Parenting and Family Factors for participant 1

Total Stress (PSI)	30	16
Parent Distress	36	20
Parent/Child Interaction Distress	48	32
Difficult Child	22	18
PSOC	67	79
K6	10	8
Thoughts and Feelings	4	4
Interpreting Behaviour	3	3
Community Involvement	4	4

Individual PSI, PSOC, K6, Thoughts and Feelings, Interpreting Behaviour, & Community

Involvement for participant 2

Total Stress (PSI)	28	24
Parent Distress	26	46
Parent/Child Interaction Distress	24	18
Difficult Child	46	22
PSOC	82	81
K6	11	11
Thoughts and Feelings	3	4
Interpreting Behaviour	3	4
Community Involvement	3	4

Individual PSI, PSOC, K6, Thoughts and Feelings, Interpreting Behaviour, & Community Involvement for participant 3

Total Stress (PSI)	86	70
Parent Distress	70	66
Parent/Child Interaction Distress	82	54
Difficult Child	98	80
PSOC	74	84
K6	14	11
Thoughts and Feelings	3	4
Interpreting Behaviour	3	4
Community Involvement	3	4

Individual PSI, PSOC, K6, Thoughts and Feelings, Interpreting Behaviour, & Community Involvement for participant 4

Total Stress (PSI)	70	46
Parent Distress	96	70
Parent/Child Interaction Distress	66	50
Difficult Child	18	10
PSOC	59	71
K6	16	12
Thoughts and Feelings	4	5
Interpreting Behaviour	4	5
Community Involvement	4	4

Discussion

The current study presents a pilot evaluation of PCRI-EI via four case studies. Results indicate preliminary support for PCRI-IE in engaging parents in therapy, expanding their reflective capacity, expectations and response repertoires, in the context of reading and responding to their child's unique cues. As an instrumental outcome, this recalibrated relationship is intended to provide a foundation for functional gains for the child and increased well-being for the parent. Gains were reflected in functional capacity as measured by the GTF. On the PSI, total and subscale scores all decreased. PSOC scores increased and there were slight improvements in a brief measure of mental health (K6). These were achieved in a context where participants described a positive alliance with their therapists, agreed goals were addressed, endorsed that their perspective was considered, that the approach resonated and that they were satisfied with the program overall. Moreover, this study and the measures and processes described were undertaken in a clinical setting, which included multiple allied health professionals.

The intervention was designed to fit and extend the practices, organisation and therapeutic culture of an early childhood development service. It introduced a way of working to allied health professionals who had not been exposed to the theories underpinning its design. This required them to adjust responses, incorporate reflective practices and develop child-friendly language to better describe and direct progress around functional goals. Whilst not systematically measured, therapists reported they felt supported through the supervision. By reflecting the child's experience and using child-friendly language they reported being able to enhance the parent's ability to promote and sustain a calm-alert state, the flow on from which included adherence and execution of homework. Taken together these aspects allowed therapists to more effectively implement targeted developmental strategies. However, given these are anecdotal reports, more systematic research is required to substantiate these findings.

When developing the protocol, we expected a reduction in parent stress, shown to be high in families having a child with a disability (Hoffman et al., 2009). As noted, parents in this study were implementing therapy tasks before the measures were introduced. Consequently, it appears from the results, specifically the pre-treatment scores that their stress in the domains measured by the PSI was already trending down compared to benchmark studies (e.g., Hoffman et al.). This outcome, if sustained in a larger group-based study, is quite significant given findings that increased stress in parents of children with a disability has been linked to problematic parenting styles, (e.g., less responsive, neglectful, authoritarian), which can lead to poorer developmental outcomes (Neece et al., 2012).

Changes in the difficult child ratings are worth emphasising. The beneficial changes seen on this subscale may be particularly meaningful when considered in the context of the literature describing the high levels of stress experienced by parents of children a disability (e.g., Higgins et al., 2005; Perry, 2005). These previous studies found high scores on this

particular scale compared to typically developing populations (Hoffman et al., 2009). This reduction may be reflective of the development of insightfulness as described by Oppenheim and Koren-Karie (2002) who suggest a lack of insightfulness creates barriers to considering a wider range of explanations of a child's behaviour, promoting the notion that the child is difficult. The reduction in that perception suggests there may be an increase in insightfulness of parents in this study. Supporting this conjecture, pre-post scores increased on two items reflecting insightfulness around child communication and behaviour.

Taken together and acknowledging this is a small pilot sample, future group comparison research is necessary and currently underway. One aspect of which is to establish with more confidence the efficacy of PCRI-EI. Pending that, findings here, in tandem with our clinical observations suggest PCRI-EI may be targeting an important mechanism for change through a combination of insightfulness and decreased stress, particularly in perception of the child as difficult. That is reduced stress and arousal may assist parents to be more in the moment for reading and sensitively responding to the child's cues. In doing so, this may help them achieve the calm alert state thought to optimise functional gains (Barfoot et. al. 2017). We also anticipated that by focusing on helping parents increase reflective capacity and their response repertoire, they also experience a greater sense of competence. The changes in the scores on the PSOC suggest improvements have occurred.

Limitations and future direction

The findings in these case studies are encouraging; however, the sample size is a limitation. Future research should test this intervention in group comparison conditions, with larger samples including a control condition and across different settings. Limitations are also evident in the measures designed for the service. Notwithstanding the need for ease of administration because of the practice-based nature of the research, developing measures that

more reliably reflect the construct insightfulness is indicated. A rigorous evaluation of therapists' experience is also planned.

The lack of variability seen on the SRS and the fidelity measure also warrants comment. The SRS shows high average scores across participants; between 9.3 and 9.4 on a 10-point scale. Although these scores when converged with fidelity ratings indicate a positive therapeutic alliance and satisfaction with services, the high alpha correlation for the fidelity measure may be a proxy for therapy satisfaction with highly satisfied clients giving blanket high item ratings that produce the near ceiling index. Additionally, the lack of sensitivity is problematic from a clinical viewpoint (e.g., in the context of client feedback) and scientific perspective (e.g., in the ability to produce a range of responses for correlation and prediction). Despite challenges and moving beyond an assessment-only function, these measures are also an integral component of feedback-informed treatment and ongoing formulation. As part of this feedback-informed ethos, they establish a dialogue between families and therapists that help monitor both relational and task aspects of treatment.

In summary, the PCRI-EI protocol has shown promising practice-based, single-case findings across four families experiencing different developmental challenges. Larger control group comparison is needed to evaluate more comprehensively what these cases are suggesting, including in terms of overall outcomes and therapy, therapy setting, therapist and parent mechanism of change. In addition, the experiences of therapists, the utility of the treatment manual and related fidelity assessment, also need more rigorous evaluation.

References

- Abidin, R.R. (2012). *Parenting Stress Index* (4th ed.). PAR.
- Abidin, R. R. (1997). Parenting Stress Index: a measure of the parent-child system. In Zalaquett, G. & Wood, R. (Eds). *Evaluating stress: A book of resources* (pp 277-291). Scarecrow Press, Inc.
- Bayley, N. (2006). *Bayley-III: Bayley Scales of Infant and Toddler Development* (3rd ed.).
- Barfoot, J., Meredith, P., Ziviana, J., & Whittingham, K. (2017a). Relationship-based approaches in early childhood intervention: Are these applicable to paediatric occupational therapy under the NDIS? *Australian occupational therapy journal*, 64, 273-276. <https://doi.org/10.1111/cch.12493>
- Barfoot, J., Meredith, P., Ziviana, J., & Whittingham, K. (2017b). Parent-child interactions and children with cerebral palsy: An exploratory study investigating emotional availability, functional ability, and parent distress. *Child: care health and development*, 43, 812-822. <https://doi.org/10.1111/1440-1630.12343>
- Bowlby, J. (1969). *Attachment and loss*. Vol. 1: Attachment. Basic Books.
- Bowlby, J. (1973). *Attachment and loss*. Vol. 2: Attachment. Basic Books.
- Bowlby, J. (1980). *Attachment and loss*. Vol. 3: Attachment. Basic Books.
- Caldwell, P. (2006). Speaking the other's language: Imitation as a gateway to relationship. *Infant and Child Development*, 15, 275-282.
- Ephraim, G. (1986). A brief introduction to augmented mothering. *Playtrack pamphlet*. Harpebury Hospital School, Radlet Herts.
- Fonagy, P., Gergely, G., Jurist, E., & Target, M. (2002). *Affect Regulation, mentalization and the development of the self*. Karmac.
- Freiberg, S. (1979) Blind infants and their mothers: An examination of the sign system. In M. Bullowa (Ed.), *Before speech: the beginning of interpersonal*

- communication* (pp.149-169). Cambridge University Press.
- Griffiths, R. (1984) A comprehensive system for measurement for the first eight years of life.
In: *The Abilities of Young Children*, (pp101-172). Association for Research in
Infant and Child Development. The Test Agency.
- Hayes, S. C., Strosahl, K., & Wilson, K. G. (1999). *Acceptance and commitment
therapy: An experiential approach to behavior change*. Guilford
Press.
- Hoffman, C. D., Sweeny, D. P., Hodge, D., Lopez-Wagner, M. C., & Looney, L. (2009).
Parenting stress and closeness: Mothers and typically developing children and
mothers of children with autism. *Focus on Autism and Other Developmental
Disorders* (3), 178-187. <https://doi.org/10.1177/1088357609338715>
- Johnston, C., & Mash, E. (1989). A measure of parenting satisfaction and efficacy. *Journal of
Clinical Child Psychology*, (18), 167-175.
<https://doi.org/10.1207/s15374424jccp1802-8>
- Kalmanson, B. (2009). Echoes in the nursery: Insights for treatment of early signs of
autism in a baby sibling. *Journal of infant, child and adolescent
psychotherapy*, 8, 40-48. <https://doi.org/10.1080/15289160802683427>
- Kessler, R. C., Andrews, G., Colpe, L. J., Hiripi, E., Mroczek, D. K.,
Normand, S. L., Walters, E. E., & Zaslavsky, A. M. (2002). Short screening scales to
monitor population prevalences and trends in non-specific psychological distress.
Psychological Medicine, 32, 959-976. <https://doi.org/10.1017/s0033291702006074>
- King, G., Strahan, D., Tucker, M., Duwyn, B., Desserud, S., & Shillington, M. (2009)
The application of a transdisciplinary model for early intervention services.
Infants and Young Children, 22, 211-223.
<https://doi.org/10.1097/iy.06013e3181abe1c3>

- Lambert, M. J. (2010). *Prevention of treatment failure: The use of measuring, monitoring, and feedback in clinical practice*. Washington, DC: American Psychological Association. <http://dx.doi.org/10.1037/12141-000>
- Marvin, R., Cooper, G., Hoffman, K., & Powell, B. (2002). The circle of security project: Attachment-based intervention with care-giver-preschool child dyads. *Attachment & Human Development, 4*, 107-124. <https://doi.org/10.1080/14616730210131635>
- Miller, S. D., Duncan, B. L., & Johnson, L. D. (2002). *The session rating scale V. 3.0*. Author.
- Muir, E. (1992). Watching, waiting, and wondering: Applying psychoanalytic principles to mother-infant intervention. *Infant Mental Health Journal, 13*, 319-328. [https://psychnet.apa.org/doi/10.1002/1097-0355\(199224\)13:4%3C319::AID-IMHJ2280130307%3E3.0.CO;2-2](https://psychnet.apa.org/doi/10.1002/1097-0355(199224)13:4%3C319::AID-IMHJ2280130307%3E3.0.CO;2-2)
- Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behaviour problems: A transactional relationship across time. *American Journal on Intellectual and Developmental Disabilities, 117*, 48-66. <https://doi.org/10.1352/1944-7558-117.1.48>
- Nind, M., & Hewitt, D. (1998) *Interaction in action*. David Fulton Press.
- Nind, M., & Hewitt, D. (2001) *A practical guide to intensive interaction*. David Fulton Press.
- Oppenheim, D., Koren-Karie, N., Dolev, S., & Yirmiya, N. (2009). Maternal Insightfulness and resolution of the diagnosis are associated with secure attachments in preschoolers with autism spectrum disorders. *Child Development, 80*, 519-527. <https://doi.org/10.1111/j.1467-8624.2009.01276.x>
- Oppenheim, D., Koren-Karie, N., Dolev, S., & Yirmiya, N. (2012). Maternal sensitivity mediates the link between Insightfulness/resolution and

- mother-child attachment: the case of children with autism spectrum disorder.
Attachment and Human Development, 14, 567-584.
<https://doi.org/10.1080/14617734.2012.727256>
- Ronan, K. R. (2009). *Goals Tracking Form*. Author.
- Ronan, K. R., Davies, G., Canoy, D., Jarrett, M., & Evans, C. (2012). *Feedback-informed family treatment for conduct disorder: Findings from a pilot study*.
Attachment and Human Development, 14, 567-584.
- Ronan, K. R., Davies, G., Browne, M., Woltmann, D., Wilkman, R., Jarrett, M., Braun, S. (2018). *Family-centered, feedback-informed therapy for complex behaviour in youth: A randomised, controlled trial of a systemic therapy approach*. Manuscript in preparation for submission.
- Ronan, K. R., Davies, G., Wikman, R., Canoy, D., Jarrett, M. & Evans, C. (2016). *Family-centered, feedback-informed therapy for conduct disorder: Findings from an empirical case studies*. *Couple and Family Psychology: Research and Practice*, 5, 137-156. <https://psycnet.apa.org/doi/10.1037/cfp0000059>
- Sanfuji, W., Yamashita, H., & Ohgami, H. (2009). Shared minds: Effects of a mother's imitation of her child on the mother-child interaction. *Infant Mental Journal*, 30, 145-157. <https://doi.org/10.1002/imhj.20208>
- Shai, D. & Belsky, J. (2011). When words just won't do: Introducing parental embodied mentalising. *Child Development Perspectives*, 5, 173-180.
<https://doi.org/10.1111/j.1750-8606.2011.00181.x>
- Singh, N. N., Lancioni, G. E., Winton, A. S. W., Singh, J. W., Curtis, W. J., Wahler, R. G., & McAleavey K. M. (2007). Mindful parenting decreases aggression and increases social behaviour in children with developmental difficulties. *Behaviour Modification*, 31, 749-771. [https://doi.org 177/0145445507300924](https://doi.org/10.1002/177/0145445507300924)

- Slade, A. (2009). Mentalising the unmentalisable: Parenting children on the spectrum. *Journal of Infant, Child and Adolescent Psychotherapy*, 8, 7-21.
Journal, 30, 145-157. <https://doi.org/10.1080?15289160802683054>
- Soderstrom, K., & Skarderud, F. (2009). Minding the baby: Mentalization-based treatment in families with parental substance abuse use disorder: Theoretical framework. *Nordic Psychology*, 61, 47-65. <https://psycnet.apa.org/doi/10.1027/1901-2276.61.3.47>
- Stanley, M. A., & Averill, P. M. (1998). Psychosocial treatments for obsessive-compulsive disorder: Clinical applications. In R. P. Swinson, M. M. Antony, S. Rachman, & M. A. Richter (Eds.). *Obsessive-compulsive behaviour: Theory, research and treatment* (pp. 277-297). Guilford.
- Tronick, E. & Beeghly, M. (2011). Infants' meaning-making and the development of mental health problems. *American Psychologist* 66, 107-119.
<https://doi.org/10.1037a0021631>
- Weatherston, D. (2007). Returning the treasure to babies: Infant mental health and early headstart. *Infant mental health journal*, 28, 246-251.
<https://doi.org/10.1002/imhj.20132>
- Whittingham, K. (2016) Mindfulness and transformative parenting. In E. Shonin, W. V. Gordon, & M. Griffiths (Eds). *Mindfulness and other Buddhist-derived approaches in mental health and addiction* (pp. 363-390). Springer.
- Whittingham, K., Wee, D., & Boyd (2011). Systematic review of the efficacy of parenting interventions for children with cerebral palsy. *Child: Care, health and development*, 3, 475-483. <https://doi.org/10.1111/j.1365-2214.2011.01212.x>

CHAPTER 3. Therapists' experience of PCRI-EI

The material contained in this chapter was published online on the 3rd of May 2021 in the *International Journal of Disability, Development and Education*, DOI: 10.1080/1034912X.2021.1910933. It is presented as it was published, except for changes to support consistent chapter formatting throughout the thesis.

Manuscript title: Involving parents in early intervention: Therapists' experience of the Parent Child Relationally Informed-Early Intervention (PCRI-EI) model of practice.

Clarification: As noted above the chapter is presented as it was published. However, following examination, a suggestion was made to clarify a question of anonymity.

To address that the sentence on page 65 (in the Methods section) should read:

Therapists responded to an anonymous survey containing 13 questions, assessing their experience of the model of practice.

Even though this was the last study in the sequence, it was evident in the literature that helping allied health therapists shift to a relationally-based practice has proved challenging.

Paradoxically, when the therapists are surveyed, they strongly endorse the approach.

However, it appears they struggle with the *how to* of doing that. This next Chapter retrospectively investigated the experiences of the therapists who worked with the model and gathers their experiences of making the shift. Included in these reflections is the unexpected impact of the challenges presented to their professional identity; something that has not been referenced or addressed in the current literature.

Abstract

Including parents of children with developmental delays in early intervention programs has been widely endorsed as best practice across the multiple disciplines that work in that context. Parents have echoed that sentiment, commenting on the benefits of being able to apply skills in broader family and community contexts. Despite a 20-plus year history of research showing the benefits of family-centred interventions, the skills required to successfully transition from therapist-lead to family-centred practice appear to have occurred through experience or chance. Systematic development of therapists' skills including through education, mentoring and reflective supervision have been promoted as being essential to facilitating the transition. This qualitative study investigated the learning experiences of 14 allied health professionals from various disciplines as they engaged in a relationally based, family-centred model, the Parent Child Relationally Informed – Early Intervention (PCRI-EI) program. Feedback indicated the systematic approach embedded in the treatment manual combined with reflective supervision built therapists' competence and confidence in working relationally. They reported being able to use these skills to develop therapeutically sound, family-centred partnerships with parents as well as promote socioemotional connection for the parent and child. These findings are discussed in the context of the successful implementation of best-practice early intervention programs.

Including parents in early intervention programs for children with developmental delays has been widely endorsed across multiple disciplines, including occupational therapy, speech pathology and physiotherapy (Hughes-Scholes & Gavidia-Payne, 2019; Pretis, 2011). Within these interventions, a substantial body of research supports the positive influence of the parent-child relationship on developmental outcomes (e.g., Guralnick, 2017). Often described as Family-Centred practice, programs that upskill parents, reflect family context and focus on increased participation in broader community and social settings are now considered best practice (Guralnick; Salisbury & Copeland, 2013); a position that has been promoted for the past 20-plus years (e.g., Mayer et al., 2002). Such programs have good face validity, with recent studies showing parents strongly endorsing the sharing of skills and strategies to allow them to extend the child's learning to multiple situations including within the family and wider community (Callanan et al., 2021; Guralnick 2011).

Despite this evidence, successful implementation of family-centred, parent-involved interventions has been difficult to achieve (Campbell et al., 2009). When this has occurred, it appears to be a function of the individual therapists' experience or chance rather than building skills at undergraduate level or through systematic, professional development (Campbell et al., 2009). In addition, working directly with parents can include challenges beyond simply introducing evidence-based strategies and having them apply these outside therapy sessions. It requires therapists to work with parents who have a lived experience that has included lengthy medical assessments, sometimes high-risk early-life health issues and where the initial expected joys of a newborn have been met with confusion, fear, and significant concerns about their future and that of their child (Kalmanson, 2009).

These same parents may be struggling with a strong sense of incompetence and high levels of individual and relational stress often associated with parenting a child with significant developmental delays (Callanan et al., 2020; Robinson & Neece, 2015). All these

factors have been linked to poorer outcomes in early intervention programs (Davis & Neece, 2017). Somewhat problematically, the skills needed to work with parents experiencing these stressors are usually seen as residing with psychologists or social workers, which is a perceived barrier to other allied health professionals working relationally (Stuart, 2008).

Systematically developing allied health therapists' capacity, either through education, professional development or mentoring, to engage relationally with parents and families appears fundamental to the successful implementation of such programs (Campbell et al., 2009). While there is a clear consensus that relationally based early interventions are best practice, the dilemma is how to train and support allied health professionals to deliver those interventions.

In prior work, we developed a manualised intervention, the Parent-Child Relationally Informed – Early Intervention program (PCRI-EI; Callanan et al., 2019), which was incorporated into the practices of a multidisciplinary allied health team working in an early childhood development centre. The premise of PCRI-EI is to develop the responsiveness of parents and therapists working with children with developmental delays. These responses must be generated in a context where the child's communication is often limited to subtle, non-verbal, idiosyncratic cueing. Whilst relational, PCRI-EI does not focus on the changed relationship. Instead, it becomes the foundation for therapy designed to increase functional capacity by including parents and reflecting family context.

To achieve that objective and address the dilemma of how to build relational skills, strategies to develop therapists' capacity were included in a treatment manual associated with the program (available from the corresponding author). An adjunct to on-the-job training and reflective supervision, the manual contains case examples and scripts that educate and build the competencies of therapists to deliver relationally based interventions. The intent is to train therapists in how to engage, empower and upskill the family, to create developmentally

informed interventions that blend parental goals with those that are clinically indicated while paying attention to parent well-being and the family situation. Contemporaneously, ongoing reflective supervision delivers the mentoring and consultation instrumental in helping therapists transition to relationally-based practices (Barfoot et al., 2017; Inbar-Furst et al., 2020).

The current study

As noted above, there is an extensive body of work describing the benefits of involving parents in early intervention. These studies have been undertaken by the various disciplines most often involved in early childhood settings over an extended period (e.g., Scales et al., 2007; Segal & Bayer, 2006). This body of work has two main conclusions. Firstly, that the shift to family-centred therapy is warranted and secondly the challenge is how to facilitate that change when the skills needed by therapists are not included in their undergraduate education or early career development (Campbell et al., 2009). Specific skills training, mentoring and reflective supervision, described by Weatherstone et al., (2010) as an “essential competence” (p.22) are often seen as the most practical solution (Barfoot et al., 2017; Campbell et al.; Snyder & Wolfe, 2008). Given the integral role of reflective supervision and mentoring in PCRI-EI as well as the strategies embedded in the treatment manual, the purpose of this qualitative study was to investigate the effectiveness of PCRI-EI in helping therapists transition to a relationally based paradigm from the perspective of those therapists.

Method

Therapists responded to a survey containing 13 questions, assessing their experience of the model of practice. They were also invited to add comments to provide an insight into their lived experience of PCRI-EI. The organization in which the early childhood development service operated provided consent and support for the study. Formal ethical

approval was secured from Central Queensland University Human Research Ethics Committee, HREC approval number 21674.

Participants

Email invitations, which included a link to the informed consent statement and questionnaire were sent to 20 allied health therapists who had worked with families using the PCRI-EI protocol. Fourteen therapists comprising four occupational therapists, two physiotherapists, three psychologists, and five speech pathologists completed the survey.

Questionnaire

As this was an exploration of the individual experience of PCRI-EI there was no ‘standardised’ measure available. Given this, the research team designed a survey (Appendix) that allowed participants to provide surface-level indices, which had a minimal time impost and offered the opportunity for them to provide more in-depth reflections if they wished. Of the 13 questions, one asked participant to select their profession and eight included Likert based response scales for participants to rate their experience. For example, responses to the question “To what extent has taking a relational approach impacted the way you work with children and their families?” ranged from 1 = *none at all* to 5 = *a great deal*. These eight questions offered participants the opportunity to provide comment or examples to expand on their rating should they wish. The remaining four questions asked for comments only.

Thematic Analysis

Analysis of the qualitative data followed the phases outlined by Braun and Clarke (2006). That is, the principal researcher (John Callanan) collated the responses from open-ended questions into a Word for Windows document and familiarised himself with the data (phase one), this was followed by generation of initial codes and collating exemplars of each code (phase two). This collated data was then independently examined by the other authors and agreeance reached on the initial codes. Using a semantic and inductive approach,

predominant themes were then derived by the principal researcher (John Callanan). All three authors then met to discuss, confirm, and interpret the themes derived from the data (phases four and five).

Results

Participants completed the questionnaire and included comments about their experience implementing PCRI-EI. Scores for each question are presented in Table 1. Overall, strong support was shown for the program ($M = 4.57$). Of note is the high value placed on reflective supervision ($M = 4.79$), which is considered a key component in helping therapists make the transition to relationally-based practice.

Table 1

Combined means and standard deviations for each question with Likert scale responses

Question	<i>M</i>	<i>SD</i>
Q2 To what extent has taking a relational approach impacted the way you work with children and their families?	4.57	0.65
Q3 Has thinking about the child's experience and their everyday life changed your approach to therapy?	4.21	0.89
Q4 Thinking about the role of parents in therapy, has the relational approach changed the way you involve parents?	4.14	0.77
Q5 Were there any changes in how you achieve therapy goals as a result of working this way?	4.29	0.91
Q6 Were there any changes in how you were able to apply evidence-based practices in your discipline working this way?	3.57	1.02
Q8 How would you rate your experience of reflective supervision as a support in this type of practice?	4.79	0.58

Q9 How would you rate your overall experience of the relational model?	4.57	0.51
Q10 Do you still apply the principles of the parent child relational approach in your therapy?	4.36	1.28

Even though the sample size was small, an exploratory investigation of whether there was any differential impact by professional group was considered valuable in the context of the overall study. Consequently, a Kruskal-Wallis test was conducted to examine the differences in scores for each question across the four health professional groups. No significant differences were found between the groups for any of the questions, $H(3) = 3.03$, $p = .387$.

As outlined in the Method for the thematic investigation, comments from each question were collated and analysed following the guidelines provided by Braun and Clarke (2006). In some cases, only a few comments were added, these responses have been summarised rather than thematically analysed noting Braun and Clarke's caution to avoid presenting questions put to participants as themes. Results are summarised by question number below.

Question 2: To what extent has taking a relational approach impacted the way you work with children and their families?

The majority (93%) of participants reported that taking a relational approach substantially impacted the way they worked with families describing it as being fundamental in the child's development, e.g., "without the relationship the development of the child is impaired" (Participant 14). Introducing parents to their child's unique cuing system developed communication within the dyad. This not only enhanced the relationship it supported a "parental shift of narrative from bad to struggling child" (Participant 10). A

perspective that also helped therapists' formulation; they described becoming more aware of the uniqueness of the child rather than just focusing on diagnostic information. Increased parental capacity in implementing the skills across settings was also noted, e.g., "I have witnessed the achievement of developmental goals to not only occur faster, but parents gain skills to apply in a variety of contexts" (Participant 3).

Question 3: Has thinking about the child's experience and their everyday life changed your approach to therapy?

Most of the participants reported thinking about the child's experience changed their approach. Participant 2 summarised this saying:

It has helped me to have more understanding of children with high physical dependence and their experience being in a body that does not move in a way that they can easily access the world, and how this can impact on their motivation to participate and assists in understanding certain behaviour.

Commonly responses suggested that thinking about the child's experience gave them a voice in therapy, which changed families' and therapists' perception of the child and provided a different perspective on how to implement strategies. In the words of Participant 5:

Working this way gives the child a voice – for some families it is a new experience and way of thinking to make sense of the child's experience. This can be quite enlightening and life-changing for families sometimes. On the other hand, it allows parents to also learn how to use their own voice in an understanding, supportive and directional way.

Question 4: Thinking about the role of parents in therapy, has the relational approach changed the way you involve parents?

The main theme in this question related to the positive impact of parents as active participants in therapy, e.g., "I now would never provide one-on-one therapy with a child as I

view the work with the parents as paramount. Parents are now actively engaged in sessions and become the conduit for intervention” (Participant 5). A second theme captured a major challenge in implementing relationally based programs. Specifically, that while parental involvement was often discussed in work settings, implementation lacked support. Participant 1 reflected this dilemma saying:

We often talk about parent-focused models but rarely are parents actually supported to do the work. By sitting back and supporting parents in their engagement with their children, the rewards are greater than in any other model of practice I have experienced.

The final theme from this question considered the difficulties for parents when they are asked to do the work. However, once involved, therapists reported seeing parents’ skills and confidence grow. Participant 9 noted that “given the relational and reflective nature of the work, it is helpful to notice this with the parent and open a helpful conversation around it”; comments that exemplify the philosophy contained in PCRI-EI and illustrate the reflective skills of the therapist.

Question 5: Were there any changes in how you achieve therapy goals as a result of working this way?

Most participants said their goal-setting process changed. Two themes emerged from their comments. The first was that goals shifted from being mostly functional to reflecting family context. For example, Participant 13 said:

Goals make more sense to me in this way. For example, a parent may say "I want him to be able to talk" and you say, "what would this mean for your family?", and they respond, "so he can tell us when he's sad". These exchanges helped me to understand that parent goals don't come from a developmental checklist. Then you think about it from the child's perspective, and they probably want to be able to do that too. You

could start by teaching the parent the sign for "sad", or you can take a step further back and say... let's teach this parent to watch their child and learn how he is already telling us that he is sad, happy, worried, frustrated, etc. Then we can add sign to that and that will mean something.

The second theme reflected a high level of collaboration with parents when setting goals, e.g., Participant 3 said:

Yes! Goals take time to get to and this is ok. Breaking down goals into manageable and meaningful steps - this way the family know what they are working towards for their bigger lives, they are able to put the work in to [sic] context and therefore practice it experientially.

The shift in goal setting extended to complex cases – where the child had significant developmental delays across many domains (e.g., physical, cognitive and communication).

To illustrate, Participant 2 said:

From working within a complex needs case load achievement of therapy goals were prolonged. However, when working within this model and having a high focus on parent involvement I feel that it assisted with parents' abilities to re-evaluate goals and at times less focused on skills development and focusing on increasing participation and community access.

Question 6: Were there any changes in how you were able to apply evidence-based practices in your discipline working this way?

Participants' feedback to this question reiterated previous comments, e.g., improved engagement with parents, better collaboration, and increased incidence of parents applying the ideas outside therapy. However, several participants reported initial difficulties in

integrating evidence-based practices with this way of thinking. For example, Participant 2 noted:

It was initially difficult attempting to apply evidence-based practices, e.g., modified constraint/bimanual therapy. However, when working within this model it assisted significantly with understanding behaviours that presented when engaging in this type of therapy including managing resistance.

Other participants reported working with their supervisors to achieve the integration, for example, Participant 5 said:

I worked with my supervisor and developed my implementation and use of AAC [Augmentative and Assistance Communication system] in context of the relational approach. This has allowed me to explore parents using the AAC systems firsthand rather than watching an ‘expert’ use the system first. It has developed parents’ confidence in using AAC.

Question 7: Did you find working with parents and children this way presented any professional or personal challenges that you would like to comment on?

Three themes emerged from comments provided to this question. Firstly, participants reported that it is hard to break the habits of therapist-lead interventions. Participant 1 summarised this challenge saying:

Its [sic] hard at first. Hard to sit back, hard to ask parents to interact differently, hard to wait, hard to not get involved. It was hard to make the necessary changes – to untrain the habits learned and polished over the years doing therapy TO children and families.

The difficulty integrating a relational approach was the second theme raised – essentially because the methodologies (therapist driven versus relationally oriented) felt so different.

Participant 5 described that dilemma as follows:

When I first started, it was difficult to add 'extra stuff' to all the other things that already needed to happen in a Speech Pathology session. This is no longer an issue for me, it just blends together naturally. I think this was a matter of practice. At times I felt uneasy about when to 'bring it in', particularly when there was a pressing issue such as feeding. Sometimes it felt unnatural to start with a comprehensive and clinical assessment, then move into the "airy fairy stuff" (I was fighting the urge to give strategies too early because I felt pressure to address parent concerns such as talking, following instructions, taking turns, sitting at the table, etc.). Over-time I became more confident in the approach of laying the foundation/setting up the environment for these skills to occur. I sometimes let parents know, "You're worried about X talking and this will help" and made subtle references back to their goals, e.g. "you just taught them a new word and they like it because it's about their play". With practice, I began to use the model naturally and this gave me more cognitive space for the other stuff. There was a time when managing both was tricky - now its [sic] one!

Finally, participants noted that when working relationally they had to be prepared to work with parents' difficult feelings when they emerged. For most this was new and at times uncomfortable. Participant 7 provided an insight into how this changed for them:

Finding the right words when all my training had been so medically oriented was difficult. I did find the feelings that would come up in the past quite challenging and sometimes was lost for words. As a physiotherapist I often have to give some difficult

news about how well the child might function as they get older. Now I can sit with the emotions a lot better than I have done in the past.

Question 8: How would you rate your experience of reflective supervision as a support in this type of practice?

Most participants rated reflective supervision as extremely valuable in helping them change their practice. Comments referenced skill acquisition and personal development:

Reflective supervision was imperative for my personal and professional development working in this model of practice. Amongst many helpful things, it allowed me to be vulnerable and comfortable to discuss gaps in knowledge or professional performance. (Participant 2).

A second theme was around the utility of reflective supervision in helping manage the personal/interpersonal issues that surfaced in sessions:

I feel that the reflective supervision offered to me was invaluable and vital in me continuing to work in this way. There was a lot more personal 'stuff' that came up during these sessions because often you are sitting in an uncomfortable space. (Participant 7).

The final theme mentioned building knowledge and expertise in the principles of the work itself e.g., the use of video reviews because they “facilitate conversations around meaning and responses, especially the therapists” (Participant 8) and that reflective supervision was important in skill development in applying the principles contained in PRCI-EI:

Because this approach really is working with parent-child dynamics in the moment it is really invaluable to get the supervision to assist in building the skills that best suit the model. Falling back into old ways of working is easy to do so the ongoing supervision assist in skill development and fidelity to the model. (Participant 11).

Question 9: How would you rate your overall experience of the relational model?

Of the eight participants who responded to this question, most referred to their own increased confidence in working relationally e.g., “easily managing dynamics in the room” (Participant 9) and “talking with families about tricky feelings” (Participant 7). Participant 1 provided a fuller reflection of the competing tensions they found when shifting to PCRI-EI saying:

It is difficult at times to introduce this model of practice especially when families have past experiences with therapy and don't see this as the 'right way' to do 'therapy'. As a therapist with many years of practice it was challenging at times to work within the model of practice and continue with evidence-based therapy. I found it challenging at times to know when it was ok to be a bit more removed from this model of practice to support a therapy goal e.g., mealtimes. The phrase that was often used (in supervision) was 'don't throw the baby out with the bathwater' meaning don't forget all your other knowledge and skills and use them within this practice model. Also learning that it is ok at times to use parts of the model to provide best supports.

Question 10: Do you still apply the principles of the parent child relational approach in your therapy?

Nine of the participants had left the service and were working in other settings at the time of the survey. Of those, two are no longer in early childhood development clinics. The remaining seven said they continue to apply PCRI-EI in their work with families. Most gave short answers, e.g., “Yes, I use these principles in all my work with parents and children. And honestly, I wouldn't work in any other way. This work is meaningful for me and the families I work with” (Participant 10). Participant 14 elaborated saying:

I still reflect on the relationship even when it is a pure 'orthopaedic' problem that the

client presents with. I note the children that recover the ‘best’ or engage the best in therapy have a supportive base with parents that support them through challenging moments and experiences and see them as they are, where they are. I find it helps to join families in noticing the strengths and skills their child has – not what they are not doing, the families usually know this too well already.

One participant (4) did respond with a caveat saying, “it depends on the child”.

Question 11: Do you have any suggestions for improvement of the practice or the model?

Six participants responded to this question with several suggesting videos demonstrating the process as being more helpful than the manual, particularly for new employees. A lack of preparation for new graduates in understanding the relationally based practice was also mentioned, with Participant 5 suggesting “I think this way of working should be included in all allied health undergraduate training”.

Question 12 In your experience were there any barriers or potential barriers you can see in the implementation of the model of practice?

Three distinct themes emerged from comments made in response to this question. The need to have all members of the team, including managers working this way (Participant 14) was mentioned by many. Several participants noted the challenges when new staff join the team:

Everyone needs to be on board or open to discussing - barriers appear when therapists don’t understand or are not comfortable with the approach. Challenges when new staff have a focus on “developmental progress and skills” and the relationship is not acknowledged or noticed. Staff that are not comfortable speaking about or discussing emotions or acknowledging their own. (Participant 13).

Having faith in the process and being able to wait for the changes in the face of pressures to *do something* was a second perceived barrier mentioned; a perspective summarised by Participant 1 who said:

It takes time to build relationships with parents and you have to trust this way of working ‘works’ or it can feel like you aren’t doing anything. It is also very different from the way therapists are trained. This model de-centres the therapist which can be uncomfortable. The therapist is no longer the expert in the room (so what are the parents paying for?). Yet when it works it is such a rewarding experience for child, parent and therapist.

The third theme referenced the funding model that is quite specific to this (Australian) setting, which is the National Disability Insurance Scheme (NDIS, www.ndis.gov.au). A recent initiative, this scheme emphasises the role of the parent in determining the direction and funding of the interventions for their child. Several participants suggested that the absence of information on the benefits of working from this family-centred perspective may perpetuate therapist-lead interventions because it is familiar to families and widely practiced by allied health therapists. Participant 5 summarised this dilemma saying:

With the roll out of the NDIS Early Childhood Early Intervention (ECEI) program, which gives parents choice of service providers and control of the frequency of therapy, I feel that there may be some resistance from parents to spend their therapy funding working in this space if they don’t have the right introduction to the work or education around its benefits. I worry that we may also not be able to work with a lot of families that need this work the most because there are so many that will offer one-on-one therapy with the child, and this is obviously easier and more comfortable for the families. I believe that clinical education around this model to the wider early childhood early intervention community is vital.

Question 13: Is there anything else you would like to share about your experience of the relational model?

Eight participants answered this question, which reflected two key themes. The first centred on their increased skills in managing the dynamic aspects of the interactions in the room. Participant 6 summarised this change saying:

I think the model has the potential to really change the way we work with parents and their children. It is challenging to manage dynamics as they occur in the room but with practice and supervision this only strengthens the skills and confidence of the clinician.

The second theme addressed the value of the shift from therapist-lead to family-centered work. Specifically, the role of the parent and developing goals that considered the family context as well as developmental imperatives. Participant 8 noted:

Having worked with and without this model, it becomes increasingly uncomfortable observing other services/therapists working in the more traditional models, including having parents wait outside the room, and observing how goals are not being achieved.

Discussion

The purpose of this study was to investigate the lived experience of allied health professionals using PCRI-EI and their perceptions of the effect of the approach. Participants' comments and responses indicate a good working knowledge and understanding of the principles of relationally based therapy. For example, parents were described as active partners in therapy, bringing family context and hopes to the process of goal setting; a perspective that has been championed in the best practice literature (e.g., Guralnick, 2017). Therapists described increased comfort and competence working with parental stress and parent-child relational challenges, including difficult behaviours. A finding that directly

addresses the view (barrier) that working relationally is the preserve of mental health professionals (Stuart, 2008). Therapists also reflected on the value of the parent-child relationship as an important therapeutic component in achieving developmental gains. Including when parents apply learned skills outside therapy. This perspective has been strongly endorsed by parents (Guralnick, 2011) and is seen as key in successful early intervention programs (Guralnick; Salisbury & Copeland, 2013).

More importantly, participants reported changes in their practice, which reflects the *how to* (emphasis added) objective fundamental to PCRI-EI. This finding is particularly salient given recent evidence from a study by Alexander et al. (2018) which noted that despite endorsing the notion that the parent-child relationship is important in early intervention, less than half the participants in the study felt comfortable utilising that relationship in their work. All participants in this study agreed that regular, reflective supervision helped integrate the theory and allowed them to safely explore the challenges of working relationally. A positive finding given the historical challenges successfully integrating reflective practices into programs for allied health professionals (Weatherston et al., 2010).

Despite an overall positive reflection, therapists did report challenges in shifting to PCRI-EI. Mentions of difficulties in moving from a therapist-lead, desire to ‘fix’ practice to one where the parent and the child became central to the therapy were common, which reflects similar observations in previous research (e.g., Alexander et al., 2018). A related challenge was developing a trust in the process, which seemed “airy fairy” (Participant 13) at first and required therapists (and parents) to wait for the changes, which somewhat paradoxically appear to occur faster when the child is given the time to process and respond to the request (Participant 3). In a similar vein, shifting from goal setting driven by

assessment and developmental checklists to working with parents to generate goals that were contextual and “meaningful” (Participant 5) was also difficult initially.

Perhaps the biggest challenge was the impact of developing a relationship with the parents. Many participants reported this introduced a broad range of feelings and experiences that were not encountered when the parent was an observer or not involved in the treatment. Given the well-documented impact of parent well-being on outcomes (Davis & Neece, 2017), the capacity of therapists to establish a therapeutic alliance that pays attention to parent well-being appears to have been addressed through the provision of regular reflective supervision. At the same time, participants agreed the reflective supervision provided a safe space for them to explore their own vulnerabilities when working relationally (Participant 2).

Limitations

That the study was undertaken in a single service site is an acknowledged limitation. Extending the program to other sites and settings is important in confirming its efficacy. Despite the high return rate, the sample size is small. Consequently, conclusions drawn from the responses and comments need to be considered in that context. There is also the risk of bias given the respondents worked closely with the principal investigator, that is, it may be those who had a less favourable experience of the program did not respond. On reflection, the questionnaire did not specifically investigate participants’ views on the utility of the treatment manual, which was included as part of the induction to service and referenced in the supervision. Understanding the relative impact of the manual and reflective supervision is important and requires further investigation.

Conclusion and recommendations.

The themes and comments raised and discussed by therapists in this investigation mirror the sentiments of other studies that have considered the utility of relationally based models (e.g., Campbell et al., 2009). However, participants’ responses here indicate the

processes and practices embedded in PCRI-EI provided the understanding, skills and confidence that helped them successfully transition to a relationally based paradigm without sacrificing their own discipline-specific practices. As well as building skills, participants described feeling more comfortable and competent in developing partnerships with parents that included educational and relational components, which are meaningful and influential factors in successful early childhood development programs (Guralnick, 2017).

In summary, these preliminary findings are promising. Through a combination of education, skills development and reflective supervision, this study has shown that the *how to* element can be systematically incorporated into a clinical setting. Implementing PCRI-EI in other clinical settings is required to test its efficacy as a stand-alone program that can be implemented independent of the program developer. Given the longstanding view that relationally based family-centred programs constitute best practice in early intervention, what is also evident from this, and other studies is in order to achieve widespread implementation of those practices, a more formal approach to training as well as supporting therapists in a reflective context is needed.

References

- Alexander, S.L., Frederico, M., & Long, M. (2018). Attachment and Children with Disabilities: Knowledge and Views of Early Intervention Professionals. *Children Australia*, 43, 245–254. doi:10.1017/cha.2018.38
- Barfoot, J., Meredith, P., Ziviana, J., & Whittingham, K. (2017). Relationship-based approaches in early childhood intervention: Are these applicable to paediatric occupational therapy under the NDIS? *Australian occupational therapy journal*, 64, 273-276. <https://doi.org/10.1111/1440-1630.12343>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101. <https://doi.org/10.1191/1478088706qp063oa>
- Callanan, J. P., Ronan, K. R., & Signal, T. (2019). Activating parents in early intervention: Preliminary findings from an empirical case study. *International Journal of Disability, Development and Education*, 69, 1-17. <https://doi.org/10.1080/1034912X.2019.162816>
- Callanan, J. P., Signal, T., & McAdie, T. (2020). *What is my child telling me? Reducing stress, increasing competence and improving psychological well-being in parents of children with special needs*. (Manuscript submitted for publication). School of Health, Medical and Applied Sciences, Central Queensland University. Rockhampton, Australia.
- Callanan, J. P., Signal, T., & McAdie, T. (2021). Engaging parents in early childhood intervention: Relationship as a platform for functional gains. *International Journal of Disability, Development and Education*. Advance online publication. <https://doi.org/10.1080/1034912X.2021.1876216>
- Campbell, P. H., Chiarello, L., Wilcox, M., & Milbourne, S. (2009). Preparing therapists as effective practitioners in early intervention. *Infants and Young Children*, 22, 21-31.

<https://doi.org/10.1097/01.IYC.000034334.26904.92>

Davis, A.L., & Neece, C.L. (2017). An examination of specific child behavior problems as predictors of parenting stress among families of children with pervasive developmental disorders. *Journal of Mental Health Research in Intellectual Disabilities*, 10, 163-177. <https://doi.org/10.1080/19315864.2016.127698>

Guralnick M. J. (2011). Why Early Intervention Works: A Systems Perspective. *Infants and young children*, 24, 6–28. <https://doi.org/10.1097/IYC.0b013e3182002cfe>

Guralnick M. J. (2017) Early Intervention for Children with Intellectual Disabilities: An Update. *Journal of Applied Research in Intellectual Disabilities* 30, 211-229. <https://doi.org/10.1111/jar.1223>

Hughes-Scholes, C. H., & Gavidia-Payne, S. (2019) Early Childhood Intervention Program Quality: Examining Family-centred Practice, Parental Self-Efficacy and Child and Family Outcomes. *Early Childhood Education Journal* 47, 719–729. <https://doi.org/10.1007/s10643-019-00961-5>

Inbar-Furst, H., Douglas, S.N. & Meadan, H. (2020). Promoting caregiver coaching practices within early intervention: Reflection and Feedback. *Early Childhood Education Journal*, 48, 21–27. <https://doi.org/10.1007/s10643-019-00980-2>

Kalmanson, B. (2009). Echoes in the nursery: Insights for treatment of early signs of autism in a baby sibling. *Journal of Infant, Child and Adolescent Psychotherapy*, 8, 40-48. <https://doi.org/10.1080/15289160802683427>

Mayer, M. L., White, B. P., Ward, J. D., & Barnaby, E. M. (2002). Therapists' perceptions about making a difference in parent–child relationships in early intervention occupational therapy services. *American Journal of Occupational Therapy*, 56, 411–421. <https://doi.org/10.5014/ajot.56.4.411>

Pretis, M. (2011). Meeting the needs of parents in early childhood intervention: The

- educational partnership with parents – good practice and challenges. *Journal of Policy and Practice in Intellectual Disabilities*, 8, 73-76.
<https://doi.org/10.1111/j.1741-1130.2011.00292.x>
- Robinson, M., & Neece, C.L. (2015). Marital satisfaction, parental stress, and child behavior problems among parents of children with developmental delays. *Journal of Mental Health Research and Intellectual Disabilities*, 8, 23-46.
<https://doi.org/10.1080/19315864.2014.994247>
- Salisbury, C. L., & Copeland, C. G. (2013). Progress of infants/toddlers with severe disabilities: Perceived and measured change. *Topics in Early Childhood Special Education*, 33, 68 – 77. <https://doi.org/10.1177/0271121412474104>
- Scales, L., McEwen, I., & Murray, C. (2007). Parents’ perceived benefits of physical therapists’ direct intervention compared with parental instruction in early intervention. *Pediatric Physical Therapy*, 19, 196– 202.
<https://doi.org/10.1097/PEP.0b013e3180cab57>
- Segal, R., & Beyer, C. (2006). Integration and application of a home treatment program: A study of parents and occupational therapists. *American Journal of Occupational Therapy*, 60, 500–510. <https://doi.org/10.5014/ajot.60.500>
- Snyder, P. A., & Wolfe, B. (2008). The big three process components of effective professional development: Needs assessment, evaluation, and follow-up. In P. J. Winton, J. A. McCollum, & C. Catlett (Eds.), *Practical approaches to early childhood professional development: Evidence, strategies, and resources* (pp. 13-51). Washington, DC. Zero to Three Press.
- Stuart, K. B. (2008) Outcomes of relationship based early intervention. *Journal of Occupational Therapy, Schools, & Early Intervention*, 1, 199-205.
<https://doi.org/10.1080/19411240802589395>

Weatherstone, D., Weigand, R. F., & Weigand, B (2010) Reflective supervision: Supporting reflection as a cornerstone of competency. *Zero to Three, 31*, 22-30.

Appendix

Q1 Please indicate your discipline.

Q2 To what extent has taking a relational approach impacted the way you work with children and their families?

Q3 Has thinking about the child's experience and their everyday life changed your approach to therapy?

Q4 Thinking about the role of parents in therapy, has the relational approach changed the way you involve parents?

Q5 Were there any changes in how you achieve therapy goals as a result of working this way?

Q6 Were there any changes in how you were able to apply evidence-based practices in your discipline working this way?

Q7 Did you find working with parents and children this way presented any professional or personal challenges that you would like to comment on?

Q8 How would you rate your experience of reflective supervision as a support in this type of practice?

Q9 How would you rate your overall experience of the relational model?

Q10 Do you still apply the principles of the parent child relational approach in your therapy?

Q11 Do you have any suggestions for improvement of the practice or the model?

Q12 In your experience were there any barriers or potential barriers you can see in the implementation of the model of practice? If so, please put your comments in the box below.

Q13 Is there anything else you would like to share about your experience of the relational model?

CHAPTER 4. Reducing parental stress and increasing their sense of competence

The material contained in this chapter was published online on the 12th of May 2021 in the *Journal of Research in Developmental Disabilities*, DOI: 10/1016/J.RIDD.2021.103984. It is presented as it was published except for changes to support consistent chapter formatting throughout the thesis.

Manuscript title: What is my child telling me? Reducing stress, increasing competence, and improving psychological well-being in parents of children with disability

The findings in chapter 3 indicate that the combination of the manualised approach and reflective supervision incorporated in PCRI-EI proved helpful in enabling allied health therapists integrate the relational elements into their practice. Given the substantial amount of research detailing the negative impact of stress and perceived incompetence on engagement and outcomes of early intervention, the logical next step was to assess the usefulness of the program in addressing these variables. This paper looked at the impact of PCRI-EI on those factors.

Abstract

High levels of stress in parents of children with a developmental disability have been extensively documented. These heightened stress levels seem independent of diagnosis and are better explained by the level of challenging behavior of the children. Furthermore, the relationship between stress level and difficult behavior appears reciprocal. The negative impact of stress on parents' skill development, response to difficult behavior, sense of competence, well-being and the child's developmental outcomes have also been thoroughly detailed. The Parent Child Relationally Informed - Early Intervention (PCRI-EI) aims to expand the response repertoires of parents to help address the challenges of parenting a child with a developmental disability, including through reducing parental stress. The current study presents a quasi-experimental assessment of the effectiveness of PCRI-EI in reducing stress levels and increasing sense of competency and psychological well-being in a sample of 22 parents of children with a variety of disabilities presenting to a community early childhood development service. Statistically and clinically significant changes in overall stress levels (Parenting Stress Index), psychological well-being (K6) and sense of competence (PSOC) were observed across time.

Key Words

Parental stress, Autism Spectrum Disorder (ASD), Children with a developmental disability, Behavior management, Parenting skills training.

There is a significant body of research reporting elevated levels of stress in parents of children with a developmental disability (Hoffman et al., 2009; Robinson & Neece, 2015). The negative impact of this stress on parenting responses, the child's developmental outcomes (Neece et al., 2012) and parents' sense of competence (Iadarola et al., 2018; Kuhn & Carter, 2006) has also been well documented. Higher levels of stress compared to parents of children without a developmental disability have been shown to be independent of diagnosis, and instead are better explained by the levels of challenging behavior of the children (Baker et al., 2005; Neece et al., 2012). Indeed, in their study of 44 parents of children aged 2.5 to 5 years with developmental delays and high levels of behavior problems, Robinson and Neece (2015) noted that parents' overall health and psychological well-being deteriorate as the challenging behaviors of their child increase. In addition, the relationship between parental stress level and difficult behavior may be reciprocal; as stress increases because of difficult behavior, punitive parental responses can precipitate further behavioral challenges, which in turn increase stress (Greenberg et al., 2006; Neece et al., 2012). Equally troubling are findings that higher levels of parental stress are associated with poorer outcomes in early intervention programs for children with a developmental disability as well as in parental skills enhancement training (Davis & Neece, 2017).

These increased stress levels and resultant impacts on well-being, behavior and outcomes have led to the development of interventions to help parents develop skills to better manage the difficult behavior(s) of their child as well as focus on enhancing parental well-being (Lindo et al., 2016). Interventions have historically been broadly categorized as: (1) Behavioral Parent Training (BPT; e.g., Chacko et al., 2016), which reduce stress levels indirectly by teaching parents strategies to manage difficult behaviors and (2) Coping Skills Interventions (CSI; e.g., Bazzano et al., 2015), which incorporate a combination of mindfulness and cognitive therapy to specifically address coping skills, particularly parental

responses in the face of the difficult behavior (Singer et al., 2007). Both approaches are delivered directly to parents and have been shown to produce positive outcomes in terms of reduced stress levels and increased sense of competency with moderate to large effect sizes (Lindo et al., 2016).

In a meta-analysis of 50 reports, containing mention of stress-related outcomes, Lindo et al. (2016) found six studies (with a cumulative total of 410 participants) that specifically focused on reducing stress levels for parents with children who have a developmental disability. Of those six, two investigated the impact of fortnightly home-based individual BPT programs, the remaining four reported on clinic-based CSI group programs. Summarizing their findings Lindo et al., suggested programs that directly address parents' mindset and well-being, as well as developing skills to help manage the challenges of having a child with a developmental disability, are likely to reduce stress levels and negative consequences.

In prior work, we developed a manualized intervention, the Parent Child Relationally Informed – Early Intervention program (PCRI-EI; Callanan et al., 2019), which includes elements of the behavioral training and coping skills described by Lindo et al. (2016) and was incorporated into the practices of an allied health team working in an early childhood development center. PCRI-EI combines constructs and programs such as: (a) Insightfulness, described as the ability to appreciate motives underpinning the child's behavior, to hold a more complex view of the child, accepting challenging behavior, and a willingness to integrate new information about the child (Oppenheim et al., 2012); (b) Reflective Functioning, the capacity to understand behavior in the context of underlying mental states and intentions (Fonagy et al., 2002); (c) Parent Embodied Mentalizing, defined as the parent's capacity to "implicitly conceive, comprehend, and extrapolate the infant's mental states from the infant's whole-body movement, and adjust their own kinaesthetic patterns

accordingly” (Shai & Belsky, 2011, p.173); (d) Active Imitation, described as interacting with body language through imitation to build up meaningful conversations (Ephraim, 1986); (e) Intensive Interaction, which involves learning the language of the communication partner in all its forms and responding to whatever has meaning for them, the experience of which creates personal meaning and lends itself to the development of a secure base from which to explore (Caldwell, 2006; Nind & Hewitt, 1998, 2001) and; (f) Circle of Security, a program to address disordered attachment patterns within the parent-child dyad (Marvin et al., 2002). It also reflects considerations from Functional Contextualism (Hayes et al., 1999) and recent developments on parents’ mindfulness and self-regulation, believed to have knock-on effects impacting a child’s acquisition of developmental skills and ability to self-regulate (Singh et al., 2007).

The premise of the PCRI-EI program is to operationalize and simplify the application of the constructs above to expand the response repertoires of parents and clinicians to more helpfully address the challenges of parenting a child with a developmental disability and at the same time support the implementation of evidence-based developmental therapies. The intervention focuses on developing parents’ sensitivity and responsiveness to the child’s experiences in meeting developmental demands, which can often precipitate difficult behavioral responses. For example, when introducing a new play idea to a child, parents may proactively help by appreciating that the child will need more time to process than the parent would need. Instead, by being sensitive to the child’s experience (the time it takes them to process) the parent supports the child’s problem-solving capacity by saying ‘it is a bit tricky, you are thinking about what to do’ and waits for the child to complete the task at their speed; promoting persistence over frustration (and associated challenging behaviors) in the context of developing problem-solving skills.

PCRI-EI also considers the potential attachment breakdowns that may occur when a child's communication capacity is compromised and limited to subtle, non-verbal, idiosyncratic cueing; characteristics that often accompany various disabilities and may also be associated with difficult behaviors (Slade, 2009). By bringing parents' attention to the question 'what is this behaviour telling me about my child's experience, wants, needs and/or feelings right now' it introduces a key concept of mindfulness and opens the opportunity for parents to apply, in the moment, different problem-solving strategies to those that are usually deployed in times of stress. To illustrate, when their young son who has a diagnosis of autism spectrum disorder (ASD) begins jumping on his sister while she is playing, instead of telling him (usually with a raised voice) to 'stop jumping on your sister!' the parent says, 'You want to play with your sister, and you can play with your Lego'. In this instance, the parent recognizes the behavior as possibly an unhelpful attempt to join in play and uses the different response of acknowledging the meaning of the behavior and offering a desirable alternative. However, according to parent reports, whilst these ideas are simple to understand and implement when things are calm, when stress levels elevate a punitive response is most often used.

In sum, the program introduces different techniques to expand response repertoires and increase the sense of competency of parents in the context of their child's unique cueing system as well as enhancing their capacity to reflect on the child's experience over and above what their diagnosis might predict. All of which are linked to more positive outcomes for the child (Oppenheim et al., 2012) via promotion of the calm-alert state that is strongly associated with optimizing developmental gains (Barfoot et al., 2017) and integration of behavior management techniques to address escalating stress levels (Feldman & Werner, 2002). In addition, reflective supervision allows treating therapists to develop skills in working with parents, extending their own capacity to consider context as well as affective,

cognitive, sensory, and physiological arousal experiences of all members of the family. This provides broader support for parents, an integral part of self-care shown to reduce stress levels (Guralnick et al., 2008).

A preliminary evaluation undertaken with four families provided initial support for the PCRI-EI intervention (Callanan et al., 2019). This evaluation utilised a simple, practitioner and family friendly design which incorporated a baseline assessment and ongoing tracking across time of functional changes, satisfaction and parental stress and sense of competence. Across the four families parental stress levels decreased and parents reported their child as ‘less difficult’ in a behavioral context following the intervention. There were also modest improvements in parental mental health and sense of competency. While these preliminary findings suggest PCRI-EI may be targeting an important mechanism for change in stress levels and potentially those associated with difficult child behaviors and parents’ sense of competency, further study with a larger sample is required to support this.

Current Study:

The purpose of this study is to extend the investigation of PCRI-EI to explore its impact on parental stress levels, sense of competence and psychological well-being in a larger sample of 22 parents of children diagnosed with developmental disabilities. Based on the preliminary case-study findings it is hypothesized that parents self-reported stress levels will decrease over the course of the intervention as will their ratings of the ‘difficultness’ of their child’s behavior. It is also hypothesized that parental psychological well-being and sense of competence will increase following participation in the PCRI-EI program.

Method

Whilst respecting the need to undertake a rigorous evaluation of the current intervention to facilitate evidence-based practice, a process often achieved via “gold standard” randomized control trial principles, there are times when the context of the

intervention prevents the use of randomized assignment to control and/or treatment groups (Faraoni & Schaefer, 2016; Kemp et al., 2013). In the current study, limitations include the sample size and the vulnerability of the population, which would be at risk if included in a control/no-treatment group. Single-case designs, where participants serve as their own control via repeated measurement across the course of an intervention, have been used extensively within allied health fields (such as Speech Pathology, Occupational Therapy, Applied Behavior Analysis) to produce data to support evidence-based practice (Ninci, 2019). Best described as quasi-experimental design, such approaches are intended to assess efficacy by establishing a causal relationship between treatment and outcome via comparison within and between participants across multiple observations and time points (Harris et al., 2006; Lanovaz & Rapp, 2016). To address limitations inherent in comparing only pre- and post- measures, the decision was made here to combine repeated measures with staggered intervention implementation. This multiple baseline approach has been used previously providing replication across individuals within a study and control over extraneous variables such as maturation (e.g., Lanovaz & Rapp, 2016; Signal et al., 2016) and removing the need to withhold or delay treatment from vulnerable families. The staggering of the intervention was naturally achieved due to different referral timelines. Parent's stress levels, sense of competency and psychological well-being were collected at three points in time. These were Time 1 (at intake); Time 2 (6 to 10 months into the intervention); Time 3 (a further 6 to 10 months after Time 2).

Participants

The participants in this study comprised 22 parents and their 22 children. Seventeen of the parents were mothers who attended on their own, five fathers attended on their own. Fourteen of the children were male aged between 18 months and 41 months ($M = 27.64$ months, $SD = 7.43$), eight were female aged between 10 months and 27 months ($M = 16.62$

months, $SD = 5.91$). Eleven of the children (eight males, three females) had a diagnosis of Autism Spectrum Disorder (ASD), four (two males, two females) had a diagnosis of Cerebral Palsy (CP), six (four males, two female) had a diagnosis of Global Developmental Delay (GDD), and one child (female) had a diagnosis of Down Syndrome (DS). The families were referred from various sources including the Public Hospital, General Practitioners, Paediatricians, Community Health Nurses, Allied Health Professionals, and the government health service. Therapy was provided at a community-based early childhood development service located in the Northern Territory of Australia. Informed consent from the adult participants was necessary for participation with treatment delivery not dependent upon research participation. The organization in which the early childhood development service operated also provided consent and support to undertake the study. Formal ethical approval was secured from Central Queensland University Human Research Ethics Committee, HREC approval number H15/09-202.

Materials

PCRI-EI intake and treatment procedures utilize several psychometric and functional measures that have been detailed previously (Callanan et al., 2019). As the purpose of this study was to examine the impact of the treatment on parental stress including in their relationship with their child, as well as changes in their sense of competency and overall psychological well-being, three specific measures have been included. These are the Parenting Stress Index Short Form 4th Edition (PSI-SF-4: Abidin, 2012), the Parenting Sense of Competency (PSOC: Johnston & Mash, 1989) and the Kessler Psychological Distress scale (K6: Kessler et al., 2002).

Parenting Stress Index – Short Form 4th Edition (PSI-4-SF: Abidin, 2012). The PSI assesses parents' perceived sources of stress in the parent-child system. The short form comprises 36 items across three subscales; (1) Parental Distress (PD), which reflects a

parent's perception of child-rearing confidence, conflict within the parental relationship, social support and restrictions on other aspects of their life; (2) Parent Child Dysfunction Interaction (P-CDI), which captures the parent's perception that the child does not meet expectations and interactions within the dyad are not reinforcing and; (3) Difficult Child (DC), which measures the parent's view of the child's behavior; specifically temperament, oppositionality and demandingness. Abidin (2012) suggests an overall percentile score equal to or above the 85th percentile as being indicative of clinically significant distress for the parent. Items are rated on a 5-point scale from strongly agree to strongly disagree and have a correlation of .87 with the long form, which has demonstrated the following reliability coefficients, Child Domain .89, Parent Domain, .93 and Total Stress .95 (Abidin & Wilfong, 1989). Reliability coefficients for this study were .91 in the PSI overall, .78 in the PD subscale, .92 on the P-CDI subscale and .91 on the DC subscale.

Parenting Sense of Competence Scale (PSOC: Johnston & Mash, 1989) contains 17 items, rated on a 6-point Likert scale from strongly agree to strongly disagree. Acceptable levels of internal consistency (range 0.75 – 0.88) have been validated for the PSOC (Gilmore & Cuskelly, 2009). Reliability analysis for this study revealed a Chronbach Alpha of .91.

The Kessler Psychological Distress scale (K6: Kessler et al., 2002), a six-item short dimensional instrument, measured levels of psychological well-being in the previous four weeks. The scales have been shown to have sound psychometric properties (Kessler et al.). As a screen for mental illness a K6 score ≥ 13 is defined as a severe mental illness, whereas a score $5 \leq K6 < 13$ is considered as mental distress at a moderate level (Prochaska et al., 2012).

Procedure

Once eligibility of the child was confirmed: i.e., aged between 0 and 72 months, falling below the first percentile (compared to same aged peers) in three of five

developmental categories (cognitive, gross motor, fine motor, speech and language, and activities of daily living/social emotional functioning) as measured by standardized assessments of developmental capacity (either the Griffiths Mental Development Scales (GMDS; Griffiths, 1984) or the Bayley Scales of Infant and Toddler Development (Bayley III; Bayley 2006), the family was allocated a key worker.

Of the 22 parents in this study, the principal researcher (Psychologist) was the designated key worker for two of the parents for the period during which this data was gathered. The remaining 20 parents were managed by the members of the allied health staff of the service – Speech Pathologists, Occupational Therapists or Physiotherapist – depending on the therapeutic goals for the child in each 12-week treatment block. Each practitioner received reflective supervision from the principal researcher for their clients. As noted, sessions were structured over 12-week therapy blocks that coincided with school terms. Depending on the level of complexity of the child's difficulties, sessions were scheduled weekly (high complexity involving multiple therapists) or fortnightly (low complexity involving a single therapist). Sessions were conducted at the early childhood development clinic for these families. At the end of each 12-week block the key therapist reviewed the goals for that block and with the parent either agreed to a continuation of existing goals (if they had not been achieved) or set new goals (if they had been achieved) for the next treatment block.

Once allocated the family, the key worker organized an initial meeting with the parents only. Key outcomes from this meeting include review of assessment results, provision of an overview of the approach, setting treatment goals and a 'parent pack' which included the measures outlined previously. Time permitting, parents completed these measures at the end of this initial session or returned them at their next scheduled

appointment, prior to the commencement of the therapy. Once returned, this Time 1 data was scored and entered into the database by the principal researcher.

All participants completed all the assessments at three points in time. Coinciding with therapy reviews, the second assessment occurred between 6- and 10-months post intake; the third occurred approximately 6 to 10 months later. The variation in times was because of the variation in treatment reviews, which were a function of the individual treatment plan for the child. During this period therapists followed the phase-based protocol contained in the treatment manual and as noted above, engaged in ongoing reflective supervision with the senior psychologist. An outline of the phases is provided in Table 1. For a more detailed explanation please see Callanan et al., 2019.

Table 1

Overview of the phases

Phase 1. *Setting the Foundation – Session 1*: Introduce collaborative approach, review goals, using play to develop skills, following the child's ideas, waiting for them, building narrative skills - telling the child what you see them doing.

Phase 2. *Reflective Functioning – Sessions 2 and 3*: Reading and responding to non-verbal and verbal cues, imitation as a communication tool, reducing the number of questions asked

Phase 3. *Affect Regulation – Sessions 4 and 5*: Noticing triggers, understanding impact of developmental challenges on regulation, using words to help the child regulate, self-regulation for parent.

Phase 4. *Understanding Behaviour and Context – Sessions 6 and 7*: What is the behavior telling you about the child's experience? Learning that behavior occurs in a context that

includes developmental capacity, learning history, relationship history and changes in environment.

Phase 5. Integration and Generalising Skills across settings – Ongoing: Learning to rely on experience rather than what diagnoses predict or what parents anticipate. Build confidence in changed responses working in different settings – particularly in community. Bringing these skills to learning/developmental demands that are now part of the discipline specific therapy.

Note. Video reviews with parents are often used throughout to illustrate learning points and parents existing strengths as well as bringing attention to the child's reactions and skills development.

Results

Wilcoxon Sign-Ranked Tests were used to assess scores between Time 1, Time 2, and Time 3 and evaluate changes in the scales of the Parenting Stress Index (PSI), parents' sense of competence (PSOC) and psychological distress (K6). The means, standard deviations and medians for the Parenting Stress Index, Parent Sense of Competency and Psychological Distress across Time 1, Time 2, and Time 3 are presented in Table 2 with decreases evident in the three recording points for overall Parenting Stress and Psychological Distress. Parents' Sense of Competence increased over that same period. Parenting Stress Index subscales that assess perceived difficultness of their child's behavior (Difficult Child), the level of difficult interactions experienced within the dyad and (Parent-Child Dysfunctional Interaction) and the measure of Psychological Distress (K6) were also assessed. Table 3 shows the decreases in scores for these subscales at Time 1, Time 2, and Time 3.

Table 2

Means, Standard Deviations and Medians for Parenting Stress, Parent Sense of Competence and Psychological Distress across Times 1, 2 and 3

Time	PSI			PSOC			Psychological Distress K6		
	Mean	SD	Median	Mean	SD	Median	Mean	SD	Median
T1	67.50	20.43	73.00	67.18	9.71	68.00	11.86	2.98	12.50
T2	50.64	21.34	59.00	77.77	8.76	75.50	9.91	2.05	10.00
T3	42.36	12.04	42.00	80.91	6.18	78.00	6.86	1.32	7.00

Table 3

Means, Standard Deviations and Medians for Parental Distress, Parent Child Dysfunctional Interactions and Difficult Child across Times 1, 2 and 3

Time	PD			P-CDI			DC		
	Mean	SD	Median	Mean	SD	Median	Mean	SD	Median
T1	61.96	20.20	67.00	68.41	20.52	72.00	69.64	24.64	74.00
T2	54.43	22.56	58.00	56.82	20.27	58.00	54.45	26.43	60.00
T3	43.04	12.21	46.00	43.73	15.30	44.00	41.95	17.66	40.00

As can be seen in Table 4 the previously noted changes (Time 1 – Time 3) in the clinical variables measured were all statistically significant.

Table 4

Summary of Wilcoxon Sign-Ranked Tests for Scales of the Parenting Stress Index, Sense of Competence and Psychological Distress.

Measure	Time 1 – Time 2		Time 2 – Time 3		Time 1 – Time 3	
	Z	p	Z	p	Z	p
Parenting Stress (Overall)	-3.888	.000	-3.197	.001	-4.116	.000
Parental Distress	-2.194	.028	-2.861	.004	-3.575	.000
Parent Child Dysfunctional Interactions	-3.384	.001	-3.927	.000	-4.112	.000
Difficult Child	-3.360	.001	-3.549	.000	-4.110	.000
Parent Sense of Competence	-4.110	.000	-3.100	.002	-4.113	.000
Psychological Distress (K6)	-2.794	.006	-4.150	.000	-4.120	.000

Of interest is the reduction in many participant's clinically problematic scores (above threshold – 85th percentile) on the Parenting Stress Index, its subscales, and the measure of Psychological Distress (K6). On the overall Parenting Stress Index, four participants (two children with a diagnosis of ASD, one of CP and one of Down Syndrome) were above

threshold at Time 1. On the Parental Distress Scale, one participant was above that level at Time 1 (child with a diagnosis of ASD). Four participants were above threshold on the Parent-Child Dysfunctional Interaction Index (two ASD diagnosis, two GDD diagnosis) at that same time. On the Difficult Child Index, seven participants scored above threshold at Time 1 (four children with a diagnosis of ASD and one each with a diagnosis of CP, DS and GDD). By Time 3 all participants scored below the threshold across the scales of the Parenting Stress Index. The results for the measure of Psychological Distress (K6) were also noteworthy. Eleven participants had scores of 13 and above at Time 1, a score that is suggestive of a severe mental illness (Prochaska et al., 2012). By Time 3 all were below that level.

Discussion

The current study sought to extend the preliminary findings of the utility of the PCRI-EI in a community based early childhood intervention service, which includes a multi-disciplinary team of allied health professionals. The aim was to investigate the impact of the program on the stress levels, sense of competency, and psychological well-being of parents of children with a developmental disability. As hypothesized, there was a substantial decrease in overall parental stress levels, including those considered clinically problematic as measured by the Parenting Stress Index across three points in time for the entire cohort of parents. This decrease was also reflected in scores for the subscales of the Parenting Stress Index, specifically those that reflect parent's perspective of difficult behaviors (Parent Child Dysfunctional Interactions and Difficult Child). At the same time there was a noteworthy increase in parents' sense of competence (PSOC) between Time 1 and Time 3. Furthermore, scores on the brief measure of Psychological Distress (K6) also decreased including to below clinical thresholds over the three time periods.

When considered in the context of extant studies showing the various impacts of high levels of parental stress (Neece et al., 2102), the apparent effectiveness of the PCRI-EI is encouraging. The effect of the program on levels of stress and psychological well-being are particularly noteworthy given their influence on outcomes in early intervention programs and in the broader family context (Davis & Neece, 2017). Indeed, an analysis of the PSI undertaken by Barroso et al., (2016) suggests the 72nd -77th percentile as a more appropriate cutoff than the 85th percentile suggested by Abidin (2012) for identifying mothers with heightened depressive symptoms and children with clinically significant behavioral and emotional difficulties. If this cutoff was applied to the participants in this study, the impact is even more pronounced with 13 of 23 parents being above the 72nd percentile on the PSI overall at Time 1 and below this at Time 2 and Time 3. None of the parents in this study scored above this proposed alternative percentile cutoff at Time 3.

The reduction in scores on the measure of Psychological Distress (K6) further emphasizes the apparent effectiveness of the program on parents' psychological well-being. When combined with the increased sense of competency, it appears the program is achieving the design aims of reducing stress levels and increasing a sense of competency; both of which are fundamental to positive outcomes in early childhood intervention treatments.

Notwithstanding these positive outcomes within the dyad and in engagement in therapy, when considered in the context of the wider family unit, the reductions in stress and improvement in psychological well-being become particularly salient. Heightened stress and consequential decreases in psychological well-being are associated with issues including marital dissatisfaction and breakdown, lack of family cohesion, poor sibling adjustment and maternal depression. In addition, parents with high stress levels have been shown to engage in behaviors that are detrimental to their health, suffer from impaired cognition and raised levels of blood pressure (Higgins et al., 2005; Lindo et al., 2016).

Further investigation of the impact of the program in these areas is warranted, however these findings when combined with anecdotal feedback from parents suggest PCRI-EI has a wider impact on family and community issues. For example, when reviewing goals at the end of treatment blocks, parents in the program have made the following comments regarding changes they have noted in their stress levels in the relational context (e.g., *We don't argue anywhere near as much, especially about how to parent, we are calmer; When I am calm, he is calm. In fact, the whole family is calmer*); in broader family life (e.g., *We go on holidays together, even catching planes, we go out to dinner as a family, shopping together – we have even got back control of the TV remote control*); for the child (e.g., *When I give him space, he talks more, plays for longer and seems a lot happier; I don't worry about meltdowns anywhere near as much, I feel confident I can manage much better when we are out, so we go out!*); and for themselves (e.g., *I have enrolled at Uni, am back at the gym and am no longer feeling constantly overwhelmed*).

The premise of the PCRI-EI is to operationalize and simplify several well substantiated theories to expand the response repertoire of parents to their children with a developmental disability. The results of the current study suggest that the PCRI-EI may be targeting an important mechanism for change through a combination of insightfulness and decreased stress. Oppenheim et al., (2012) describe the capacity of insightfulness as being able to consider a wider range of explanations of behavior rather than simply the notion that the child is difficult. By bringing parents' attention to their child's experience i.e., what is their behavior telling me about their experience, the program helps parents develop a much broader appreciation of the impact of speech and language deficits, cognitive and physical demands, and affective challenges on their child's behavior. This altered frame of reference then allows them to work (in sessions, at home and in community settings) on expanding their responses, including to sometimes difficult to interpret verbal and non-verbal cues,

based on present moment experience. The reductions in scores on both the Difficult Child and Parent-Child Dysfunctional Interaction subscales, both of which measure aspects of difficult behavior appear to reflect parents' broadened perspective of behavior; arguably breaking the escalating two-way relationship between stress and difficult behaviors (Greenberg, et al., 2006; Neece et al., 2012). At a functional level, reduced levels of parental stress have been shown to improve outcomes in early intervention programs, thereby enhancing capacity and quality of life for the child and the family unit. Furthermore, the capacity of PCRI-EI to address both stress and competency is supported by the increased scores in parents' sense of competency (PSOC).

Limitations and Future Direction

Managing the tension between “gold standard” RCTs and practice-based investigations presents design challenges and limitations. Because the study is set in an operational clinic offering services to children with the most significant developmental disabilities, specific baseline data was not able to be gathered. However, these children arrived at the clinic from referrers who provided well-documented histories of developmental delays and difficulties associated with those delays. In addition, the Time 2 and Time 3 data shows multiple (repeated/replicated) demonstrations of the effectiveness of the intervention across different diagnoses, families, and points of time. Furthermore, that the positive outcomes found in this study occurred across a variety of personal, family and community factors over time points to the generalisability of the program. As previously noted, the sample size of this study is relatively small, and the representation of diagnoses is uneven (e.g., only one child with Down Syndrome). This coupled with the inability to include a waitlist control group due to potential risk to a vulnerable population is an acknowledged limitation and was addressed as far as possible in the study's design. Notwithstanding these limitations, what is clear from the present study's results, is that for each parent, there were

important improvements in measures of stress (particularly in those that reflect perceptions of the child as being difficult), competence and well-being across the three time periods. Future research needs test this intervention in group comparison conditions, with larger samples, including any differential impact of diagnoses and across different settings and contexts. An investigation of the impact of the program on functional capacity and wider family well-being is warranted and underway. Investigations into the experience of therapists would also be useful to understand the impact of the reflective supervision and model of practice on their own sense of competence.

In summary, PCRI-EI has shown promising outcomes in reducing stress levels and improving psychological well-being in parents of children with a developmental disability. At the same time there were noteworthy increases in parents reported levels of competence. This was achieved in a community-based early childhood development service employing a mixture of allied health professionals. Testing the protocol in group comparison conditions and linking these changes to functional and broader family outcomes as well as better understanding therapists' experience of the protocol and reflective practice require further investigation.

References

- Abidin, R. R. (2012). *Parenting Stress Index* (4th ed.). PAR.
- Abidin, R. R., & Wilfong, E. (1989). Parenting stress and its relationship to child health care. *Child Health Care, 19*, 114-116. https://doi.org/10.1207/s15326888chc1802_9
- Baker, B. L., Blacher, J., & Olsson, M. B. (2005). Preschool children with and without developmental delay: Behaviour problems, parents' optimism, and well-being. *Journal of Intellectual Disability Research, 49*, 575-590. https://doi.org/10.1111/j1365-2788.2005.00691_x
- Barfoot, J., Meredith, P., Ziviani, J., & Whittingham, K. (2017). Parent-child interactions and children with cerebral palsy: An exploratory study investigating emotional availability, functional ability, and parent distress. *Child: Care, Health and Development, 43*, 812-822. <https://doi.org/10.1111/cch.12493>
- Bayley, N. (2006). *Bayley-III: Bayley Scales of Infant and Toddler Development* (3rd ed.). Harcourt Assessment.
- Barroso, N. E., Hungerford, G. M., Garcia, D., Graziano, P. A., & Bagner, D. M. (2016). Psychometric properties of the Parenting Stress Index-Short Form (PSI-SF) in a high-risk sample of mothers and their infants. *Psychological Assessment, 28*, 1331-1335. <https://doi.org/10.1037/pas0000257>
- Bazzano, A., Wolfe, C., Zylowska, L., Wang, S., Schuster, E., Barrett, C., & Lehrer, D. (2015). Mindfulness based stress reduction (MBSR) for parents and caregivers of individuals with developmental disabilities: A community-based approach. *Journal of Child and Family Studies, 24*, 298-308. <https://doi.org/10.1007/s10826-013-9836-9>
- Caldwell, P. (2006). Speaking the other's language: Imitation as a gateway to relationship. *Infant and Child Development, 15*, 275-282. <https://doi.org/10.1002/icd.456>

- Callanan, J. P., Ronan, K. R., & Signal, T. (2019). Activating parents in early intervention: Preliminary findings from an empirical case study. *International Journal of Disability, Development and Education*, 69, 1-17.
<https://doi.org/10.1080/1034912X.2019.1628186>
- Chacko, A., Jensen, S. A., Lowry, L. S., Cornwell, M., Chimklis, A., Chan, E., Lee, D., & Pulgarin, B. (2016). Engagement in behavioral parent training: Review of the literature and implications for practice. *Clinical Child and Family Psychology Review*, 19, 204-215. <https://doi.org/10.1007/s10567-016-0205-2>
- Davis, A. L., & Neece, C. L. (2017). An examination of specific child behavior problems as predictors of parenting stress among families of children with pervasive developmental disorders. *Journal of Mental Health Research in Intellectual Disabilities*, 10, 163-177. <https://doi.org/10.1080/19315864.2016.1276988>
- Ephraim, G. (1986). *A brief introduction to augmented mothering*. Playtrack pamphlet. Harpebury Hospital School.
- Faraoni, D., & Schaefer, S.T. (2016). Randomized controlled trials vs. observational studies: why not just live together? *BMC Anesthesiology*, 16, 102.
<https://doi.org/10.1186/s12871-016-0265-3>
- Feldman, M. A., & Werner, S. E. (2002). Collateral effects on behavioral parent training on families of children with developmental disabilities and behavior disorders. *Behavioral Interventions*, 17, 75-83. <https://doi.org/10.1002/bin.111>
- Fonagy, P., Gergely, G., Jurist, E., & Target, M. (2002). *Affect Regulation, mentalization and the development of the self*. Karmac.
- Gilmore, L., & Cuskelly, M. (2009). Factor structure of the Parenting Sense of Competence scale using a normative sample. *Child: Care, Health and Development*, 35, 48-55.
<https://doi.org/10.1111/j.1365-2214.00867.x>

- Greenberg, J. S., Seltzer, M. M., Hong, J., & Orsmond, G. I. (2006). Bidirectional effects of expressed emotion and behavior problems and symptoms in adolescents and adults with autism. *American Journal on Mental Retardation*, 114, 229-249.
[https://doi.org/10.1352/0895-8017\(2006\)111\(229:BEOEEA\)2.0.CO;2](https://doi.org/10.1352/0895-8017(2006)111(229:BEOEEA)2.0.CO;2)
- Griffiths, R. (1984). *The abilities of young children: A comprehensive system for measurement for the first eight years of life*. The Test Agency Ltd.
- Guralnick, M. J., Hammond, M. A., Neville, B., & Connor, R. T. (2008). The relationship between sources and functions of social support and dimensions of child- and parent-related stress. *Journal of Intellectual Disability Research*, 52, 1138-1154.
<https://doi.org/10.1111/j.1365-2788.2008.01073.x>
- Harris, A. D., McGregor, J. C., Perencevich, E. N., Furuno, J. P., Zhu, J., Peterson, D. E., & Finkelstein, J. (2006). The use and interpretation of quasi-experimental studies in medical informatics. *Journal of the American Medical Informatics Association*, 13, 16–23. <https://doi.org/10.1197/jamia.M1749>
- Hayes, S. C., Strosahl, K., & Wilson, K. G. (1999). *Acceptance and commitment therapy: An experiential approach to behavior change*. Guilford Press.
- Hoffman, C. D., Sweeny, D. P., Hodge, D., Lopez-Wagner, M. C., & Looney, L. (2009). Parenting stress and closeness: Mothers and typically developing children and mothers of children with autism. *Focus on Autism and Other Developmental Disorders*, 3, 178-187. <https://doi.org/10.1177/1088357609338715>
- Higgins, D. J., Bailey, S. R., & Pearce, J. C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, 9, 125-137. <https://doi.org/10.1177/1362361305051403>
- Iadarola, S., Levato, L., Harrison, B., Smith, T., Lecavalier, L., Johnson, C., Swiezy, N., Bearss, K., & Scahill, L. (2018). Teaching parents behavioral strategies for Autism

- Spectrum Disorder (ASD): Effects on stress, strain, and competence. *Journal of Autism and Developmental Disorders*, 48, 1031-1040. <https://doi.org/10.1007/s10803-017-339-2>
- Johnston, C., & Mash, E. (1989). A measure of parenting satisfaction and efficacy. *Journal of Clinical Child Psychology*, 18, 167-175. <https://doi.org/10.1207/s15374424jccp1802-8>
- Kemp, K., Signal, T., Botros, H., Taylor, N., & Prentice, K. (2013). Equine Facilitated Therapy with children and adolescents who have been sexually abused: A program evaluation study. *Journal of Child & Family Studies*, 23, 558-566. <https://doi.org/10.1007/s10826-013-9718-1>
- Kessler, R. C., Andrews, G., Colpe, L. J., Hiripi, E., Mroczek, D. K., Normand, S. L., Walters, E. E., & Zaslavsky, A.M. (2002). Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychological Medicine*, 32, 959-976. <https://doi.org/10.1017/s0033291702006074>
- Kuhn, J. C., & Carter, A. S. (2006). Maternal self-efficacy and associated parenting. *Orthopsychiatry*, 76, 564-575. <https://doi.org/10.1037/0002-9432.76.4.564>
- Lanovaz, M. J., & Rapp, J. T. (2016). Using single-case experiments to support evidence-based decisions: How much is enough? *Behavior Modification*, 40, 377-395. <https://doi.org/10.1177/0145445515613584>
- Lindo, E. J., Kliemann, K. R., Combes, B. H., & Frank, J. (2016). Managing stress levels of parents of children with developmental disabilities: A meta-analytic review of interventions. *Family Relations*, 65, 207-224. <https://doi.org/10.1111/fare.12185>
- Marvin, R., Cooper, G., Hoffman, K., & Powell, B. (2002). The circle of security project: Attachment-based intervention with care-giver-preschool child dyads. *Attachment & Human Development*, 4, 107-224. <https://doi.org/10.1080/1461673021013163> 5

- Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behavior problems: A transactional relationship across time. *American Journal on Intellectual and Developmental Disabilities, 117*, 48-66. <https://doi.org/10.1352/1944-7558-117.1.48>
- Ninci, J. (2019). Single-case data analysis: A practitioner guide for accurate and reliable decisions. *Behavior Modification*. Advance online publication. <https://doi.org/10.1177/0145445519867054>.
- Nind, M., & Hewitt, D. (1998). *Interaction in action*. David Fulton Press.
- Nind, M., & Hewitt, D. (2001). *A practical guide to intensive interaction*. David Fulton Press.
- Oppenheim, D., Koren-Karie, N., Dolev, S., & Yirmiya, N. (2012). Maternal sensitivity mediates the link between insightfulness/resolution and mother-child attachment: The case of children with autism spectrum disorder. *Attachment and Human Development, 14*, 567-584. <https://doi.org/10.1080/14617734.2012.727256>
- Prochaska, J. J., Sung, H. Y., Max, W., Shi, Y., & Ong, M. (2012). Validity study of the K6 scale as a measure of moderate mental distress based on mental health treatment need and utilization. *International Journal of Methods in Psychiatric Research, 21*, 88-97. <https://doi.org/10.1002/mpr.1349>
- Robinson, M., & Neece, C.L. (2015). Marital satisfaction, parental stress, and child behavior problems among parents of children with developmental delays. *Journal of Mental Health Research and Intellectual Disabilities, 8*, 23-46. <https://doi.org/10.1080/19315864.2014.994247>
- Shai, D., & Belsky, J. (2011). When words just won't do: Introducing parental embodied mentalizing. *Child Development Perspectives, 5*, 173-180. <https://doi.org/10.1111/j.1750-8606.2011.00181.x>

- Signal, T., Taylor, N., Prentice, K., McDade, M., & Burke, K. J. (2016). Going to the dogs: A quasi-experimental assessment of animal assisted therapy for children who have experienced abuse. *Applied Developmental Science, 21*, 86-93.
<https://doi.org/10.1080/10888691.2016.1165098>
- Singer, G. H., Ethridge, B. L., & Aldana, S. I. (2007). Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities: A meta-analysis. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 357-369. <https://doi.org/10.1002/mrdd.20175>
- Singh, N. N., Lancioni, G. E., Winton, A. S., Singh, J., Curtis, W. J., Wahler, R. G., & McAleavey, K. M. (2007). Mindful parenting decreases aggression and increases social behavior in children with developmental difficulties. *Behavior Modification, 31*, 749-771 /10.1. [https://doi.org/10.1002/1097-4268\(200705\)31:5%3C749::AID-BM8092%3E3.0.CO;2-4](https://doi.org/10.1002/1097-4268(200705)31:5%3C749::AID-BM8092%3E3.0.CO;2-4)
- Slade, A. (2009). Mentalizing the unmentalizable: Parenting children on the spectrum. *Journal of Infant, Child and Adolescent Psychotherapy, 8*, 7-21.
<https://doi.org/10.1080/15289160802683054>

CHAPTER 5. Functional and family gains

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Findings of the previous studies offered strong support for the program and its ability to upskill both therapists and parents in working relationally. As noted in Chapter 1, while this outcome is certainly desirable and a key focus of early intervention programs designed to address disrupted relationships, when the child has a disability there is a requirement that the primary focus is on functional gains for the child. Specifically, their functional capacity in the context of family priorities and goals. This chapter examined that issue. How well does the program address the best practice objective of increased functional capacity for the child that prioritises family goals?

Abstract

Interventions to develop functional capacity for children with developmental difficulties have tended to be therapist driven. Such approaches can present difficulties for parents who describe increased stress and feelings of incompetence in a paradigm that can feel imposed. Recent findings have questioned the efficacy of the approach given a deeper understanding of the impact of social and relational influences on child development. This questioning has prompted the development of programs where the parent-child relationship is considered a fundamental component of early childhood intervention. The parent child relationally informed – early intervention (PCRI-EI) was developed to establish a relational foundation upon which evidence-based interventions are delivered. The current study presents a quasi-experimental assessment of the effectiveness of PCRI-EI in achieving functional gains in a sample of 56 children with differing diagnoses presenting to a community early childhood development service. Significant and marked (i.e., large effect size) increases in functional capacity were observed across time. The gains did not differ by diagnosis and parental feedback indicated the improvements were generalised across social, community and educational settings.

Historically, interventions to develop functional capacity in children with a disability were addressed within discipline boundaries e.g., speech pathology, occupational therapy, and physiotherapy (King et al., 2009). Described as a functional diagnostic model (Matthews & Rix, 2013), treatment was therapist driven and focused on activities that increased capacity. This approach often strongly influenced parenting and early family experiences (Rix & Paige-Smith, 2008). It also increased stress for parents who reported feeling that the interventions were imposed and that their parenting skills were being constantly assessed (Matthews & Rix). Recent evidence has suggested that these clinically informed, evidence-based practices may not be as efficacious when applied without considering the wider social and relational influencers in child development (Barfoot et al., 2017a). This questioning has resulted in the development of a philosophy and practice of relationship-focused interventions where the parent-child relationship is considered a fundamental component in the delivery of treatment (Barfoot et al., 2015; Callanan et al., 2019; Salisbury & Copeland, 2013).

Relationally-based practice is informed by attachment theory and its developmental consequences, which include regulation, communication, language, and cognition (Bowlby, 1969; 1973; 1980). In sum, relationally-based practice contends that child development occurs within a well attuned relationship where the parent sensitively responds to the cues of the child. Somewhat akin to a control system, where the child controls the type and intensity of the responses and the parent attunes and responds accordingly (Whittingham, 2016), this relationship is thought to facilitate a calm-alert state fundamental in learning and development (Barfoot et al., 2017b). However, parents of a child with developmental delays, are required to interpret a cueing system that seems incomprehensible, appears as happenstance, or as epiphenomena of a diagnosis. Additionally, given the compromises in

their child's development, parents also have to deal with high levels of stress and sense of incompetence (Callanan et al., 2019; Slade, 2009).

In prior work, we developed a manualised intervention, the parent child relationally informed – early intervention (PCRI-EI; Callanan et al., 2019), which was incorporated into the practices of an allied health team working in an early childhood development centre. PCRI-EI combines constructs including: (a) insightfulness, (Oppenheim et al., 2012); (b) reflective functioning (Fonagy et al., 2002); (c) parent embodied mentalising (Shai & Belsky, 2011) (d) active imitation (Ephraim, 1986); (e) intensive interaction (Caldwell, 2006; Nind & Hewitt, 1998, 2001) and (f) circle of security (Marvin et al., 2002). It also incorporates ideas from functional contextualism (Hayes et al., 1999) and mindful parenting approaches that have been shown to influence a child's acquisition of skills and ability to self-regulate (Singh et al., 2007).

The program presents the key features of these theories to enable parents and therapists to implement them in therapy and in the wider community. PCRI-EI relies on parents and therapists sensitively responding to the challenges the child faces meeting the developmental demands targeted in therapy. These demands can be cognitive, physical, sensory, and affective. Furthermore, the way the child communicates their experience of these demands is often limited to subtle, non-verbal, idiosyncratic cueing. Whilst the program promotes a changed relationship between parent and child, that is not the end goal. Instead, the changed relationship provides a foundation for functional changes that are the focus of evidence-based interventions. Put another way, when parents identify the meaning of, and sensitively respond to the child's cues, they are better equipped to generate more accurate, child-friendly language that helps the child integrate skills and generalise them in different settings (Callanan et al., 2019).

To illustrate, a parent telling a child with Cerebral Palsy that it is difficult for them when their body is not doing what they want demonstrates a reflective capacity (Fonagy et al., 2002), meaning making (Tronick & Beeghly, 2011) and an attuned response (Weatherston, 2007). Consequently, using child-friendly language, the parent might say: “you’re frustrated because your body is not doing what you want, you can do it”. A response that is more likely to promote task persistence, resilience and facilitate an optimal calm-alert state for ongoing learning.

In addition to engaging parents in therapy, PCRI-EI considers other aspects of the early family experience, including the process of diagnosis, interactions in the wider community and other relational influences and impacts because of their effect on development (Barfoot et al., 2017b). When parents arrive at the service the final, unifying diagnosis is usually new. Furthermore, the referral criteria mean that the child has significant developmental delays - below the first percentile in three of five developmental domains. By this time, parents have lived an experience where the initial expected joys of a newborn have been met with confusion, fear, and significant concerns about their future and that of their child (Kalmanson, 2009). Additionally, there is the subjective, difficult to describe experience of unrequited love that can be a function of the mismatches between parent and child in their early relationship (Kalmanson). Parents have also been through lengthy medical assessments and sometimes high-risk early-life health issues for the child. All of which must be managed in the absence of the skills of how to parent a child with severe developmental challenges (Slade, 2009).

As well as building skills, PCRI-EI seeks to bring the process of parenting under appetitive control through the introduction of values-oriented parenting (Hayes et al., 1999). To illustrate, at intake parents are asked what they hope their children will have in their lives when they reach their early twenties. They are also asked what they believe their roles are in

supporting their children achieve this. The outcome of this discussion is usually a description of them as the best parent they can be in the context of their child's broader life experience beyond parameters suggested by the diagnosis. This process of broadening the reference point for the therapy to include the wider social, family and community influences, extends to goal-setting at the initial and subsequent reviews. In addition to a functional goal being agreed, the therapist asks what difference a change in that developmental domain will make for the child outside of therapy and what will be different for the family as a result. For example, when talking about a communication goal – e.g., for the child to use an alternate communication device – a parent of a three-year old boy with a diagnosis of autism spectrum disorder said “this will help me know if he is hurting, or hungry. With my help, his sister might find it easier to play with him”. This feedback is recorded and referenced in therapy to make sense of and reinforce the work the parent does in session and in the wider community.

A preliminary case study evaluation of PCRI-EI showed promising results, including in functional gains, decreased parental stress and increased sense of competence (Callanan et al., 2019). These outcomes were achieved in a setting where parents described a positive alliance with their therapists and agreed that their perspective and expertise was considered throughout treatment and treatment planning (Callanan et al.). A follow up study investigating the impact of PCRI-EI on parental stress and sense of competency showed reductions in stress, improved psychological well-being and an increased sense of competence (Callanan et al., 2020).

The current study

This study seeks to extend the investigation of the utility of PCRI-EI in achieving functional gains. It appears PCRI-EI reduces parent stress levels and increases their sense of competency. These factors are strongly linked to reductions in perceived difficult behaviour, creating a calm-alert state for the child and increasing participation in treatment programs

(Lindo et al., 2016). Furthermore, by introducing the parents to their child's experience they appear to be able to shift their perspective from their child being difficult to include a broader understanding of behaviour, e.g., what their child is telling them through behaviour as well as appreciating the influence of functional deficits (e.g., speech and language delays, cognitive delays and motor difficulties) on behaviour and the child's ability to participate in various settings, including school (Callanan et al., 2020).

Notwithstanding the positive impacts of PCRI-EI on parents' stress and sense of competence, the underlying premise of the program is that relational change is not the ultimate outcome. Instead, the recalibrated view of the child, changed response repertoire and values-driven parenting provide a platform for the capacity building that is the primary function of early childhood interventions (King et al., 2009). For that premise to hold, PCRI-EI needs to reflect functional gains through the development and execution of evidence-based therapy plans that engage and involve parents and are delivered by allied health professionals. The purpose of this study is to investigate that premise. Consequently, it is hypothesised that functional gains will be achieved across time through the delivery of evidence-based practices within the relational framework. As a result of the preliminary findings of the case study, we expect those gains will not be impacted by diagnosis. In addition, given the assertion that the efficacy of therapy in early intervention influences, and is influenced by, wider social and community contexts, the study will also investigate the impacts of changed functioning on wider family and community activities.

Method

Participants

Participants in this study comprised 56 children aged between 0 and 6 years (41 males and 15 females). Service eligibility included being aged between 0 and 6 years, falling below the first percentile (compared to same aged peers) in three of five developmental categories

(cognitive, gross motor, fine motor, speech and language, and activities of daily living/social emotional functioning) as measured by standardised assessments of developmental capacity, either the Griffiths Mental Development Scales (GMDS; Griffiths, 1984) or the Bayley Scales of Infant and Toddler Development (Bayley III; Bayley, 2006). It is important to stress that the service accepts referrals for children up to 6 years of age with the most significant developmental delays. The children are discharged to the government child development service once they reach 6 years of age where there can be waitlists for therapy. This often means there is limited time and significant pressure on therapists to address the global nature of their delays.

Twenty-three children (17 male, 6 female) had a diagnosis of Autism Spectrum Disorder (ASD), fifteen (13 male, 2 female) had a diagnosis of Global Developmental Delay (GDD), nine (6 male, 3 female) had a diagnosis of Cerebral Palsy, five (3 male, 2 female) had a diagnosis of a Syndromal Disorder (SD) and four (2 male, 2 female) had a diagnosis of Down Syndrome (DS). Families were referred from the Public Hospital, General Practitioners, Paediatricians, Community Health Nurses, Allied Health Professionals and the government health service. Therapy was provided at a community-based early childhood development service located in the Northern Territory of Australia. Informed consent from the adult participants was necessary for participation in the project, however treatment delivery was not contingent upon research participation. The organisation in which the early childhood development service operated also provided consent to undertake the study. Ethical approval was secured from Central Queensland University Human Research Ethics Committee, HREC approval number H15/09-202.

Materials

PCRI-EI intake and treatment procedures utilise several psychometric and functional measures that have been detailed previously (Callanan et al., 2019). As the purpose of this

study was to examine the impact of the treatment on functional outcomes, one specific measure was included. This was the Goal Tracking Form (GTF: Ronan, 2009). The decision to use the GTF over the Goal Attainment Scale (GAS: Kiresuk & Sherman, 1968), which is used extensively in paediatric services across disciplines and diagnoses (King et al., 1999) was based on practicality within the current setting. An advantage of the GTF is the ease of completion and understanding for the families. The visual analogue nature of the GTF allowed parents to easily define the child's current level of functioning— see below for a detailed description. In contrast, feedback from parents and therapists in the early stage of implementation of goal setting indicated that developing the various levels of competence (+1, +2, 0, -1, -2), which the GAS prescribes was difficult, time-consuming and at times confusing.

Goal Tracking Form (GTF: Ronan, 2009): The GTF uses a visual analogue scale on a 10cm line. Parents mark the line between Never Happens and Always Happens indicating their assessment of functioning. The measure follows the principles of the Subjective Units of Distress Scale (SUDS; Stanley & Averill, 1998) and is particularly useful because of ease of administration by therapists and parents (Ronan et al., 2016; 2018).

Procedure

Following assessment and eligibility being confirmed, the family was allocated a key therapist. Which allied health professional (Occupational therapist, Physiotherapist, Psychologist or Speech pathologist) filled this role was determined by the developmental needs of the child. Once allocated the family, the key therapist organised a meeting with the parents only. There were several outcomes expected from this meeting, which have been detailed previously (see Callanan et al., 2019). Setting goals was one of those. This conversation included the assessment results, which set a standardised developmental benchmark across the functional domains for each child. Results were reviewed to orient

parents to the developmental age of their child, strengths and weaknesses in the domains measured as well as answer any questions they had. The key therapist also explained the process of ongoing goal evaluation to inform therapy including when their child would have a change in therapy direction e.g., from speech pathology for communication goals to occupational therapy for fine motor goals. Goal setting began once that was completed. As mentioned above, this process initially considered the long term hope for the child (e.g., having some independence, friends, making choices about work, being engaged in the community), it progressed to establishing shorter term goals (3 to 6 month) which included these examples: functional capacity (e.g., fine/gross motor skills, feeding, and activities of daily living), developmental imperatives (e.g., communication, problem solving, relationships, play, and school-readiness) and psychosocial factors (e.g., resilience, agency, self-regulation and independence). Short-term goals were reviewed every 12 weeks during which time the child attended between 6 and 12 therapy sessions (depending on the complexity of their developmental difficulties).

When setting goals for the first time, the key therapist explained the reasoning and process, including the collaborative nature of the goal setting as well as the mechanics of the GTF. As noted, goals were informed by the child's developmental profile, the parent's therapy objectives as well as in a broader family and community context. Sometimes parents would suggest goals that were beyond the current capacity of the child. For example, for a non-verbal child the parent might suggest a goal of talking or in the case of a child with significant gross motor challenges the parent might suggest a goal of walking. If this happened the therapist introduced and described the reasoning for an alternative goal that addressed precursor skills or building blocks that were functionally appropriate and achievable at that time. For example, the parental goal of talking became understanding the cues your child is using now and responding to them. The goal of walking became pulling to

stand on nearby furniture. In addition, when discussing the broader family and community settings, the therapist would ask “what would be different for your family if this goal was achieved?” To illustrate, when asked this in relation to a communication goal, a parent (Mother of a 3-year-old boy with a diagnosis of ASD) said “so I know when he is hurt, or sick, or what he might need from me”. These comments reminded parents and therapists that behind the sometimes-clinical nature of the goal setting process, there was a broader context for goals that reflected things a child would say or do outside therapy. Scripts and scenarios to help therapists have these discussions are contained in the treatment manual associated with PCRI-EI and available from the corresponding author. Once the goal was agreed, parents were asked to mark on a line their view of the child’s current level of functioning between never happens and always happens. Because of the 12-week timeframe, goals were limited to a maximum of four.

Reviews occurred at the end of the therapy block at which time goals were also set for the next block. When reviewing goals, parents were given a blank GTF form listing the goals for the just completed therapy block and asked to mark on the line their view of the child’s capacity post the therapy block. The therapist would ask the parent what they had seen or experienced that informed that decision and add their own clinical observations. If there was a disparity between the parent’s and therapist’s observations further discussion would occur to understand these differences and they came to an agreed level of functioning. They would then compare this to the score from the beginning of the therapy block. It is important to stress it was incumbent on the therapist to use their clinical judgement to guide these discussions to develop an accurate level of competency even if it was a difficult thing to do. The conversation also covered whether the differences they had hoped for more broadly (in the family or in the community) had also improved and if so, what had changed.

When setting goals for the next block, several issues were considered. First was the score achieved in the previous block. Because of the operational constraints of the service – limited staffing resources and time, persevering with a goal until it reached a score very close to always happens was not sustainable and often unachievable given the developmental capacity ceiling of the child. Instead the discussion considered: (1) the gains made e.g., from a score of two to a score of six; (2) the parent’s skill level in continuing to work on that goal outside the clinic (e.g., in play at home); (3) the capacity to employ role-release between disciplines (a feature of the transdisciplinary approach utilised in the clinic – see King et al. (2009) for detail) and; (4) the need to address other developmental domains in the time available before discharge or because of changed circumstances in the child’s life such as starting school. Often this would mean the child’s goals for the next block would change despite the score not reaching the always happens range. If, as part of the review it was evident the goal needed further input from the existing key therapist, it would continue into the next treatment block. Once completed, the GTF was sent to the principal researcher who entered the parent’s score (between 0 and 10) into a spreadsheet. All the families in this study completed a minimum of three goal-setting reviews.

Once the GTFs were received, the principal researcher allocated a functional category to the goal (see below) as well as recording comments made in the context of impacts on the family. This step was intended to identify any differential impact of the program by goal category. Based on an initial sample, ten categories were established. Including examples they were: parenting skills (e.g., responding differently to difficult behaviour); communication (e.g., my child uses sounds to get my attention); fine motor (e.g., use both hands to gesture when Mum sings “twinkle, twinkle”); gross motor (e.g., move forward along the floor); behavioural (e.g., understand the purpose of and reduce escaping behaviour); managing emotions (e.g., self-manage distress); social play skills (e.g., take turns in play);

attentional/persisting (e.g., stay at play activity for longer); problem solving (e.g., complete a jigsaw puzzle) and activities of daily living (e.g., eating different foods).

In the first therapy session, the therapist reminded the parent of their role in the therapy, the goals they had agreed, the broader context of those goals, explained the room set-up and specific plans for the session. The parent and the therapist then worked collaboratively to engage the child. The overarching principle being to have the parent work with the child as the primary source of instruction, encouragement, and feedback. The therapist would coach the parent on the purpose of the activity allowing the parent to support the child's engagement and skill development. Reflecting on the child's responses/reactions/engagement was an ongoing dialogue between parent and therapist. During these conversations, parents were urged to apply child-friendly language to encourage effort and manage resistances. Some examples of often used phrases are "you are thinking about what to do" when a child is investigating the components of play; "that's a bit tricky" when there is some hesitancy engaging in the task and waiting while they process information before saying "good job, you did it". The therapist also prompts the parent to wait for the child to work through things rather than pre-emptively helping. This is particularly challenging for parents who often see their role is to teach skills. Whilst these responses seem simple initially, they often replaced a response repertoire that instead of creating a calm-alert state, increased arousal or precipitated escape behaviours that often would result in escalation by both parties (Callanan et al., 2020). Session summaries, including tasks for homework were completed at the end of every session.

Results

A total of 453 goal tracking forms were completed for the 56 children over three therapy blocks. As can be seen in Table 7, each diagnosis was characterised with differing profiles across the ten categories of goals. Communication goals were proportionally high

comprising 46% of total goals for all participants; they were particularly prominent in the profile of those with a diagnosis of ASD along with the development of social play skills (11% of all participants' goals). In contrast, for children with a diagnosis of CP, developing motor skills was prioritised (22% of overall total). The distribution of goals for children with global delays (GDD) was spread across goal types as were the goals for children with a diagnosis of GS.

Table 7.

Number of goals per category by diagnosis across the three therapy blocks

<u>Category</u>	<u>ASD</u>			<u>CP</u>			<u>DS</u>			<u>GDD</u>			<u>GS</u>		
	<u>Block</u>			<u>Block</u>			<u>Block</u>			<u>Block</u>			<u>Block</u>		
	1	2	3	1	2	3	1	2	3	1	2	3	1	2	3
Parenting Skills	1	0	0	0	0	0	0	0	0	0	0	1	0	0	0
Communication	33	35	34	10	13	10	4	4	4	10	14	10	7	10	9
Fine Motor	0	1	1	4	7	5	1	2	2	3	4	3	2	4	5
Gross Motor	3	1	0	4	4	5	4	1	0	8	4	9	4	4	1
Behavioural	2	3	3	3	0	0	0	1	0	1	2	2	1	0	1
Managing Emotions	2	2	3	2	0	0	0	0	0	3	1	0	1	0	0
Social Play Skills	7	8	11	0	0	0	0	1	1	4	5	7	1	2	1
Attentional/Persisting	7	4	5	1	1	1	0	0	0	2	1	0	3	0	0
Problem Solving	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Daily Living Activity	4	7	6	1	2	1	2	1	1	4	3	3	2	3	2

The brief parental feedback to the question “what would be different for your family if this goal was achieved?” was collected and reviewed. In the communication goal category, most responses reflected changes in engagement within the family, specifically connecting

with the child because of an increase in the parent's skill in interpreting and responding to the meaning of the child's unique cues and non-verbal communications e.g. "the whole family has learned how to speak his language" (Father of a 4-year old boy with a diagnosis of ASD); "It has helped me know what I need to do at home to help him" (Mother of a 3-year old boy with a diagnosis of Angelman's Syndrome); "I know when she needs my help, is hungry or worried and I react differently now" (Mother of a 2.5-year old girl with a diagnosis of CP); "She and her sister are playing together more and with less fighting" (Mother of a 4-year old girl with a diagnosis of CP).

In the motor skill category (the second largest number of goals overall), responses included descriptions of the child bringing increased physical capacity to play and leisure activities in wider community settings e.g., "Now he can feed the ducks with me, instead of watching from the verandah and we go to the park" (Mother of 4-year old boy with diagnosis of CP whose goal was to independently use his walker); "She has made the transition to mainstream school and her friends – and there are a lot of them – don't seem to notice she is using a walker. It is such a relief to see her enjoying school" (Mother of a 6-year-old girl with a diagnosis of CP – here the goal was to be able to engage in a mainstream school).

Similar comments were made when reflecting gains in play skills; "His teachers have commented on how much better he is playing with his friends" (Mother of a 6-year-old boy with a diagnosis of GDD). Changes in behavioural and managing emotions categories were often associated with increased participation in community activities e.g., "We are spending more time as a family out and about, going shopping, to the waterpark, just doing normal things" (Father of a 4-year-old boy with a diagnosis of ASD). Improvements in activities of daily living often related to family experiences, however because they often were to do with feeding/eating difficulties they also included descriptions of reductions in stressors for parents e.g. "We get to eat together, and he looks like he is enjoying being part of the family

rather than us battling around mealtimes” (Mother of a 5-year-old boy with a diagnosis of ASD). In summary, most parents’ responses to the question reflected changes in the child’s ability to participate in activities considered a part normal daily life, whether in community, engaging in leisure activities with the family or within the family unit.

To test the hypothesis that there would be a difference in goal scores pre- and post-therapy block, paired-samples t-tests were conducted to compare pre- and post- goal scores (range of 0 – 10, where 0 = rarely happens and 10 = happens all the time) by diagnosis across each of the three, 12-week therapy blocks. As shown in Table 8, there were significant increases in average goal scores over the three time periods for each diagnosis. Across most blocks and diagnoses, the effect size for this analysis exceeded Cohen’s (1988) convention for a large effect (i.e., were greater than 0.8). The effect size for children with a diagnosis of ASD fell into the small to medium range in block 2 (0.44), which may reflect the unique challenges around developing communication and social skills for these children. Notwithstanding this variation, the effect sizes found in the study overall suggest significant, material change in functioning for all participants across time and within a variety of developmental goals.

Table 8.

Results of t-tests, Descriptive statistics, and effect sizes for goal scores across therapy blocks by diagnosis

Therapy	95% CI for									
	<u>Pre</u>		<u>Post</u>		n	Mean				
	Block	M	SD	M		SD	Difference	<i>t</i>	df	<i>p</i>
<u>ASD</u>										
1	2.96	1.90	4.56	2.04	59	-2.18, -1.10	-6.30	58	.000	0.82
2	2.95	1.92	3.94	2.45	61	-1.57, -0.42	-3.45	60	.001	0.44
3	2.65	1.71	4.92	2.35	63	-2.86, -1.68	-7.72	62	.000	0.97

<u>CP</u>											
1	2.83	1.71	5.00	1.75	25	-3.10, -1.25	-4.87	24	.000	0.99	
2	3.83	2.60	5.46	2.15	27	-2.45, -0.81	-4.10	26	.000	0.80	
3	3.49	2.12	5.38	1.82	22	-3.12, -0.66	-3.20	21	.000	0.68	
<u>DS</u>											
1	1.82	1.85	4.05	2.76	11	-4.22, -0.23	-2.49	10	.032	0.75	
2	3.18	1.89	5.37	3.38	10	-4.23, -0.15	-2.43	9	.038	0.78	
3	2.20	1.56	5.71	3.14	8	-5.26, -1.76	-4.74	7	.002	1.67	
<u>GDD</u>											
1	2.83	2.07	4.39	2.28	35	-2.34, -0.79	-4.10	34	.000	0.69	
2	2.06	1.41	3.84	2.15	34	-2.40, -1.15	-5.76	33	.000	0.99	
3	2.27	1.97	5.30	2.72	35	-3.84, -2.22	-7.64	34	.000	1.29	
<u>GS</u>											
1	1.89	1.54	3.74	3.39	20	-2.91, -0.80	-3.69	19	.002	0.82	
2	1.92	1.61	5.28	2.87	23	-4.56, -2.17	-5.86	22	.000	1.22	
3	1.87	1.46	3.91	2.51	19	-3.11, -0.97	-3.99	18	.001	0.92	

To investigate any differential impact by diagnosis, a comparison of the mean goal scores for the five diagnostic groups across the therapy blocks was undertaken using a repeated measures ANOVA. The independent variable represented the diagnostic groups with five diagnoses represented: 1) Autism Spectrum Disorder (ASD); 2) Cerebral Palsy (CP); 3) Down Syndrome (DS); 4) Global Developmental Delay (GDD); and 5) Genetic Syndromes (GS). The dependent variable was the goal score pre- and post-therapy block. Results of the ANOVA showed no statistically significant difference between mean goal scores and diagnoses across the three blocks $F, (4,446) = 2.324, p = 0.56$.

Discussion

This study sought to further investigate the utility of PCRI-EI in a community-based early childhood intervention service. The intention of PCRI-EI is to engage parents using a relationally-based platform to facilitate targeted, developmentally informed, evidence-based therapy. The primary aim was to investigate the hypothesis that functional gains were able to be achieved in the context of the relational approach incorporated in PCRI-EI. As expected, there were significant and marked (i.e., large effect size) increases in functional capacity for all participants as measured by mean goal scores across the three therapy blocks. The hypothesis that the gains would not differ by diagnosis was also supported. Additionally, comments gathered in the brief parental feedback about the impact of the increased levels of functioning reflected positive changes for the child in broader social (including family), community and educational settings.

The range of effect sizes (0.44 – 1.67) found in this study are substantive and were achieved across a variety of functional categories, diagnoses, and multiple points in time. When considered in the context of parents' comments about the impact of these changes, the findings suggest the components of the therapy are being generalised across family and community milieus by the parents. Furthermore, these results compare favourably with similar investigations. For example, Salisbury and Copeland (2013) investigated parent involvement in early intervention in a study involving 21 children with severe disabilities who attended a community clinic. Using similar categories, they described strong effect sizes (0.88 – 0.92) across settings; suggesting the current results are in line with previous findings in a similar context. In addition, Strauss et al. (2013) specifically looked at behavioural management interventions that included parents and children with a diagnosis of ASD; they also describe medium to large effect sizes across the six programs investigated.

Notwithstanding the promising results in this study, there are some non-significant, diagnoses-based differences within them that prompt questions around the influence of the program on children with ASD compared to other diagnoses. To illustrate, the difference in effect size for children with ASD in block 2 as well as other data comparing the effect of diagnosis on changes in goal scores, at face value suggest the program may have a larger influence on the outcomes for children with other diagnoses than for those with a diagnosis of ASD. Slade (2009) offers an insight into a possible underlying factor in what seems to be a difference in timing rather than one of differential impact. Slade coins the phrase “mentalising the unmentalisable” (p 7.), when describing the challenges in parenting a child with ASD, specifically the absence of reciprocity and the overwhelming experience of disconnection for the parents. Remembering that thoughtful responding to the child’s cues facilitates the calm-alert state, it may be that this process takes longer for parents of children with ASD compared to parents of children with other diagnoses. When they do unlock those unique cues, parents and therapists can respond in ways that support the delivery and integration of the evidence-based practices being deployed (as evidenced by the effect size in block 3). It just takes time.

Parental feedback on how changed functioning positively affected family and social setting activities is particularly salient when considering the impacts of having a child with a disability in these contexts (Davis & Neece, 2017). Specifically, on parent’s ability to generalise what they learn in the clinic to these different environments, where a range of natural reinforcers are available to strengthen the developing skills. To illustrate, during early discussions with parents on their goals, they often described difficulties in just going out with their children. Often, they had reached a point where the level of distress experienced by their child and themselves when they were in the community meant they stopped trying altogether. Consequently, their lives *got smaller*, and they were unable to avail themselves of the natural

respite and learning experiences that family outings bring. When parents were involved in the therapy, they were able to practice the skills that helped the child with goals that were cooperatively developed to reflect not only developmental deficits but also to reflect contextual functioning e.g., feeding the ducks not just becoming mobile. In simple terms their lives *got bigger* because the child's capacity could generalise to multiple settings.

Limitations and future directions

The nature of practice-based studies presents design challenges and limitations. Operational demands, limited resources and the significant global delays of the children presented design difficulties. The inability to have a waitlist control group because of potential risk to a vulnerable population is an acknowledged limitation, which has been discussed previously (Callanan et al., 2020). Having to change the direction of goals because of operational or contextual demands at scores that seem less than perfect is also challenging when trying to establish efficacy of the program over time. Further, whilst the number of GTFs collected was substantial, the representation of diagnoses is uneven; there were 23 children with a diagnosis of ASD and only four children with a diagnosis of Down Syndrome. Notwithstanding these limitations the data, including parents' feedback shows multiple demonstrations of PCRI-EI and evidence-based practice working together to effect improvements in functional capacity across a variety of diagnostic presentations, family circumstances and points of time. Future research could test this combination of parent and therapist in group comparison conditions with larger samples across different settings, including those where therapist lead interventions predominate.

In summary, the findings in this study are important because they support the contention that working within a relational framework and applying evidence-based practices across disciplines delivers noteworthy, sustainable, and functional gains for the children across time. The findings also show this being achieved in an operational setting with limited

resources and pressured timeframes. Additionally, the study highlights the value of understanding context – what difference the changes make for families – in overall treatment planning and outcomes. Furthermore, the reflective stance integral to PCRI-EI not only becomes part of the parent’s perspective of their child, it also becomes part of the therapists’ skill set; a therapeutic capacity that is not generally part of their training. That said, a more comprehensive understanding of therapists’ experiences is warranted and planned. Testing PCRI-EI in group comparison conditions as well as investigating the unique contribution of the relational aspect of the protocol to the functional gains also require further investigation.

References

- Barfoot, J., Meredith, P., Ziviana, J., & Whittingham, K. (2015). Relationship-based parenting to support developmental outcomes for a young child with cerebral palsy: a practice application. *British Journal of Occupational Therapy*, 78, 640 – 643. <https://doi.org/10.1177/2F0308022615583304>
- Barfoot, J., Meredith, P., Ziviana, J., & Whittingham, K. (2017). Relationship-based approaches in early childhood intervention: Are these applicable to paediatric occupational therapy under the NDIS? *Australian Occupational Therapy Journal*, 64, 273-276. <https://doi.org/10.1111/cch.12493>
- Bayley, N. (2006). *Bayley-III: Bayley Scales of Infant and Toddler Development* (3rd ed.). Harcourt Assessment.
- Bowlby, J. (1969). *Attachment and loss*. Vol. 1: Attachment. Basic Books.
- Bowlby, J. (1973). *Attachment and loss*. Vol. 2: Attachment. Basic Books.
- Bowlby, J. (1980). *Attachment and loss*. Vol. 3: Attachment. Basic Books.
- Caldwell, P. (2006). Speaking the other's language: Imitation as a gateway to relationship. *Infant and Child Development*, 15, 275-282. <https://doi.org/10.1002/icd.456>
- Callanan, J. P., Ronan, K. R., & Signal, T. (2019). Activating parents in early intervention: Preliminary findings from an empirical case study. *International Journal of Disability, Development and Education*, 69, 1-17. <https://doi.org/10.1080/1034912X.2019.162816>
- Callanan, J. P., Signal, T., & McAdie, T. (2020). *What is my child telling me? Reducing stress, increasing competence and improving psychological well-being in parents of children with disability*. (Manuscript submitted for publication). School of Health, Medical and Applied Sciences, Central Queensland University.

- Davis, A. L., & Neece, C. L. (2017). An examination of specific child behaviour problems as predictors of parenting stress among families of children with pervasive developmental disorders. *Journal of Mental Health Research in Intellectual Disabilities*, 10, 163-177. <https://doi.org/10.1080/19315864.2016.1276988>
- Ephraim, G. (1986). A brief introduction to augmented mothering. *Playtrack pamphlet*. Harpebury Hospital School, Radlet Herts.
- Fonagy, P., Gergely, G., Jurist, E., & Target, M. (2002). *Affect Regulation, mentalization and the development of the self*. Karmac.
- Griffiths, R. (1984). *The abilities of young children: A comprehensive system for measurement for the first eight years of life*. The Test Agency Ltd.
- Hayes, S. C., Strosahl, K., & Wilson, K. G. (1999). *Acceptance and commitment therapy: An experiential approach to behaviour change*. Guilford Press.
- Kalmanson, B. (2009). Echoes in the nursery: Insights for treatment of early signs of autism in a baby sibling. *Journal of Infant, Child and Adolescent Psychotherapy*, 8, 40-48. <https://doi.org/10.1080/15289160802683427>
- King, G., McDougall, J., Palisano, R. J., Gritzan, J., & Tucker, M. A. (2000). Goal Attainment Scaling, *Physical and Occupational Therapy in Pediatrics*, 19, 31-52. https://doi.org/10.1080/J006v19n02_03
- King, G., Strahan, D., Tucker, M., Duwyn, B., Desserud, S., & Shillington, M. (2009). The application of a transdisciplinary model for early intervention services. *Infants and Young Children*, 22, 211-223. <https://doi.org/10.1097/iyc.06013e3181abe1c3>
- Kiresuk, T. J., & Sherman, R. E. (1968). Goal attainment scaling: A general method for evaluating community mental health programs. *Community Mental Health*

- Journal*, 4, 443-453. <https://doi.org/10.1007/BF01530764>
- Lindo, E. J., Kliemann, K. R., Combes, B. H., & Frank, J. (2016). Managing stress levels of parents of children with developmental disabilities: A meta-analytic review of interventions. *Family Relations*, 65, 207-224. <https://doi.org/10.1111/fare.12185>
- Marvin, R., Cooper, G., Hoffman, K., & Powell, B. (2002). The circle of security project: Attachment-based intervention with care-giver-preschool child dyads. *Attachment & Human Development*, 4, 107-224. <https://doi.org/10.1080/14616730210131635>
- Nind, M., & Hewitt, D. (1998). *Interaction in action*. David Fulton Press.
- Nind, M., & Hewitt, D. (2001). *A practical guide to intensive interaction*. David Fulton Press.
- Oppenheim, D., Koren-Karie, N., Dolev, S., & Yirmiya, N. (2012). Maternal sensitivity mediates the link between Insightfulness/resolution and mother-child attachment: The case of children with autism spectrum disorder. *Attachment and Human Development*, 14, 567-584. <https://doi.org/10.1080/14617734.2012.727256>
- Rix, J., Paige-Smith, A., & Jones, H. (2008). “Until the cows came home” Issues for early intervention activities. Parental perspectives on the early years learning of their children with Down Syndrome. *International Journal of Contemporary Issues in Early Childhood* 9, 66–79. <https://doi.org/10.2304/2Fciec.2008.9.1.66>
- Ronan, K. R. (2009). *Goals tracking form*. Rockhampton, Queensland: Author.
- Ronan, K. R., Davies, G., Browne, M., Woltmann, D., Wilkman, R., Jarrett, M., & Braun, S. (2018). *Family-centered, feedback-informed therapy for complex behaviour in youth: A randomised, controlled trial of a systemic therapy approach*. Manuscript in preparation for submission.
- Ronan, K. R., Davies, G., Wikman, R., Canoy, D., Jarrett, M., & Evans, C. (2016). Family-centered, feedback-informed therapy for conduct disorder: Findings from an empirical case study. *Couple and Family Psychology: Research and Practice*, 5,

- 137-156. <https://psycnet.apa.org/doi/10.1037/cfp0000059>
- Salisbury, C. L., & Copeland, C. G. (2013). Progress of infants/toddlers with severe disabilities: Perceived and measured change. *Topics in Early Childhood Special Education, 33*, 68 – 77. <https://doi.org/10.1177/0271121412474104>
- Shai, D., & Belsky, J. (2011). When words just won't do: Introducing parental embodied mentalising. *Child Development Perspectives, 5*, 173-180.
<https://doi.org/10.1111/j.1750-8606.2011.00181.x>
- Singh, N. N., Lancioni, G. E., Winton, A. S., Singh, J., Curtis, W. J., Wahler, R. G., & McAleavey, K. M. (2007). Mindful parenting decreases aggression and increases social behaviour in children with developmental difficulties. *Behaviour Modification, 31*, 749-771. <https://doi.org/10.1177/0145445507300924>
- Slade, A. (2009). Mentalising the unmentalizable: Parenting children on the spectrum. *Journal of Infant, Child and Adolescent Psychotherapy, 8*, 7-21.
<https://doi.org/10.1080/15289160802683054>
- Stanley, M. A., & Averill, P. M. (1998). Psychosocial treatments for obsessive-compulsive disorder: Clinical applications. In R. P. Swinson, M. M. Antony, S. Rachman, & M. A. Richter (Eds.). *Obsessive-compulsive behaviour: Theory, research and treatment* (pp. 277-297). Guilford.
- Strauss, K., Mancini, F., & Fava, L. (2013). Parent inclusion in early interventions for young children with ASD: A synthesis of meta-analysis from 2009 to 2011. *Research and Developmental Disabilities, 34*, 2967 – 2985.
<https://doi.org/10.1016/j.ridd.2013.06.007>
- Tronic, E., & Beeghly, M. (2011). Infants' meaning-making and the development of mental health problems. *American Psychologist, 66*, 107-119.
<https://doi.org/10.1037/a0021631>

Weatherston, D. (2007). Returning the treasure to babies: Infant mental health and early headstart. *Infant Mental Health Journal*, 28, 246-251.

<https://doi.org/10.1002/imhj.20132>

Whittingham, K. (2016) Mindfulness and transformative parenting. In E. Shonin, W. V. Gordon, & M. Griffiths (Eds). *Mindfulness and other Buddhist-derived approaches in mental health and addiction* (pp. 363-390). Springer.

CHAPTER 6: Mentalising the unmentalisable

The guiding principle in the development of PCRI-EI was to operationalise sound theories of child development so parents and therapists could apply them in therapy and (for parents) in their everyday lives. If this was effective, it was hypothesised that many of the challenges faced by families of a child with a disability would be mitigated. Therapy would be less distressing; functional gains would be realised, family goals would be prioritised, and parents included as active participants in sessions. Parents' confidence in their ability to create the secure base from which their child could explore, and grow would increase and consequently, lives would get bigger as families spent more time in the community. Importantly, the stress often associated with having a child with a disability would reduce. Developing therapists' skills to work relationally was included in the program because of their central role in activating parents and prioritising family goals. Reflective supervision supported their shift in practice and the impacts of those elements of PCRI-EI have been summarised in the sequence of research described in the preceding chapters.

To complete the overall picture of the project, this final chapter will underscore the major therapy initiatives and themes that emerged as PCRI-EI was implemented. It will also describe insights gained as the program developed. Links to the underpinning theories and outcomes of the research will be highlighted where appropriate. Limitations will then be considered. Future directions and potential challenges implementing PCRI-EI will also be discussed. Concluding remarks will summarise the project overall and importance of the research.

The child's experience and reframing behaviour.

At intake, most parents talked about the challenges they had with their child. Some descriptions included difficulties associated with the diagnosis. However, as they continued to explain their lived experience, behavioural challenges dominated discussions. Reports of

inexplicable meltdowns that could not be managed provided some insight into the distress they experienced. It also marked the beginning of an overarching attribution of the child as difficult. This is a phenomenon that is associated with significant negative consequences in a developmental context (see Oppenheim & Koren-Karie, 2013). At a practical level, this perspective distracted therapy and negatively impacted outcomes as parents grappled to understand *why* their child was behaving as they did. They also struggled with managing their own reactions to perceived behavioural problems. Building the capabilities described in reflective functioning (Fonagy et al., 2002) and insightfulness (Oppenheim & Koren-Karie, 2013) was the first step in addressing this sometimes-all-encompassing perspective.

Asking parents, “What do you think it is like for your child?” when they reported their observations seemed to build their reflective capacity and insightfulness. Bringing attention to the child’s experience prompted a different conversation around the meaning of difficult behaviours. Initial responses from parents to that question were usually variations on “I don’t know”. However, with prompting and talking about the diagnosis in simple terms that reflected the (possible) child’s experience e.g., the frustration of having an idea and not being able to communicate it (for a child with cerebral palsy), parents started to see their child as not just simply difficult. Instead, they appreciated that their child was struggling to make sense of the world with limited resources to do that. High levels of fear and frustration were incorporated into their understanding of what it might be like for their child. Confused was another word that was frequently used. Put simply, parents shifted their perception to seeing their child as struggling rather than difficult. As a result, parents changed their responses to better match the child’s behavioural cues and their functional capacity. Most importantly, parents’ engagement and participation in therapy increased.

To illustrate, when asked the question what it might be like for his child, the father of a 4-year-old child with ASD said “it is like he is in the eye of a cyclone, if he moves in any

direction, it is into chaos, things going so fast he can't make sense of it – it must be frightening". This conceptualisation allowed Dad to slow down and not get involved (in the play) pre-emptively. In the next session he was able to sit and wait for his son to complete a task, which the child did – much to Dad's surprise. Within a few sessions, the child began to reference Dad as he played. Eventually they found a pace that worked based on the child's capacity to process information and integrate skills (e.g., fine motor skills) rather than on the (understandable) desires of the father to "teach him how to do things". In fact, the descriptions, metaphors, and analogies prompted by this question (What do you think it is like for him?) became part of the language of therapy. It was much more salient to remind Dad of the cyclone than ask him to slow down and wait for the child to process. In summary, introducing parents to their child's experience and how that might manifest behaviourally was fundamental in building reflective capacity and the sensitive (to the child) responsiveness essential to successful outcomes. It also increased parents' sense of competency and was arguably instrumental in the reductions in relational and individual stress seen in Chapter 2. A more comprehensive understanding of this relationship between seeing the child as struggling and resulting reductions in stress levels and increased competency is warranted and worthy of investigation.

A natural flow on from this question was a reframing of behaviour overall. Informed by the insightfulness literature (Oppenheim et al., 2009) – specifically the benefits of being able to see a wide range of behaviours, parents were introduced to ideas about behaviour to broaden their view of their child. This information also set a platform for a different way to generate more helpful responses situationally. Parents were introduced to behaviour as communication. Emotionally charged language like "attention seeking" was reframed as connecting behaviour, which was further defined as either helpful or unhelpful. That behaviour served a purpose that was often about managing distress or demands proved

enlightening for parents. The idea that language may represent an internal state rather than being a literal truth was extremely valuable in reducing the battles that often occurred in this context. For example, a father reported his 5-year-old son called him an idiot. Dad's response was to admonish the child. They then engaged in 20 minutes of back and forth that was highly distressing for both. When asked what preceded the comment, Dad said "I took his iPad away". The ah-ha moment. Dad realised the "you're an idiot" comment was because his son was cranky. Future similar comments were met with "you are cranky with me", which reduced the time they spent in potentially mutually coercive interactions (Neece et al., 2012).

This reframing of behaviour and the introduction of the question "What are they telling me (about their experience) right now" proved highly valuable in therapy. Parents reported it gave them time to think about their child's internal state and the purpose of the behaviour in a present moment context. Consequently, they were more likely to respond in a situationally appropriate way, which still included letting the child know the behaviour was not OK when required. The difference was they were not as likely to react punitively. Instead, they let the child know the behaviour was not helpful (another very effective use of language) in what the circle of security proponents would describe as being a *bigger, stronger, kinder, wiser* parent (Marvin, 2002). This changed response arguably addressed the both-way relationship between punitive parenting and increases in difficult behaviour (Neece et al., 2012). Therapists were able to use these questions and observations in session to build parents' reflective capacity and, more importantly generate more sensitive (to the child's context) responses. In combination, thinking about the child's experience and wondering what the behaviour was communicating proved a simple and effective way to increase parents' reflective capacity. It may also go some way towards mentalising the unmentalisable that Slade (2009) describes as being so elusive for parents in this situation.

Language – bringing different words to the situation

After parents were introduced to the ideas around behaviour, their most frequent response was “that makes complete sense”. Then the conversation turned to *how to do* this differently in therapy and in the community. Informed by the work of Koren-Karie et al. (2003) around the use of matched dialogues, the use of language was the simple and challenging answer. Challenging because of the requirement for parents to alter patterns of language that had been well habituated. This different use of language was transformative for parents, the child and for therapists. It is also where the program has substantially grown and developed over time. Changed language had wide ranging impacts including on therapy outcomes, parents’ ability to self-regulate, managing behaviour, reducing conflict, understanding internal states and in generating sensitive responses in difficult situations. A particularly meaningful illustration of all these elements involved the mother of a 4-year-old girl who had Cerebral Palsy.

Clinical observations estimated the child’s cognitive capacity to be in the average range. She had significant physical disabilities including in her ability to talk. Experience in sessions indicated her receptive language capacity was age appropriate. Mum raised an emerging problem – described as meltdowns. When her daughter talked to her, Mum found it very difficult to understand. She could only (naturally) think to say, “I don’t understand”. This precipitated high levels of distress for the child. Reflecting on what that might be like – having ideas, wanting to share them and not being understood – allowed Mum to pause and think about what a more helpful response might be. The upshot was a change in Mum’s language. She changed her response to, “let me think about what you are saying”. The child waited. Mum’s own arousal level reduced, and she found herself more able to guess what her daughter was saying. If she got it wrong, her daughter just shook her head for no. Mum then said – “you can show me”. Over time Mum said this insight and reconsidered use of language “was life changing”. The meltdowns stopped, family members and teachers responded

similarly, which expanded the child's ability to participate in activities at school, with friends and in the community. In addition, Mum often talked of how by waiting and wondering about what her child was telling her Mum changed many of her own unhelpful automatic language responses across a range of settings and situations.

Changing language became central to the work in the parent-child dyad. Shortening sentences to meet the child's processing capacity promoted attention and task persistence. Not being hooked by language e.g., "I'm bored" and instead responding to the (possible) underlying meaning i.e., "you can't think of what to do" changed previously frustrating and time-consuming interactions. The children also developed more functional problem-solving skills as a result. Reflecting affective components of challenges e.g., "you are a bit worried, and you can do it" increased the willingness to explore and promoted problem-solving. Noting disappointment e.g., "you are disappointed, and you can fix it" was transformative for some families who struggled to find a way to help their children manage when the child's functional skills were lacking. Finally, parents reported that using fewer words, less questioning and offering alternative, more functional options to the child had a marked effect on their own levels of frustration and stress.

These same principles were incorporated into the relationship between therapists and parents with similar outcomes. What words to use became a central feature of reflective supervision and appeared instrumental in helping therapists shift to relationally-based work. This component of the research appears to have wide ranging implications across dyadic work in general. Future research that specifically investigates the impact of changed language in a relational context, including on reducing stress for parents and increased functionality in both disability and mental health settings is warranted.

Habituating and generalising skills.

Early in the implementation of PCRI-EI it became evident that despite assurances of understanding what was being asked of them, parents reported they “forgot what to do, what I was supposed to say” in the face of a challenging situation. Parents also noticed and often spoke of how much they talked in these situations, even when they had become aware that their child could not process the amount of information they were presenting. This situation prompted some thinking about the role talking played in helping parents regulate when things were difficult, or they could not understand their child’s cues – beyond the scope of this thesis and an area that deserves further research attention.

Applying ideas from a therapy session into other settings was difficult in practice, when real life pressures hijacked thinking (a phrase often used with parents when talking about this phenomenon). Early on in the implementation of the program, parents often reported failure in implementing the skills outside of sessions, which was quickly internalised as them being a bad parent. When asked to elaborate, parents described significant effort – they were trying to implement the ideas at every opportunity, which was exhausting (for parents and children). It also reflected the desire of the parents to do the very best they could without necessarily understanding the capacity of the child to learn. For therapists who were struggling to decentralise themselves, these reports (of failure) were akin to a perfect storm whereby they felt pressured to take over, to fix the parents’ and unwittingly perpetuate the therapist-lead paradigm as the solution.

This dilemma prompted a change in methodology that was reflected in the manual’s phased approach, and which became known as *setting the foundations*. The objective of which was to prioritise building parents’ relational skills (and changing their language) early in therapy while still presenting opportunities for the child to engage in developmentally appropriate play. The goal being to help parents habituate the different responses in the (initially) low stress context of the therapy room where a low demand (initially) context for the

child was created and few difficult responses were generated. For therapists, this was challenging as they were in fact leading the therapy, at face value contradicting a cardinal feature of family-centred practice. The difference here was they were prompting parents to apply the skills derived from the underpinning theories with their child in real time. The manual was modified to include markers of competence so therapists could decrease the amount of coaching they did (decentralising themselves). As this occurred, therapists also increased the task demands for the child, which allowed parents to apply the ideas in slightly more stressful contexts – e.g., the child resisting a task or struggling emotionally in session. Not only did parents habituate the skills more easily, their arousal levels did not escalate as precipitously in the face of the child's distress. Worksheets, which were completed each session, provided direct observed feedback that parents were encouraged to collate and reference in the time between sessions. An unexpected outcome of this practice was parents going back through their worksheets when a behaviour re-emerged. In other words, they had a reference point that they could turn to outside sessions that was specific to their child and their family context. Parents commented on how that helped them when they got “stuck” (parent of a 4-year-old boy with ASD). Many families used the worksheets to upskill the parent who could not attend sessions, which was seen as very helpful in achieving consistent parenting for the child.

In addition to providing the opportunity to apply skills in sessions, parents were encouraged to play with their child at home using the language developed in the centre (and captured in the worksheet) for 10 to 15 minutes at a time (a timeframe supported by the work of Sanfuji et al., (2009)). Because these developmental – play based activities occurred when the child was much less aroused and for a shorter time, parents said they integrated the skills more easily and their sense of competence increased. Several parents also reported feeling much less stress when playing with their child when previously they struggled with how to interact.

For therapists.

The process of helping therapists transition to relationally-based, family-centred practice proved to be more complex than simply providing professional development, education, and reflective supervision. Best illustrated by the finding that despite endorsing the importance and value of the approach, a large proportion of allied health professionals report a lack of confidence in implementing the practice (Alexander et al., 2018). It was clear from the survey feedback (Chapter 2) that while some of the difficulties experienced could be addressed through education, mentoring and reflective supervision, moving from leading the therapy to supporting parents as the active agent presented significant, almost professional existential, issues for therapists. This was unexpected and proved a valuable insight in helping therapists shift their practice and provided some ideas around the contradictory (i.e., support for relationally-based practice and difficulty in engaging in the work) findings within the literature (e.g., Alexander et al., 2018).

What is not well articulated in the literature is that in being the lead in the therapy, therapists form their professional identity. They feel confident they are providing *easily identifiable* value to clients and the organisation. That is, parents can see what they are paying for. Therapists felt they were providing value for that money. The idea that therapists lead treatment starts in the early days of training and is unwittingly reinforced in the workplace. Sitting to the side and waiting for parents and children created substantial distress for therapists in the study, especially for the more senior clinicians. In one case an experienced therapist said to the senior psychologist, “So you are paying me to wait and do nothing”. The challenge with that perspective is the perception that waiting is doing nothing. Interestingly such comments rarely came up in supervision. Mostly they were raised in or after joint sessions with the senior psychologist/program developer. Despite repeated reassurances about the expectations of the organisation about the role, sitting with parents

and waiting for the child certainly increased their concerns about how they were seen (and saw themselves) as professionals.

Much like the work with parents, for therapists these concerns could only be addressed through the experience and observation of the process working. Having faith was mentioned in feedback. Sometimes it was talked about in supervision as taking a leap of faith. Supporting evidence helped. As our own measures of notable functional gains began to accumulate, and satisfaction survey results supported parent's direct comments about their experience, the evidence of changes was no longer anecdotal. Parents reported successfully using the strategies in other settings, which was different to (therapists) past experiences of parents struggling to apply the skills. Relational changes between parent and child in session were observed and further mitigated the disquiet for the therapists. The most compelling evidence came from the children themselves. Therapists began to recount and share experiences of unexpected responses (including based on diagnosis) from the children. Evidence and parents' comments about changes when goals were reviewed not only reinforced the value of the approach, but it also allowed therapists to recalibrate their view of themselves in a professional context.

On reflection, respecting the professional identity dilemma when it presented and being able to stay the course in the face of some quite high levels of distress for therapists was essential. A good example of how this resolved for one experienced therapist came at a presentation the program developer was asked to make to a professional body. When introducing the session, the therapist said:

When I was interviewing for this job I thought, what a lovely man, what a lovely idea. I also thought it would never work in practice. Had tried it before. When I started at the clinic, I was surprised at the detail that had been put together on working this way. However, in sessions I could not do it. I recall once sitting beside (the program

developer) and he was telling me to wait – incessantly. In fact, at one point he was almost restraining me – telling me to wait, wait, and wait. At the end of the session, I said – so you are paying me to do nothing. He replied, no we are paying you to focus on the goals you have agreed with the parent and build their skills in working with their child to meet those goals. To do that I am asking you to sometimes wait, wait and if needs be wait a little longer. Give the child a chance to explore and process information or prompts. Help the parent to learn how to work with their child – as they should. So, I did. I can still recall the internal struggle in the room as I waited – way too long in my mind. Then I saw the child complete the task. I remember being shocked as I was convinced that was never going to happen. Then I saw the same thing with other kids, and I saw the joy for parents as they realised their value in helping their child grow. I kept that in mind every time I felt like I was not doing my job by waiting.

In summary, it seems a simple task to support therapists' transition. Intellectually the benefits and evidence are compelling. Much like parents, when the stress levels rise the desire to revert to previously endorsed and reinforced practices (taking control) emerge. This potential block to the work was addressed by doing joint sessions with the senior psychologist/program developer, which provided a lower stress environment and support for therapists to integrate and habituate the different skills needed to make the shift. The professional identity challenges were a surprise. Thankfully, the process of reflective supervision created an environment where they could be raised safely and addressed thoughtfully. Future research into the rollout of relationally-based programs could explicitly address this phenomenon and more accurately assess its impact on uptake.

Limitations

Limitations of the individual studies are detailed in their respective chapters. Overall small numbers of participants make it difficult to generalise findings with certainty. However, as discussed extensively in Chapter 4, the small sample does not impact the validity of the single subject design methodology. The lack of a waitlist control was also a limitation. There is also a risk of bias given the author developed the manual and undertook the reflective supervision. Taken together these limitations mean the findings should be viewed with some caution and future research to support generalisability is needed. Including waitlist controls and a larger sample size of the various diagnoses.

Despite these limitations, the outcomes for parents, children and therapists are consistent with what would be expected based on the extant literature. They were achieved across multiple time points, with a range of families, diagnoses and presentations. Most noteworthy is the fact that the program was introduced and integrated into the practices of an operating clinic. This included introducing measures of wellbeing, clinical outcomes, and parents' feedback on how they viewed the service. In addition, the insight into the professional identity challenges for therapists making the transition to this style of working does not appear to have been considered in current literature. Given the challenges in achieving widespread uptake of relationally-based family-centred practices, this finding may provide a different avenue from which to approach therapists' misgivings.

Future directions

The overall objective of this thesis was to investigate the ability of PCRI-EI to embed relationally-based family-centred practices in an early childhood development service. The findings from the individual studies indicate the program shows promise. Limitations need to be addressed. These can be considered in future research that include comparison studies and in different settings and a different lead therapist providing the reflective supervision. Of

particular interest is the role of the therapist and how to better support their changed sense of professional identity in shifting to these practice models.

Although the scope of this study was limited to a quite specific population, because of several factors, including conference presentations, other organisations have begun to implement the program in different settings. Two rural allied health teams in South Australia have been implementing PCRI-EI. The treatment manual has been shared and reflective group supervision is undertaken monthly via Skype with the author. This has been in place for almost 4 years. For the program to be funded, the service has been measuring changes in practice and therapists' experience when it comes to working relationally with families. These results suggest this process is achieving notable changes in practice – in line with the experiences of therapists in the clinic itself. The manager of the rural service has noticed an impact on new graduates. In a recent conversation with the author, he said from his experience of placing graduates, those who are part of the reflective supervision provided by the program developer seem to mature as clinicians more quickly than those who do not (M. Manders, personal communication, October 19, 2018). Given the challenges of remote service provision, further investigation of this anecdotal experience may prove valuable.

Another group based in a metropolitan Child and Adolescent Mental Health setting are also integrating the principles of the program in cases with families with younger children. Over the past 12 months they too have engaged in monthly group supervision, which covers case reviews as well as building understanding of the principles underpinning the program. This group are finding the different use of language as well as the practical means of developing reflective capacity to be very helpful clinically (M. Lloyd, personal communication, July 9, 2020). Changes reported include notable decreases in relational stress within the dyad and reductions in challenging behaviours. Interestingly, they also report a shift in parents' perspectives around their child as difficult. Much like the parents in the

developmental setting, these parents are more able to see their child as struggling. Applying the question “what is your child really telling you” to (sometimes) provocative and distressing language has also proved helpful for these parents in therapy. A more rigorous investigation into how the language and changed input from the clinician impacted outcomes would be useful.

Conclusion

Relationally-based, family-centred approaches are widely endorsed as best practice in early childhood development settings. Existing literature across various disciplines practicing from this perspective describe outcomes that improve well-being and clinical outcomes for families. Parents endorse such programs reporting substantial benefits when they are involved and upskilled. However, systematic widespread uptake appears challenging to achieve. Building therapists’ capacity to manage the nuances of the work seems a simple solution. Reflective supervision is cited as being essential. Professional development is also required. At one level, it seems a simple sequence of events. Build therapists’ capacity and skills to do the work. In turn, therapists bring their new skills to the context and execute the well documented principles described in the literature. Upskilled parents generalise these skills across different settings. All of which contribute to achieving contextually prioritised developmental goals for the child – life gets bigger.

What this study has demonstrated is that to successfully achieve those objectives there needs to be a systematised approach that incorporates sound theory, procedures and practices and embeds those elements into the operational requirements of the service. Despite the complexity of many of the underpinning theories, parent and therapists were able to implement them because of the *how-to* priority that guided the development of the program. Parents and therapists report increased skill capacity and perspectives of the child that are congruent with the underpinning theories. The outcomes of the studies suggest PCRI-EI

achieves outcomes expected of relationally-based family centred-work. In summary, it appears the approach documented in PCRI-EI can facilitate the integration of relationally-based family-centred practice into early childhood development settings. In fact, it may be the program has managed go some way toward addressing the dilemma of mentalising the unmentalisable and returning the child to the parent.

References

- Alexander, S. L., Frederico, M., & Long, M. (2018). Attachment and children with disabilities: Knowledge and views of early intervention professionals. *Children Australia*, 43, 245–254. <https://doi.org/10.1017/cha.2018.38>
- Fonagy, P., Gergely, G., Jurist, E., & Target, M. (2002). *Affect Regulation, mentalization and the development of the self*. Karmac.
- Fonagy, P., Steele, M., Moran, G., Steele, & Higgins, A. (1991). The capacity for understanding mental states: The reflective self in parent and child and its significance for security in attachment. *Infant Mental Health Journal*, 13, 200-216. [https://doi.org/10.1002/1097-0355\(199123\)12:3<201::AID-IMHJ2280120307>3.0;2-7](https://doi.org/10.1002/1097-0355(199123)12:3<201::AID-IMHJ2280120307>3.0;2-7)
- Koren-Karie, N., Oppenheim, D., Haimovich, Z., & Etzion-Carasso, A. (2003). Dialogues of seven-year-olds with their mothers about emotional events: Development of a typology. In R. N. Emde, D. P. Wolf, & D. Oppenheim (Eds.), *Revealing the inner worlds of young children: The MacArthur Story Stem battery and parent-child narratives* (pp. 338-354). Oxford University Press.
- Marvin, R., Cooper, G., Hoffman, K., & Powell, B. (2002). The circle of security project: Attachment-based intervention with care-giver-preschool child dyads. *Attachment & Human Development*, 4, 107-224. <https://doi.org/10.1080/14616730210131635>
- Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behavior problems: A transactional relationship across time. *American Journal on Intellectual and Developmental Disabilities*, 117, 48-66. <https://doi.org/10.1352/1944-7558-117.1.48>

- Oppenheim, D., & Koren-Karie N. (2013). The insightfulness assessment: Measuring the internal processes underlying maternal sensitivity. *Attachment & Human Development, 15*, 545–561. <https://doi:10.1080/14616734.2013.820901>
- Oppenheim, D., Koren-Karie, N., Dolev, S., & Yirmiya, N. (2009). Maternal Insightfulness and resolution of the diagnosis are associated with secure attachments in preschoolers with autism spectrum disorders. *Child Development, 80*, 519-527. <https://doi.org/10.1111/j.1467-8624.2009.01276.x>
- Sanfuji, W., Yamashita, H., & Ohgami, H. (2009). Shared minds: Effects of a mother's imitation of her child on the mother-child interaction. *Infant Mental Journal, 30*, 145-157. <https://doi.org/10.1002/imhj.20208>
- Slade, A. (2009). Mentalising the unmentalisable: Parenting children on the spectrum. *Journal of Infant, Child and Adolescent Psychotherapy, 8*, 7-21. <https://doi.org/10.1080/15289160802683054>