



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

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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 efficacy 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.

1. Introduction

There is a significant body of research reporting elevated levels of stress in parents of children with a developmental disability (Hoffman, Sweeny, Hodge, Lopez-Wagner, & Looney, 2009; Robinson & Neece, 2015). The negative impact of this stress on parenting responses, the child's developmental outcomes (Neece, Green, & Baker, 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, Blacher, & Olsson, 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, Seltzer, Hong, & Orsmond, 2006; Neece et al., 2012). Equally troubling are findings that higher levels of parental stress are associated with poorer outcomes in early intervention

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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, Kliemann, Combes, & Frank, 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, Ethridge, & Aldana, 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, Ronan, & Signal, 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, Koren-Karie, Dolev, & Yirmiya, 2012); (b) Reflective Functioning, the capacity to understand behavior in the context of underlying mental states and intentions (Fonagy, Gergely, Jurist, & Target, 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, Cooper, Hoffman, Pow, & ell, 2002). It also reflects considerations from Functional Contextualism (Hayes, Strosahl, & Wilson, 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 behavior 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, Meredith, Ziviani, & Whittingham, 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, Hammond, Neville, & Connor, 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.

2. 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.

3. 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, Signal, Botros, Taylor, & Prentice, 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, Taylor, Prentice, McDade, & Burke, 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).

4. 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.

5. 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, Sung, Max, Shi, & Ong, 2012).

6. 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).

7. 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

Table 1
Overview of the phases

<u>Phase 1.</u> 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.
<u>Phase 2.</u> 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
<u>Phase 3.</u> 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.
<u>Phase 4.</u> 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.
<u>Phase 5.</u> 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.

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.

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

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.

8. 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., 2012), 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, Hungerford, Garcia, Graziano, and Bagner, (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 efficacy 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, Bailey, & Pearce, 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*

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

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

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 efficacy of PCRI-EI to address both stress and competency is supported by the increased scores in parents' sense of competency (PSOC).

9. 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.

CRedit authorship contribution statement

John Callanan: Conception and design, analysis and interpretation, writing, drafting and production. **Tania Signal:** Validation, writing and review, development of methodology, statistical analysis review. **Tina McAdie:** Validation, writing and review, development of methodology. Statistical analysis review.

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