

**Exploring Associations between Parent  
Involvement and Performance and Self Efficacy  
Outcomes in Children with Cerebral Palsy**

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## **Abstract**

**Background:** Although many professionals consider parental involvement to be an essential component of an intervention, little research has been carried out to examine this and the evidence that exists offers conflicting findings. Little research has been done on parent involvement and outcomes in children with Cerebral Palsy (CP).

**Purpose:** The goal of this study was to explore the degree to which parent involvement during and after a 12-session intervention is correlated with performance and self-efficacy outcomes in children with CP.

**Methods:** Data for this study were collected as part of a larger study which examined a new treatment approach for children aged 7 to 12 with CP. A total of 12 intervention sessions were provided. Child outcomes were measured using the Canadian Occupational Performance Measure (COPM), the Activity Scale for Kids (ASK), the Performance Quality Rating Scale (PQRS), and Self-efficacy Probe. Involvement was measured using a parent log book to track involvement between intervention sessions and a therapist log book to track involvement during intervention sessions.

**Results:** Higher parent involvement was associated with better performance outcomes but this finding was reversed at follow-up where more parent involvement was associated with poorer outcomes.

**Conclusion:** These results suggest that further investigation into the correlations between parent involvement and outcomes is warranted.

# Table of Contents

Abstract .....	iii
Table of Contents .....	iv
List of Tables .....	vi
<b>Chapter 1. Introduction .....</b>	<b>7</b>
1.1. Statement of the Problem .....	7
1.2. Background of the Study .....	7
1.3. Purpose of the Study .....	9
1.4. Research Questions .....	10
1.5. Definition of Terms .....	10
1.6. Organization of the Thesis .....	11
<b>Chapter 2. Literature Review .....</b>	<b>13</b>
2.1. Introduction .....	13
2.2. Cerebral Palsy .....	13
2.3. Parent involvement .....	14
2.4. Family Centered Care .....	15
2.5. Parental Involvement in Interventions .....	15
2.6. Parent Involvement and Children with Cerebral Palsy .....	16
<b>Chapter 3. Methodology .....</b>	<b>21</b>
3.1. Participating Sites .....	21
3.1.1. Participating Occupational Therapist .....	21
3.1.2. Child and Parent Participants .....	22
3.2. Instrumentation .....	22
3.2.1. Demographics and Sample Description .....	23
Child and Family Demographic Form .....	23
Gross Motor Function Classification System .....	23
Kaufman Brief Intelligence Test – 2 .....	23
3.2.2. Parental Involvement Measures .....	23
Parent Logs .....	23
Therapist Logs .....	24
Child Intervention Outcomes .....	24
The Canadian Occupational Performance Measure .....	24
The Performance Quality Rating Scale .....	25
The Activity Scale for Kids .....	25
Self-efficacy Probe .....	25
Data Collection .....	26
3.2.3. Intake .....	26
Pre-Intervention .....	27
Post-intervention .....	28
Follow-up .....	28
Data Analysis .....	28

<b>Chapter 4. Results .....</b>	<b>30</b>
4.1. Grouping of Data .....	30
4.2. Organization of Chapter .....	30
4.3. Descriptive Statistics of Participants.....	30
4.3.1. Children .....	30
4.3.2. Parents .....	31
4.4. Intervention Statistics .....	32
4.4.1. Parent Involvement Variables .....	32
4.4.2. Intervention Outcome Variables .....	34
4.4.3. Parent Involvement Variables by Intervention Group.....	36
4.5. Research Question 1 .....	36
4.6. Research Question 2.....	37
4.7. Research Question 3.....	41
<b>Chapter 5. Discussion .....</b>	<b>42</b>
5.1. Introduction.....	42
5.2. Parent Involvement and Child Outcomes .....	42
5.3. Recommendations for Further Research .....	46
5.4. Limitations .....	46
5.5. Conclusions .....	46
<b>Chapter 6. References .....</b>	<b>48</b>
Appendix .....	54
Appendix A .....	54
Appendix B .....	57
Appendix C .....	60
Appendix D .....	61
Appendix E .....	62
Appendix G .....	64
Appendix H .....	66
Appendix I.....	69

## List of Tables

Table 1	Summary of Measures.....	26
Table 2	Socio-demographic Profile of Children Participants.....	31
Table 3	Socio-demographic Profile of Parent Participant .....	32
Table 4	Parent Involvement Variables Summary.....	33
Table 5	Parents Self-Report of Perceived Contribution and Perceived Skill by Week.....	34
Table 6	Children Outcome Variables.....	35
Table 7	Parent Involvement Variables by Intervention Group .....	36
Table 8	Correlations for Parent Involvement Variables and Child Demographic Variables.....	38
Table 9	Correlations for Parent Involvement Variables and Parent Demographic variables .....	40
Table 10	Independent Samples t-test Between Intervention Groups and Parent Involvement Variables.....	41

# **Chapter 1. Introduction**

## **1.1. Statement of the Problem**

The contemporary emphasis in health care research is on evidence-based studies to improve client care and to use limited resources effectively (Novak et al., 2013). This trend is also seen in paediatric rehabilitation, where there have been several calls for empirical outcomes research (Law & Baum, 1998; Novak et al., 2013). Although many professionals consider parental involvement to be an essential component of an intervention, little research has been carried out to examine this (Brilli et al., 2014) and the evidence that exists offers conflicting findings. Little research has been done on parent involvement and outcomes in children with CP.

## **1.2. Background of the Study**

Data for this study were collected as part of a randomized control pilot study to examine the feasibility of conducting a large-scale trial of a new treatment approach for children with cerebral palsy (CP). The initial primary study by Cameron and colleagues (2016) was comprised of two groups of children with CP; those receiving the Cognitive Orientation to daily Occupational Performance (CO-OP) approach and those receiving the approach used in current usual practice (CUPA).

All children in the CO-OP group were able to learn the strategies and achieve their chosen goals, thus demonstrating the feasibility of the approach. Both approaches equally promoted skill acquisition and skill maintenance at follow-up. Effect sizes suggest that CO-OP may show some advantage for transfer and maintenance. One of the key features of the CO-OP approach is parent involvement (Polatajko & Mandich, 2004). Accordingly, as part of that primary study, data were collected not only on variables related to the children's performance but also on parent involvement. The present study examined those data. to

determine if parent intervention was correlated with performance and self-efficacy outcomes of the children.

Cerebral palsy (CP) is the most prevalent form of childhood physical disability, impacting about 2.5 of every 1,000 live term births and 22 of every 1,000 live premature births (Oskoui, Joseph, Dagenais, & Shevell, 2013). CP is a blanket term used to describe a group of permanent non-progressive neurological conditions that affect movement, posture and co-ordination. The presentation of CP is person dependent, but is likely to be associated with challenges in behaviour, communication, intellect, mobility, perception, proprioception, and sensation. As a result of these impairments, many children with CP face obstacles when engaging in activities of daily living (Kruijssen-Terpstra et al. 2015). Rehabilitation and intervention programs assume a vital role in improving the lives of children with CP (Wright & Majnemer, 2014).

Over the last decade, delivery of paediatric rehabilitation has shifted as service providers have embraced family-centered care (FCC) as the foundational approach (King & Chiarello, 2014; Brilli et al., 2014). The field has chosen a philosophical shift away from almost exclusively addressing the physical impairments underlying functional problems to adopting an approach that recognizes the needs of the family as a whole. In practice, FCC focuses on involving the whole family in ways that will improve child functioning, make the most out of the child's environment, expand their independence in daily activities, and maximize their ability to participate (King & Chiarello, 2014; Dodd, Saggars & Wildy, 2008). The ideologies promoted by FCC are now considered the gold standard of practice in the field of pediatric rehabilitation (Novak & Cusick, 2006).

The adoption of FCC philosophy by the field of rehabilitation has redefined the concept of parent involvement from a once passive role, to an active one (Bazyk, 1989; Dodd et al., 2008). Parents are now considered team members who guide the care to their child (Bazyk, 1989; King & Chiarello, 2014). Therapists report that working with parents optimizes the impact of intervention on children. Currently, however, the evidence addressing how and if parent involvement impacts intervention outcomes is highly debated in child rehabilitation literature (Conway, Johnson & Edgman Levitan, 2006).

Investigation of whether parent involvement affects treatment outcomes has occurred in a number of child rehabilitation areas including anxiety disorders (Brendel, 2011), child psychotherapy, linguistics (Bowen & Cupples, 2004), cognitive behavioural therapy in obsessive-compulsive disorder, and autism (Bennett, 2012). There exists a plethora of literature on parental involvement and its role in various types of therapeutic interventions across many paediatric disabilities. There are, however, discrepancies in the literature however about how parent involvement affects treatment outcomes. A meta-analysis of 48 studies by Dowell and Ogles (2010) on the effect of parent participation on child psychotherapy outcome compared individual child treatment to treatments that included parents found that youth who received parent-child interventions improved significantly more than those who received individual treatment ( $d = 0.27$ ). In contrast, a review by Thulin, Svirsky, Serlachius, Andersson, and Öst, (2014), that directly compared parent-involved treatments with child-only treatments in children with anxiety disorders reported a small, non-significant effect towards the child-only treatments ( $d = 0.10$ ).

In terms of parent involvement and children with CP specifically, there are few studies; many focus on parent's role in home programs. However, an extensive review of the literature found little empirical evidence about the relationship between parent involvement and the outcomes of intervention.

### **1.3. Purpose of the Study**

The purpose of this study was to explore the degree to which parent involvement during and after a 10-session intervention is correlated with performance and self-efficacy 1.4 outcomes in children with CP.



## 1.4 Research Questions

Is there a correlation between parent involvement and the observed child outcomes on the COPM, ASK, PQRS, self-efficacy after completing an intervention program?

1. Is there a correlation between the total number of days that parents spent in the intervention sessions (either observing or immediate post-intervention discussions with the therapist) and child outcomes?
  - a. Is there a correlation between the total amount of time (in minutes) parents spent in the intervention sessions (either observing or immediate post-intervention discussions with the therapist) and child outcomes?
  - b. Is there a correlation between the total number of days that parents were able to practice activities/ideas/exercises between intervention sessions and child outcomes?
  - c. Is there a correlation between the total amount of time (in minutes) parents were able to practice activities/ideas/exercises between intervention sessions and child outcomes?
  - d. Is there a correlation between the parents' perceived quality of the time they were able to review activities/ ideas/ exercises between-session and child participant outcomes?
2. Is there a correlation between parent involvement and demographic variables of either the parent or child participants?
3. Is there a difference in parent involvement measures between the specific intervention that the children received?

## 1.5 Definition of Terms

**Cerebral Palsy:** A general term for a group of permanent neurological (brain) injuries that affect an infant in the womb, during birth or in the months following birth. Cerebral palsy impacts communication between the brain and muscles and may cause limited motor skills, speech difficulties, learning disabilities or other problems (Carlson, 2005).

**CO-OP:** CO-OP is a client-centred, performance based, problem-solving approach created in response to the need for effective treatment interventions for children

who experience difficulty learning to perform new motor-based skills (Polatajko & Mandich, 2004).

**Current Usual Practice Approach:** In this study, this was defined as what the occupational therapist would usually do with a client with CP. (Cameron et al., 2016)

**Family-centered care:** Defined as a partnership approach to health care decision-making between the family and health care provider (King & Chiarello, 2014; Dodd et al., 2008).

**Parent:** In this study, parent was defined as any primary caretakers of the child participant – this could be parents or guardians, foster parents, adoptive parents, grandparents or other relatives.

**Parental Involvement:** In this study, parent involvement was defined as the number of minutes and number of days that parents spent either observing or participating in the interventions sessions or asking questions afterwards as well as the number of minutes and number of days that parents spent practicing activities/ideas/exercise between sessions.

**Primary Parent:** For the purposes of this study, the primary parent is the one who participated in the initial intake sessions and completed the demographic forms.

**Secondary Parent:** This was the partner of the primary parent.

## 1.6. Organization of the Thesis

This thesis is presented in five chapters. Chapter I includes the background of the study, statement of the problem, purpose of the study, significance of the study, definition of terms, and research questions.

**Chapter II** presents a review of the literature, which includes background on children with CP, family-centred care influences on intervention, parent involvement and pediatric rehabilitation, parent involvement and outcome intervention.

**Chapter III** describes the methodology used for this research study. It includes the selection of participants, instrumentation, data collection, and data analysis procedures.

**Chapter IV** presents the study's findings including demographic information, correlation matrix pertaining to each research question, and results of the data analyses for the three research questions.

**Chapter V** provides a summary of the entire study, discussion of the findings, implications of the findings for theory and practice, recommendations for further research, limitations of the study, and conclusions.

## **Chapter 2. Literature Review**

### **2.1. Introduction**

The current emphasis in health care research is on evidence-based studies to improve client care and to use limited resources effectively (Novak et al., 2013). This focus is also seen in paediatric rehabilitation, where there has been a suggested need for more outcomes research (Law & Baum, 1998; Novak et al., 2013). An area of research in pediatric rehabilitation that has importance for client outcomes and for the effective use of limited resources is the involvement of parents in their children's interventions. Many professionals consider parent involvement an essential component of an intervention (Brilli et al., 2014). The empirical evidence available regarding the relationship between parent involvement and intervention outcomes offers mixed results and there are few studies regarding parent involvement and outcomes for children with CP. In this chapter, a review of the available evidence is presented as an overview of parent involvement in children's intervention. An overview of cerebral palsy is presented, followed by a review of parent involvement. Next, a brief discussion of some studies on parent involvement and interventions more generally and finally a more detailed review of the literature on parent involvement and outcomes in children with CP.

### **2.2. Cerebral Palsy**

As mentioned in the introduction, cerebral palsy (CP) is the most prevalent disability in children in Canada, affecting 2 to 2.5 per 1000 children every year (Oskoui et al., 2013). CP is an umbrella term used to describe a group of motor impairments affecting body movement and co-ordination. It is a neurodevelopmental disorder, characterized by non-progressive anomalies of the brain that arise in the early stages of development (Carlson, 2005). Although CP is non-progressive, abnormal movements, altered posture, seizures, and medication may cause new physical and functional problems as children develop. In addition to motor impairment, children with CP often present with coexisting health conditions, including seizures related to epilepsy, hearing loss, swallowing restrictions, and difficulty with visual processing (Rosenbaum, 2007). Moreover, many

children may experience learning sensory impairments, have difficulties communicating and present with learning disabilities (Mayston, 2011).

There is no cure for cerebral palsy, but supportive treatments, medications, and surgery can help many children improve their physical functioning and ability to communicate with the world. Although the effects of CP vary widely among individuals, the symptoms associated with CP generally limit the ability to successfully perform many of the activities of everyday living, impacting both the children and their families (Rogers, 2005). Difficulties in physical functioning and movement may lead to challenges to independence and autonomy, and subsequently impact on quality-of-life (Mayston, 2011). Children with CP receive rehabilitation services aimed at improving function and quality of life.

### **2.3. Parent involvement**

Attitudes and beliefs regarding parent and family participation in intervention have changed significantly during the past few decades (Bazyk, 1989; Rosenbaum, King, Law, King & Evans, 1998; Novak, 2014). The field has seen a philosophical shift away from almost exclusively addressing the physical impairments underlying functional problems to adopting an approach that recognizes the importance of everyday function in the context of a family and the needs of the family as a whole (King & Chiarello, 2014; Brill et al., 2014). Historically many children with disabilities were institutionalized and parents were all but excluded from their care. In the more recent past, pediatric rehabilitation services for children were provided with a child centred focus, in which health professionals created goals that focused on bringing about changes in the child, separate from the family (Novak, 2014). Within these approaches, professionals were seen as experts. Initially, parents were expected to be passive recipients of therapy services rather than active participants (Bazyk, 1989). Most recently a more family-centered perspective has emerged. It is now recognized that parents must be involved in their children's care; that the children's needs must be addressed in the context of the family and its needs. Now, a family-centered philosophy pervades (King & Chiarello, 2014; Dodd et al., 2008).

## **2.4. Family Centered Care**

Family-centered care (King & Chiarello, 2014; Novak, 2014) has been put forward as a superior model of service provision, better equipped to meet the needs of the whole family. Over the last two decades, delivery of paediatric rehabilitation has shifted as service providers have embraced family-centered care (FCC) as the foundational approach (King & Chiarello, 2014). FCC is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families, and providers that recognizes the importance of the family in the patient's life. In pediatrics, FCC is based on the understanding that the family is the child's primary source of strength and support. Further, this approach to care recognizes that the perspectives and information provided by families, children, and young adults are essential components of high quality clinical decision-making, and that patients and family are integral partners within the health care team (King & Chiarello, 2014; Dodd et al., 2008; Novak, 2013). While family-centered care emphasizes the importance of parent involvement in the care of children with disabilities it does not specify the nature of that involvement in interventions.

## **2.5. Parental Involvement in Interventions**

The belief that parental involvement is a pivotal factor for improving performance outcomes (Whittingham, & Boyd, 2011) in children with disabilities has become increasingly widespread (Brendel, 2011; Bowen, Cupples, 2004; Bennett, 2012). Increasing or enhancing parental involvement is featured as a central component in major policies and reforms worldwide (Desforges & Abouchaar, 2003). Surveys of parents and professionals as well as scholarly writing have suggested that parental participation is crucial for improving performance in children with disabilities (Dowell & Ogles, 2010). Therapists promote parent involvement as a fundamental component of home based interventions (Mai, 2015; Novak, 2009). Therapists report that working with parents optimizes the impact of intervention on children (Whittingham & Boyd, 2011). As mentioned earlier, parent involvement is a key component of some interventions such as CO-OP with a belief that this involvement will impact on the generalization and transfer of skills gained during the intervention.

While the belief that there should be parental involvement in interventions is widely shared, the nature of that involvement is less clear. Numerous models of involvement exist, ranging from those where parents deliver the interventions to ones where parents support the intervention or those where parents are provided with more general education.

In this era of parent involvement, researchers in pediatric health care have been interested in exploring the effects that parental involvement has on intervention outcomes. Investigation of whether parent involvement affects treatment outcomes has occurred in a number of child rehabilitation areas including, anxiety disorders (Brendel, 2011), child psychotherapy, linguistics (Bowen, & Cupples, 2004), cognitive behavioural therapy in obsessive-compulsive disorder, and autism (Bennett, 2012). This has led to a number of articles on the role of parental involvement in various types of therapeutic interventions across many pediatric disabilities. However, there are discrepancies in the literature about the effects of parent involvement on treatment outcomes. For example, Dowell and Ogle's (2010) meta-analysis of 48 studies on the effect of parent participation on child psychotherapy outcome compared treatments that included parents to individual child treatment and found that youth who received parent-child interventions improved significantly more than those who received individual treatment ( $d = 0.27$ ). In contrast, a review by Thulin et al. (2014) reported a small, non-significant effect in favor of child-only treatments ( $d = 0.10$ ), when directly comparing parent-involved treatments with child-only treatments in children with anxiety disorders. The evidence regarding how and if parent involvement impacts intervention outcomes is highly debated in the child rehabilitation literature.

## **2.6. Parent Involvement and Children with Cerebral Palsy**

When the focus is narrowed to look specifically at studies which examined the relationship between parent involvement and outcomes in children with cerebral palsy, the literature is very small. In a review of the years 1980 to 1996, concerning parental involvement in intervention programs for children with cerebral palsy Ketelaar, Vermeer, Helders and Hart (1998) found only thirteen studies they noted that the literature at the time suffered from a number of issues including: lack of definition of parent involvement, poor design (no control groups), lack of standardized measures to assess outcome

measures and the use of both intervention programs and measured outcome variables that varied across all the studies. None-the-less, they concluded that all the studies (N=8) specifically designed to examine the effects of parental involvement had a positive effect on child-related outcome variables.

A recent systematic review on the efficacy of parent interventions for children with cerebral palsy by Whittingham et al. (2011), provides the latest summary of research in this area. The authors found three publications (Clawson, Kuchinski & Bach, 2007; Pennington, Thomson, James, Martin, McNally, 2009; and Tait, Sigafos, Woodyatt, O'Reilly & Lancioni, 2004).. The authors concluded that "in all of the studies reviewed, parenting intervention was associated with child behavioural change" (p. 479). Tait and colleagues (2004) provided evidence that the use of parent training of communication skills to children with CP increase performance outcomes. However, Pennington et al. (2009) did not have a control group so maturation effects cannot be ruled out and in Clawson et al. (2007) it is difficult to separate the parenting component from the other intervention that was also provided; it can be argued that there was both a parenting component and an intervention program involved in the study.

There are several studies of note that were not included in the above reviews or have been published since 2011. In 2007, Novak, Cusick and Lowe did a pilot study on the impact of an occupational therapy home program (OTHP) for young children with CP ages 2-7yrs involving 20 children. Parent involvement was measured using a home program log. Participants were asked to estimate the total amount of time per day (minutes) that they took part in home program activities (defined as giving therapeutic help). Although the OTHP intervention resulted in significantly higher outcomes for all of the independent variables, there was no correlation between the amount of parent involvement (defined as number of days and/or number of minutes) and functional outcomes.

In a follow up study Novak et al. (2009) assessed the effectiveness of an OTHP, compared with no OTHP, with respect to function and parent satisfaction with child function, participation, goal attainment, and quality of upper limb skill in school-aged children with cerebral palsy. Thirty- six children with a diagnosis of CP were equally (12



randomly assigned to either an OTHP group of 4 weeks, an OTHP group of 8 weeks or no home program. There were no specific guidelines for the OTHP, however they used a 5 step process (1) establishing collaborative relationships between parents and therapist; (2) setting mutually agreed-upon family and child goals; (3) selecting therapeutic activities that focus on achieving family goals and are supported by the best available evidence; (4) supporting parents through education, home visiting, and progress updates, to sustain motivation for program use; and (5) evaluating outcomes. Parents determined how frequently and for how long they would implement the home program. The average frequency for the 2 groups was taken and the halfway point was reported (17.5 times per month). The mean session length was 15.66 minutes (range: 5– 60 minutes) for the 4-week OTHP and 17.63 minutes (range: 4.28 – 40 minutes) for the 8-week OTHP. There was no significant difference in total implementation time between the intervention groups ( $P = .49$ ). Participants in both groups improved on all measures at 4-weeks, and significantly improved on all measures at 8-weeks, as compared to the control group. However, 9 participants within the 4-week group did not discontinue the program after 4-weeks, contrary to instruction, leaving only a few real data points in the 4-week treatment group. The integrity of the study was compromised by this continued participation.

A more recent longitudinal study by Bult et al. (2013) investigated which child, family and environmental variables measured at two- years of age predicted leisure participation in formal and informal activities in school aged children (6 years) with CP. The authors of the study did not provide any type of intervention to the participants in the study, although they specifically investigated family participation as a predictor variable. This type of study provides a unique insight into how family participation patterns relate on their own to an important aspect of life for a child with CP, such as leisure. A multivariable analysis was performed on the child, family and environment variables. The multivariate model analysis revealed that for child variables, gross motor function was predictive of later participation, explaining 17% of variance ( $R^2 = 0.17$ ,  $P < 0.05$ ) in formal activities and movement ability and social functioning of the child were most predictive, together explaining 62% of variance ( $R^2 = 0.62$ ,  $P < 0.001$ ) in informal activities. Family participation for both the formal and informal activities measured at age 2.5 years was predictive, explaining 12% of variance for formal activities ( $R^2 = 0.12$ ,  $P < 0.05$ ) and 25% for informal activities ( $R^2 = 0.25$ ,  $P < 0.05$ ). Type of daycare was the only significant

predictor of informal activities explaining 16% of variance ( $R^2 = 0.16$ ,  $P < 0.05$ ). To identify which predictors had the strongest association with leisure participation the authors constructed a model from the significant results from the previous analysis. In the final multivariable model for the formal activities, movement ability was the single strongest predictor of participation in leisure activities. This variable explained 17% of variance ( $R^2 = 0.17$ ,  $P < 0.05$ ). For the informal activities movement ability and social skills were the best overall predictors of participation. Together they explained 62% of variance ( $R^2 = 0.62$ ,  $P < 0.001$ ). Parent variables were no longer significant when the second measure was completed.

Whittingham, Sanders, McKinlay, and Boyd, (2016) conducted an randomized controlled trial (RCT) on parenting intervention with families of children with CP. The study combined two different interventions, the Stepping Stones Triple P (SSTP) and the Acceptance and Commitment Therapy (ACT), to examine the effects on child functioning, quality of life, and parental adjustment. The sample consisted of 67 parents (97.0% female) of children with a mean age 5.3 (SD =3). The three groups were wait-list control, SSTP, and SSTP + ACT. It was found that both the SSTP and SSTP + ACT group showed increased functional performance and quality of life as well as decreased parental psychological symptoms, when compared to the control group. Child outcomes on functional performance were measured by parent report. No differences were found in levels of parent confidence across groups.

A very recent study by Jackman, Novak, Lannin and Froude (2016) explored the experience of six parents of children with CP who participated in an intensive Cognitive Orientation to daily Occupational Performance (CO-OP) intervention. The CO-OP intervention group was run daily for one hour for ten days. It was mandatory that parents be at every session and that they be active participants although 'active' was not specifically defined. They were instructed to guide their children in the CO-OP process while their children practiced their own self-selected goals. Parents participated in semi-structured interviews conducted via phone that were approximately 30 minutes long. A grounded theory approach was used and the overarching themes of the parent experience were coded. One of the themes was benefits of CO-OP and highlighted the outcomes of the approach as perceived by the parents. Parents felt that CO-OP was a worthwhile

intervention that leads to achievement of goals involving upper limb function. They felt that the training had the capacity to be transferred to future goals or tasks their children wanted to explore. All parents perceived their children showed improvements in goals as a result of participation in CO-OP. Parents used words such as “amazing”, “beneficial”, “grateful”, “valuable” and “priceless” to describe involvement in the CO-OP program.

With a foundation laid by researchers such as Novak, Whittingham, Jackman and others, a previously neglected area of study— parent involvement and interventions of children with CP —has begun to garner attention from those who practice in pediatric rehabilitation. Each new study helps us to understand the role of parent involvement in this underserved population more. More evidence-based research is needed in this area using various combinations of parent and child intervention variables. Even with this new foundation, however, research specifically focused on if and how parent involvement in an intervention is associated with outcomes of children with CP is scarce. The present study aims to contribute knowledge to this literature.

## **Chapter 3. Methodology**

As noted in Chapter 1, the data for this study were collected as part of a larger pilot randomized controlled study conducted to examine the feasibility of using the Cognitive Orientation to daily Occupational Performance (CO-OP) approach to improve the performance of children with CP, and to estimate the effects of CO-OP when compared to a Current Usual Practice Approach (CUPA) (Cameron et al., 2016). As a key feature of CO-OP is parent involvement (Polatajko & Mandich, 2001), the primary study collected data regarding parent involvement. The goal of the study reported here was to explore how parent involvement, during and between ten sessions of intervention, correlates with performance and self-efficacy outcomes of children with CP. This chapter outlines the methods used to explore parent involvement. It is organized into the following sections: (a) participants, (b) instrumentation, (c) data collection, (d) data analysis and (e) summary. Refer to Cameron et al. (2016) for more details regarding the procedures for the randomized trial.

### **3.1. Participating Sites**

Two large children's rehabilitation centers, in the greater Toronto area were used for participant requirement. Both health-care facilities serve to an ethnically and diagnostically diverse populations of children with disabilities and their families.

#### **3.1.1. Participating Occupational Therapist**

Ten occupational therapists (OTs) participated in the primary study; all were hired specifically for this purpose. They carried out the interventions and collected some of the data including some of the parent involvement data used for this study. All individuals were qualified occupational therapists and had worked with children with cerebral palsy. All therapists were required to attend a general information session describing their role in the study and explaining study procedures and a further training session if using the CO-OP approach. For the Current Usual Practice Approach (CUPA), therapists were instructed to do what they would normally do with a child of this age and type with their

specific chosen goals. During the information session therapists were provided with a detailed overview of the study, and given an information package binder detailing their roles and responsibilities (See Appendix A). During this information session, OTs also reviewed the Toronto Police Services Guidelines for Safety during Home Visits as a reminder of home safety protocols.

### **3.1.2. Child and Parent Participants**

The data used for the present study were collected from eighteen children and their parents who participated in the primary study. The data came from all 18 children included in the study. All the children had a diagnosis of CP (hemiplegia or spastic diplegia); were between 7–12 years of age, had a Gross Motor Function Classification Scale [GMFCS; Palisano, Rosenbaum, Walter, Russell, Wood, & Galuppi, (1997)], level 1, 2 or 3; an IQ score > 84 on either the verbal or performance section of the Kaufman Brief Intelligence Test 2 [KBIT2; Kaufman & Kaufman, 2004]; normal or corrected to normal, hearing and vision; were able to communicate with and be understood during intervention; and provided child assent. None of the children had previously received, or were simultaneously receiving, a cognitive treatment for motor-based performance problems; used an alternative communication device; and/or regularly received Botox injections. There was a total of 36 parents involved in this study (two per child participant) and the primary contact parent gave written consent.

## **3.2. Instrumentation**

The data collected in the larger study that were used in this study included both child and parent participants' descriptive data, parent involvement data and child outcome data.

### **3.2.1. Demographics and Sample Description**

#### ***Child and Family Demographic Form***

Demographic and clinical profile data were collected through the use of an investigator-designed form titled the Child and Family Demographic Form (CFDF) developed by the research team of the larger study (Appendix B). The CFDF questionnaire consisted of 3 sections: (1) contact information, (2) background information of the child participant and, (3) background information of the parent(s).

#### ***Gross Motor Function Classification System***

The Gross Motor Function Classification System (GMFCS) (Palisano et al., 1997) identifies five levels of classification for cerebral palsy based on the child's motor performance and describes the degree of impairment in gross motor skills. The GMFCS is widely used with children with cerebral palsy and has excellent psychometric properties.

#### ***Kaufman Brief Intelligence Test – 2***

KBIT-2 is a revision of the initial Kaufman Brief Intelligence Test (Kaufman & Kaufman, 2004). It is used as a screening tool that measures two distinct cognitive functions: the verbal subtest contains two item types (verbal knowledge and riddles) that measure crystallized ability; the nonverbal subtest includes a matrices subtest that measures fluid reasoning. The KBIT-2 provides a good estimate of the range of a child's intellectual ability (average, above average).

### **3.2.2. Parental Involvement Measures**

Parent involvement data came from two sources, the parents themselves and therapist records.

#### ***Parent Logs***

The parent log-book (Appendix C), which was collected on a weekly basis, was used by parents to document the length of time they spent reviewing and or using activities/ideas/exercises with their child outside the intervention session that particular week. The log book also included two questions about the perceived quality of their

involvement (The Quality Scale), adapted from Law and King (1993). Each day of a given therapy week, parents were asked to record whether or not they spent therapy-related time with their children, and if yes, how much time in minutes. The Quality Scale was completed once per week and the parents answered two Likert-type questions regarding their agreement about whether they felt that they were skilled in carrying out the home program (0=strongly disagree to 4=strongly agree) and their agreement that the time spent practicing the activities/ideas/exercise contributed to their child's learning of those principles (0=strongly disagree to 4=strongly agree). As there were 10 intervention weeks, there were a maximum of 10 parent logs per child participant. The rationale to use a logbook as a measure of parent involvement is based on research that has found that parental ratings of their compliance in the home program correlated significantly with the number of days a logbook was used (Law & King, 1993).

### ***Therapist Logs***

The therapists completed a session summary in their log books (see Appendix D) following each week's intervention session. Therapist were asked to document the length of time (in minutes) that parents spent involved in their child's **treatment** during each session and/or how many minutes the parents spent asking questions following the **treatment** session.

### ***Child Intervention Outcomes***

Four child outcome measures were used the larger study. The data from all four measures were used in this study.

### ***The Canadian Occupational Performance Measure***

The COPM 5th edition (Law et al., 2014) is a semi-structured interview, which was designed as an outcome measure of occupational performance. The COPM is used to help clients identify performance problems in the areas of self care, productivity (school) and leisure. The COPM is a well established measure with strong psychometric properties. The COPM data used in this study were collected by having the child participants in the larger study identify 3 occupational issues and then having both child and parent participants rate their performance and satisfaction with performance, on a 10-

point scale at three points: pre and post intervention and at 4-month follow-up. In addition, parents picked two goals that were not focused on in the intervention sessions but were used to measure transfer and they rated their performance and satisfaction with performance on these two goals at pre and post intervention and at 4-month follow-up.

### ***The Performance Quality Rating Scale***

The Performance Quality Rating Scale (PQRS) (Polatajko & Mandich, 2004), is an video-based observational measure, that provides clinicians and researchers with a way to measure participants' actual performance on a specific task. The PQRS uses a retro-active behavioural observation approach using the videos of participants to measure the quality of a participants' performance of a specific task. The quality of a participants' ability to perform the specific task is rated using a 10-point scale. A value of 1 indicates that the client 'cannot perform the task at all' and a value of 10 indicates that the client 'can perform the task well'. A recent study (Martini et al., 2015) on the psychometric properties of the PQRS scoring found that test-retest reliability was substantial ( $ICC > 0.8$ ) and internal responsiveness was high. The inter-observer reliability for the primary study was high. See Cameron et al. (2016) for more details.

### ***The Activity Scale for Kids***

The Activity Scale for Kids (ASK) is a self-report measure used to assess physical function in children with chronic health disorders (Young, Williams, Yoshida & Wright, 2000). The ASK scale consists of two sections with each section represented by a separate booklet. The ASK capability (ASKc) measures physical activities of daily living the child could potentially do, and the ASK performance (ASKp) measures the same activities but asks what the child actually does. Participants are asked to answer the questions based on the previous week. Items are organized into seven domains (personal care, dressing, other skills, locomotion, play, standing, and transfers).

### ***Self-efficacy Probe***

The Self-Efficacy Probe developed by Mendes & Polatajko (2004) uses a frequency count framework for quantifying self-efficacy by tracking the number of positive and negative self-statements a participant uses while they complete a specific task. The



measure (see Appendix E) is organized into 5 categories: (1) child comments on his or her capability, (2) child comments on the ease/difficulty of the task, (3) child comments on future performance (4) child comments on the knowledge of own skills and (5) child comments on needing or attempts to increase or decrease challenge. The inter-observer agreement reported for the data used in this study was study was 87% (Cameron et al., 2016).

### **Data Collection**

Data for the current analyses were sourced from all four phases of the larger study (1) intake, (2) pre-intervention, (3) post-intervention, and (4) 4-month follow-up. A summary of the data collection procedure detailed in Cameron et al. (2016) is provided below. A flow chart of data collection procedures is also provided to indicate the measure and from what phases of the larger study they were derived (Table 1).

**Table 1 Summary of Measures**

<b>Measures</b>	<b>Intake</b>	<b>Pre-intervention</b>	<b>Post-intervention</b>	<b>Intervention Follow-up</b>
<b>Demographic</b>				
CFDF	XX			
GMFCS	XX			
K-BIT	XX			
<b>Parent Involvement</b>				
Therapist Logs		XX	XX	XX
Parent Logs		XX	XX	XX
<b>Child Intervention Outcomes</b>				
COPM Child		XX	XX	XX
PQRS		XX	XX	XX
ASK		XX	XX	XX
Self-efficacy Probe		XX	XX	XX
COPM Parent Transfer		XX	XX	XX

*Note.* CFDF=Child and Family Demographic Form; GMFC= Gross Motor Function Classification System; K-BIT= Kaufman Brief Intelligence Test (2nd edition); COPM=Canadian Occupational Performance Measure; PQRS=Performance Quality Rating Scale; ASK=Activities Scale for Kids.

### **3.2.3. Intake**

The intake data used in this study were collected during the in person intake assessment conducted by the research coordinator (RC), and included both the child and parent(s) participants. The RC administered both The Kauffman Brief Intelligence Test –

2 (KBIT-2) and recorded the child participant's Gross Motor Function Classification System (GMFCS) score to verify that the child participant met the inclusion criteria. Once a child participant qualified for the study, the RC verbally reviewed the consent and assent forms with the parent and the child participants respectively. Once consent was confirmed by all involved, the RC provided the parent(s) with the demographic information form, the daily activity log (see Appendix F), and the ASK booklet #1 and the contact information for their assigned OT, who would later facilitate the intervention sessions. Once inclusion criteria were met, participants were randomly assigned to treatment group by the RC who drew their assignment from an envelope.

### ***Pre-Intervention***

Scheduling the start of the intervention sessions with the therapist was collaboratively decided among the child and their families and the OT, independent from the RC. Children participants were assigned to receive either CO-OP or a CUPA intervention program. Both the CO-OP and CUPA intervention programs followed different treatment protocols, as can be seen in Appendix G. However, each group received twelve, sixty-minute individualized sessions (ten interventions and one pre and post session), at the rate of one or two a week, by a certified OT. A detailed account of the therapist responsibilities for each session is detailed in the Therapist Tracking Sheet (Appendix H).

During the pre-intervention session child participants used the COPM to help identify three skills that, (a) they needed to do, (b) they wanted to do, or (c) were expected to know how to do (e.g. bike riding, handwriting, dressing). The three skills selected by the children participants became the intervention target skills. Parent participants were asked to identify two additional performance tasks they would like the child to improve on. The two performance tasks selected by the parent participants were used to explore transfer of the intervention to other tasks. Although the therapists were privy to the parent chosen tasks, they did not specifically address them during the intervention sessions. The child participants were not made aware of their parent(s) selected tasks. The COPM was administered independently to both the child and parent participants and they were each asked to score performance and satisfaction with performance for the three child chosen goals. The parents were also asked to score the two parent transfer goals for both performance and satisfaction with performance. Subsequently, baseline PQRS data was

established by having the child participant perform each of the three target skills while being videotaped and having the videotapes rated at a later date by a research assistant.

### ***Post-intervention***

The post intervention data used in this study were collected during the post intervention session, upon completion of the 10 intervention session. The COPM was re-administered independently to both the child and parent participants for the three child chosen participant target skills and then the parents rated the two parent selected tasks. The children also performed each of the three target skills while being videotaped for later PQRS ratings. The therapist then provided parents with ASK #2 booklets, which were then completed and mailed back to the RC. All child participants received a personalized certificate in recognition of their participation in the study. Once the RC received the ASK #2 booklets, the ASK #3 was mailed out to the parent participants with the instruction to have them completed by the scheduled 4-month follow-up appointment with the RC.

### ***Follow-up***

The follow-up data used in this study were collected by the RC who arranged a 4-month follow-up appointment, where the COPM was re-administered independently to both the child and parent participants for the three child participant target skills and two parent transfer tasks. As well, the child performed each of the three target skills while being videotaped again for later PQRS ratings. Finally, the RC collected the ASK #3 booklets.

### ***Data Analysis***

This study was exploratory in nature, designed to explore the correlations between parent involvement and (1) intervention performance and self-efficacy outcomes, (2) socio-demographic characteristics, and (3) intervention type. Data were analyzed using the Statistical Package for Social Sciences (SPSS 23.0 for Mac) software program. Initially all data were coded and entered into a data file. Data were then cleaned to detect any errors in data entry and to identify any outliers prior to running data analysis. Descriptive statistics were run to generate summary profiles for both child and parent participants. Independent two samples t-tests were used to examine differences between intervention

type (CO-OP or CUPA) and parent involvement variables. Pearson's product moment correlation coefficient ( $r$ ) or the Spearman rank order correlation coefficient ( $r_s$ ) was used to estimate correlations between parametric and non-parametric variables, respectively.

A total of 7% of the data points were missing from the child participant outcome data (PQRS, COPM-C, COPM-P, COPM-T, ASK). These missing data points were replaced using the Missing Completely at Random (MCAR) data method. The MCAR is a validated computational method that can be employed through SPSS to input missing data points considered missing completely at random. In order to use the MCAR method the data set must first pass a computational analysis within SPSS to verify that there is no systematic underlying process (except for random variation) as to why data points are missing for any of the given variables missing data points.

## **Chapter 4. Results**

### **4.1. Grouping of Data**

As reported by Cameron and colleagues (2016), there were no significant group differences on the outcome measures for the children receiving the CO-OP when compared to those receiving Current Usual Practice Approach (CUPA). Accordingly, the decision was made that for the purposes of this study the outcome data for the child participants from the two intervention groups would be grouped for research question 1 and 2. For question 3, however, the data was separated by intervention into CO-OP and CUPA to explore if there was a difference in parent involvement data between intervention groups as no analysis re: parent involvement data was completed previously.

### **4.2. Organization of Chapter**

This chapter presents the results of the data analysis arranged in three sections. The first section presents a descriptive profile of study participants. Section two presents summary statistics of both parent involvement and outcomes variables. Section three presents a correlation matrix to answer the first two research questions and relevant tests of differences for the third research question.

### **4.3. Descriptive Statistics of Participants**

#### **4.3.1. Children**

The Child and Family Demographic Form was used to gather demographic and clinical profile information for both the child and parent participants. Table 2 provides the descriptive statistics mean and standard deviation(SD) of demographic variables for all child participants (N=18), age, gender, diagnosis, measured intelligence (IQ), and Gross Motor Functional Classification Scale (GMFCS) level. The descriptive statistics of all demographic variables for child participants when divided into intervention groups CO-OP and CUPA) is also provided in Table 2. As reported in the primary study by Cameron et al

(2016), no differences were found between the two groups for any of the demographic/intake variables between groups.

**Table 2**      **Socio-demographic Profile of Children Participants**

Children Demographics	Intervention		Total Group (N%)
	CO-OP (N, %)	CUPA (N, %)	
<b>N</b>	9	9	18
Age (M, SD)	9.84 (2.2)	9.45 (1.4)	9.64 (1.7)
Years of Education (M, SD)	4.3 (1.9)	3.9 (1.4)	4.0 (1.5)
KBIT-2 (M, SD)	97.7 (14.5)	92.8 (13.7)	95.2 (13.9)
<b>Gender</b>			
Female	3 (33.3)	2 (22.2)	5 (27.7)
Male	6 (66.7)	7 (77.8)	13 (72.2)
<b>Primary Diagnoses</b>			
Spastic Diplegia	2 (22.2)	3 (33.3)	5 (27.7)
Hemiplegia	6 (66.7)	6 (66.7)	12 (66.6)
Ataxic	1 (11.1)	0 (0.0)	1 (5.5)
<b>GMFCS</b>			
I	6 (66.7)	5 (45.5)	11 (61.1)
II	2 (22.2)	2 (22.2)	4 (22.2)
III	1 (11.1)	2 (22.2)	3 (16.6)

Note. CUPA, current usual practice; CO-OP, Cognitive Orientation to daily Occupational Performance; KBIT, Kaufman Brief Intelligence Test; M, Mean; SD, standard deviation \* p < .05 \*\* p < .01 \*\*\* p < .001.

### 4.3.2. Parents

Each child participant had two parents involved in the study. In each case one parent was the primary participant, labelled as primary parent (N=18) for the purposes of the study, the other was labelled secondary parent (N=18). Table 3 provides descriptive statistics for both the parent participants as a group (N=36) as well as for the primary parent group and secondary parent group separately on the demographic variables, gender, education level achieved, employment status and language. The data for the parent participants are also provided by intervention groups (CO-OP = 18; CUPA=18). No significant difference was found between groups for any of the demographic variables.

**Table 3          Socio-demographic Profile of Parent Participant**

<b>Parent Demographics</b>	<b>Primary Parent</b>	<b>Secondary Parent</b>	<b>Parent (Pairs)</b>
<b>Gender</b>			
Female	17	1	1
Male	1	17	17
<b>Highest Level of Education Achieved</b>			
Elementary School (Grades 1-8)	0	0	0
High school (Grades 12 or 13)	4	5	5
College or Technical Training	8	6	6
University Degree	2	4	4
Graduate University Degree(s)	4	3	3
<b>Employment Status</b>			
Working	11	17	17
Not working	7	1	1
<b>Language</b>			
English	13	13	13
Other	5	5	5

## **4.4. Intervention Statistics**

### **4.4.1. Parent Involvement Variables**

Table 4 provides the means and SD on the parent involvement variables, total amount of time parents participated in session, total percentage of days that parents participated in session, total amount of time parents practiced out of session, and total number of days that parents practiced out of session for each of the parent pairs (N=18). The number of submitted parent logs and therapist logs is also provided. Important to note is the large number of un-submitted weekly parent logs. Two pairs of parents did not submit any logs. These participants were not excluded from the study because other parent involvement data were obtained from the therapist logs for those participants.

**Table 4 Parent Involvement Variables Summary**

Parent (s)	Parent Involvement Variables				Logs Completed	
	Total Amount of Time Parents Practiced In Session	Total Percentage of Days Parent Practiced In Session	Total Amount of Time Parents Practiced Out Session	Total Number of Days Parent Practiced Out Session	Therapy Logs	Parent Logs
P1	620	100	430	26	11	5
P2	635	100	525	29	11	9
P3	280	75	191	19	12	5
P4	560	100	380	27	12	5
P5	460	100	500	55	11	9
P6	600	100	35	6	10	2
P7	595	100	1325	36	12	9
P8	620	100	400	10	12	3
P9	70	100	69	13	10	6
P10	660	85	437	41	12	10
P11	320	91	0	0	11	0
P12	645	100	1925	63	11	11
P13	230	100	225	6	12	1
P14	265	100	500	18	10	9
P15	280	100	187	27	10	5
P16	80	91	138	32	11	11
P17	25	44	0	0	10	0
P18	197	100	230	18	10	9
<b>Mean</b>	<b>396.8</b>	<b>90</b>	<b>416.5</b>	<b>23.7</b>	<b>11</b>	<b>6.1</b>
<b>SD</b>	<b>225.2</b>	<b>10</b>	<b>484.7</b>	<b>17.6</b>	<b>0.84</b>	<b>3.7</b>
<b>Min -Max</b>	<b>25 to 660</b>	<b>44 to 100</b>	<b>0 to 1925</b>	<b>0 to 63</b>	<b>10 to 12</b>	<b>0 to 11</b>

Table 5 shows the parent pairs' self-reported data for each of the sub-scale questions (perceived skill, and perceived contribution) in a timeline that spans the duration of the intervention program. Visual inspection of the self-reported scales reveals little to no change in the scores over time.



**Table 5 Parents Self-Report of Perceived Contribution and Perceived Skill by Week**

Week Number		Parent Participant														
		P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	P15
1	C	4							4	2						
	S	4							4	2						
2	C	2			3				5	4	5	5				
	S	4			3				5	4	5	5				
3	C		4			3	1	5	4		5	4		5		4
	S		4			2	1	5	4		5	4		5		4
4	C	4	4		4	3	1	5			5	4		5		
	S	4	3		4	2	1	5			5	4		5		
5	C	5	4			2		5		2	5	4		4		
	S	5	2			2		5		3	5	4		4		
6	C		4	4		2		5		3	5	4		4		5
	S		4	4		2		5		5	5	4		4		5
7	C	4	1	3	4	3		5		4	5	4		4		5
	S	4	1	3	4	3		5		5	5	4		4		5
8	C		1	4	5	3		5		3	5	4		4		5
	S		1	4	5	3		5		5	5	4		4		5
9	C	4	4	4	4	3		4		3	5	3		4		5
	S	4	4	4	4	3		4		5	5	3		4		5
10	C	4		3	4	3		4		5	5	4		4		5
	S	4		3	5	3		4		5	5	4		4		5
11	C							4			4					
	S							4			4					

Note. C = Contribution; S = Skill

#### 4.4.2. Intervention Outcome Variables

Table 6 provides the means and SDs for change scores from baseline to post intervention (T2-T1) and post-intervention to 4-month follow-up (T3-T2) for all the intervention outcome variable

**Table 6 Children Outcome Variables**

	<b>Outcomes</b>							
	<b>COPM</b>				<b>ASK</b>			
	<b>Performance</b>		<b>Satisfaction</b>		<b>Capability</b>		<b>Performance</b>	
	Change 1-2	Change 2-3	Change 1-2	Change 2-3	Change 1-2	Change 2-3	Change 1-2	Change 2-3
Mean (SD)	4.3 (1.6)	0 (1)	4.5 (2)	-0.5 (1.1)	9.3 (20.1)	-0.1 (2.7)	13 (19.4)	0.7 (3.2)
Min-Max	1.7 to 8.7	-2.3 to 1.7	1.3 to 8	-3 to 2	-4 to 85.2	-5.3 to 6.8	-5.9 to 80.9	-6.6 to 7.5
	<b>COPM Scores (Parent)</b>							
	<b>Child-selected Goals</b>				<b>Parent-selected Goals</b>			
	<b>Performance</b>		<b>Satisfaction</b>		<b>Performance</b>		<b>Satisfaction</b>	
	Change 1-2	Change 2-3	Change 1-2	Change 2-3	Change 1-2	Change 2-3	Change 1-2	Change 2-3
Mean (SD)	4.5 (2.5)	0.1 (1.4)	4.3 (2.3)	-0.2 (1.6)	3 (2.3)	-0.3 (1.6)	2.8 (2.4)	-0.2 (1.7)
Min-Max	0 to 8	-2 to 3.3	0.3 to 8.7	-2.7 to 3.3	0 to 9	-2.5 to 3.5	-0.5 to 9	-5 to 2.5
	<b>Self-Efficacy</b>							
	<b>PQRS</b>		<b>Number of Self-statements</b>					
			<b>Positive</b>		<b>Negative</b>			
	Change 1-2	Change 2-3	Change 1-2	Change 2-3	Change 1-2	Change 2-3		
Mean (SD)	4.1 (1.8)	-0.3 (1.0)	3.1 (4.2)	-2.9 (5.0)	-2.6 (4.8)	-0.9 (2.8)		
Min-Max	0 to 6.3	-2.7 to 1.7	-2 to 13	-16 to 4	-14 to 4	-8 to 3		

### 4.4.3. Parent Involvement Variables by Intervention Group

Table 7 provides the mean, SD and range of all parent involvement variables including total amount of time parents participated in session, total percentage of days parent participated in session, total amount of time parents practiced out of session, total number of days parent practiced out of session, the number of submitted parent logs, and self-reported data for each of the sub-scale questions, perceived skill, and perceived contribution, by intervention group their child was allotted to (CO-OP = 18 and CUPA=18).

**Table 7 Parent Involvement Variables by Intervention Group**

Intervention Group	Parent Involvement Variables					
	Total Amount of Time Parents Practiced In Session	Total Percentage of Days Parent Practiced In Session	Total Amount of Time Parents Practiced Out Session	Total Number of Days Parent Practiced Out Session	Therapy Logs	Parent Logs
<b>CO-OP</b>						
(M, SD)	493 (195)	97% (.8)	428 (381)	25(15)	11 (1)	6 (5)
MIN - Max	70 (635)	75%- 100%	35 -1325	6-55	10 - 12	2-9
<b>CUPA</b>						
(M, SD)	300 (220)	90 (18)	404 (594)	23 (21)	10 (2)	6 (5)
MIN - Max	25 - 660	44 -100	0 - 1925	0 -63	10 -13	0-11

Note. Min = Minimum; Max = Maximum; SD = Standard Deviation; M = Mean

## 4.5. Research Question 1

Is there a correlation between parent involvement and the observed child outcomes on the COPM, ASK, PQRS, self-efficacy after completing an intervention program?

A correlation analysis Person  $r$  correlation was used to explore the correlations between all parent involvement variables and the intervention change scores of all child participants on primary outcomes measures (COPM, ASK, PQRS, self-efficacy) at both post intervention (T2-T1) and 4-month follow-up (T3-T2). The results of all these correlations can be found in are shown in Appendix I.

The total amount of time parents participated in session was negatively associated with the follow-up (T3-T2) change in COPM Performance parent transfer goals (the two goals identified by parents but not treated during intervention)  $r = -.52$ ,  $p = .001$ . The ASK Capability change score at 4-month follow (T3-T2) up was also negatively associated  $r = -.52$ ,  $p = .05$ . At post intervention change (T2-T1), parents' COPM satisfaction rating for two transfer goals was negatively associated with the total number of days that parents practiced outside of therapy sessions  $r = -.48$ ,  $p = .05$ . One of the most interesting findings of the study was that the total number of days that parents practiced out session was positively correlated with higher PQRS scores post intervention change scores (T2-T1),  $r = -.59$ ,  $p = .01$ . but was negatively correlated with PQRS 4-month follow-up change scores (T3-T2)  $r = -.61$ ,  $p = .05$ . Moreover, the amount of time parents spent with their children practicing outside the intervention session, followed the same trend of being positively correlated with post intervention change scores,  $r = .41$ ,  $p = .09$  (approaching significance) and significantly negatively correlated with follow-up change scores  $r = -.49$ ,  $p = .05$ .

## **4.6. Research Question 2**

Is there a correlation between parent involvement and demographic variables of either the parent or child participants?

A correlation analysis Person  $r$  or Spearman  $\rho$  correlation was used to explore the associations between all parent involvement variables and demographic variables of both child and parent participants. The results are displayed in Table 8 (child demographics) and Table 9 (parent demographics). None of the demographic variables were found to be correlated with parent involvement variables.

**Table 8 Correlations for Parent Involvement Variables and Child Demographic Variables.**

Measure	AGE	Gender	Diagnosis	Education	KBIT	GMFCS
Total Amount of Time Parents Practiced In Session	0.238	-0.168	-0.304	0.357	-0.072	0.209
Total Percentage of Days Parent Practiced In Session	0.016	0.075	-0.01	0.124	0.326	0.033
Total Number of Days Parent Practiced Out Session	0.218	-0.216	-0.191	0.256	-0.197	0.048
Total Amount of Time Parents Practiced Out Session	0.124	0.193	-0.168	0.297	-0.109	-0.041
Parents self report of perceived skill	0.014	0.351	0.235	0.2	-0.466	0
Parents self-report of perceived contribution	0.097	0.279	0.213	0.241	-0.437	-0.067



**Table 9 Correlations for Parent Involvement Variables and Parent Demographic variables**

Measure	Parent_1	Parent_2	Parent_1_ED	Parent_2_ED	Parent_1 _EMPLOY	Parent_2_E MPLOY
Total Amount of Time Parents Practiced In Session	-0.146	0.146	0.235	0.018	-0.181	0.351
Total Percentage of Days Parent Practiced In Session	0.111	-0.111	0.332	0.253	0.295	0.047
Total Number of Days Parent Practiced Out Session	-0.081	0.081	0.006	0.155	-0.049	-0.118
Total Amount of Time Parents Practiced Out Session	0.043	-0.043	-0.011	-0.229	-0.24	0.143
Parents self report of perceived skill	0.095	-0.095	0.674	-0.252	0.05	0.674
Parents self- report of perceived contribution	0.119	-0.119	0.674	-0.278	-0.003	0.674

### 4.7. Research Question 3

Is there a difference in parent involvement measures between the specific intervention that the children received?

For the purpose of this question, data were separated into the two intervention groups. An Independent Samples t -Test was used. There was no significant difference between the CO-OP and CUPA intervention groups in terms of percentage of days that parents practiced in session time between CO-OP and CUPA intervention groups, total amount of days practiced out of session, total amount of time parents practiced out session or the total amount of time parents practiced in session (See table 10). However, the in-session time approached significance ( $p=0.1$ ,  $d=1.34$ ) and a visual inspection suggests the numbers seem quite different.

**Table 10** Independent Samples t-test Between Intervention Groups and Parent Involvement Variables

Parent Involvement	t-test	df	p
In Session Time	1.9	8	0.1
Out Session Time	0.09	8	0.93
In Session Days	1.7	8	0.09
Out of Session Days	0.21	8	0.84

Note: CUPA, current usual practice; CO-OP, Cognitive Orientation to daily Occupational Performance; M, Mean; SD, standard deviation

\*  $p < .05$  \*\*  $p < .01$  \*\*\*  $p < .001$ .



## **Chapter 5. Discussion**

### **5.1. Introduction**

Chapter V consists of a summary of the study, discussion of the findings, implications for practice, recommendations for further research, limitation and conclusions. The purpose of the discussion is to expand upon the concepts that were studied in an effort to provide a further understanding of their possible influence on intervention outcomes as they are related to children with CP, and to present suggestions for further research targeting the limitation uncovered from both the previous research and the current thesis. Finally, a synthesizing statement is offered to capture the substance and scope of what has been attempted in this research.

### **5.2. Parent Involvement and Child Outcomes**

Overall, six outcome variables were associated with parent involvement variables and one was trending towards significance. Associations found in both the parent and child self-reported outcomes are summarized followed by the objective assessor-rated outcomes, the demographic variables and the intervention type.

At post-intervention, only one outcome was associated with parent involvement. Specifically, the parents who spent more days practicing with their children outside of therapy sessions rated their satisfaction of their child's two untreated goals after intervention lower. At the four-month follow-up, parent involvement was found to be significantly negatively correlated with two outcome variables, one reported by parents and one by the child participants. The parents who spent more time observing or participating in intervention sessions rated the performance of their children's two untreated goals lower. Similarly, the children of the parents who spent more time in intervention sessions reported lower scores on the ASK-p which measures physical activities of daily living that children said they could potentially do. In contrast, in terms of the PQRS scores (an objective scoring of performance done by an individual blind to timing or treatment allocation), higher performance change scores after the intervention

were positively correlated with both the number of days and the number of minutes' parents spent practicing outside of therapy sessions. Interestingly however, higher performance change scores from post-intervention to four-month follow-up were observed to be negatively associated with more parent involvement. None of the parent involvement variables were associated with demographic variables of either the parent or child participants. Regarding the relationship between type of intervention and outcomes, there was no significant difference in parent involvement between and the specific intervention that the children received. However, the CO-OP intervention group were found to spend almost twice the amount of time in session than parents whose child received in the CUPA intervention and this result was approaching significance.

As mentioned above, parental involvement was significantly correlated with child outcomes at the end of intervention as measured by the PQRS. This finding is consistent with existing literature which suggests that parent involvement has a positive effect on outcome. However, this positive correlation did not hold up for the post-intervention to 4-month follow-up time period, for which a negative correlation between parent involvement and child outcomes was found on the PQRS. Based on the exploratory nature of this study, it is not possible to fully interpret these mixed findings. One could speculate that increased involvement decreases the child's independence as has been discussed in some literature. However, in this study there are insufficient data available to support or refute such an explanation. What this study does support is the need for further investigations. The results here indicate that it would be interesting to examine child and parent psychology theories that explore what happens when parents rescue too quickly or provide children with too much assistance thereby removing the need for them to navigate hardships and solve problems on their own. It is possible that the higher levels of parent involvement seen during the intervention phase were not maintained during the follow up period. Unfortunately, these data were not collected. It is also possible that terminating the intervention led to the drop off in scores although a significant drop off from post intervention to follow up in PQRS scores was not seen in the primary study.

An examination of the average number of days of practice and average number of minutes of practice spent by parents in between sessions in this study offers an interesting comparison to the findings outlined in the Novak et al. (2009) paper. Significant functional

changes, and parent satisfaction of that function, as well as, quality of upper limb skills were found when a home program (which included goal setting, parent education and home program) was implemented at an average frequency of 17.5 times per month for 16.5 min per session in children with CP. Interestingly when comparing our recent results to Novak's we found very similar conclusions. Our total number of minutes and days were 17.1 times per month for an average of 13.5 minutes per sessions (this was parent and therapist time combined).

As discussed in the results, there was no significant difference in the parent involvement seen between the CO-OP and CUPA. However, the CO-OP group did spend almost twice as much time as the CUPA group which did approach significance. The difference in in-session minutes between the intervention groups is interesting, as it relates to previous research indicating that that certain types of intervention programs lend themselves more to parent involvement. For example, Jackman (2016) found CO-OP to be a promising intervention approach that is conducive to increasing parent involvement. Investigating interventions and how they a) get parents involved and b) encourage parents to be involved in different ways, might help contribute to an understanding of the effects of parent involvement.

It is interesting to note that the more recent studies including our own reflect the current philosophy of FCC. The studies by Novak (2007;2009) specifically identified FCC as guiding their programs and had the clients specifically chose their own goals for intervention as was done in our study. In Whittingham et al. (2016) their intervention (Stepping Stones Triple-P) also utilized FCC in its design. The older studies did not reflect this approach. All of the more recent studies of parent involvement and children with CP, from 2004 and beyond have collected information on demographic variables from both the parent and child participants. A glaring demographic variable consistent across most is the ratio of female to male parents being represented in the studies. This was again reflected in the current thesis with a dramatic 17 to 1 ratio of mother as the primary parent.

Surprisingly none of the previous literature has found any consistent association of sociodemographic variables to parent involvement. Specifically, Bult et al., (2012) provided an in-depth look at a number of sociodemographic variables but found no

association. This is in direct contrast to literature pertaining to parent involvement and academic outcomes. Although, not a predictor, but an interesting consistent finding in the child participant demographic research is the use of the GMFCS as a standardized assessment tool. This simple and yet very sound measure allows for some consistency in the CP population that is very inconsistent in terms of its presentation of symptoms.

Although many professionals consider parental involvement to be an essential component of an intervention, there have been only a limited number of studies in the past 35 years that examine how it impacts outcomes for children with CP. The lack of research in this area seems surprising in light of the current emphasis in pediatric rehabilitation on FCC and evidence based practice. The purpose of the current thesis study was to explore if the involvement of parents during an intervention showed any correlation to outcomes for this population. The study used a variety of ways of quantifying parent involvement and a number of outcome measures. This allowed for an exploration of the association between parent involvement and outcomes

Despite the number of studies which claim to examine 'parental involvement', the existing body of pediatric rehabilitation research presents many issues. Firstly, the inconsistencies in the definition of 'parental involvement' used across studies means that any claims about 'parental involvement' must be interpreted with caution. Twenty years ago, Georgiou (1997) referred to the empirical literature on parental involvement and indicated that there appeared to be a lack of consistency about the operationalization and measurement of parent involvement. There were thought to be at least two reasons for this; one having to do with the concept's complexity and the second being the confusion that has been generated amongst the authorities in the area because of the lack of a clear definition. Presently, this situation still seems to exist. The conflicting findings in the parent involvement literature may be influenced by the grouping of all the outcome variables i.e. behavioural (Whittingham et al. 2016) performance (Novak 2007 and 2009) leisure (Bult et al, 2012) cognitive (Jackman et al., 2016), functional (Tait et al. 2004), motor (Clawson et al., 2007), communication (Pennington et al., 2009), social (Gross et al., 1982).

Another issue is the lack of parent involvement studies using experimental designs. The vast majority of studies conducted in this area including ours have been

correlational in nature and thus our ability to infer causal relationships about parental involvement and therapy outcomes is limited. The review of the literature in Chapter 2 illustrates the need for high-quality studies that examine the types of parent involvement and how these might impact on outcomes. Well-controlled single-case experimental design studies, such as Tait et al. (2004), could also provide valuable evidence as to the potential effects of parental involvement for children with CP.

### **5.3. Recommendations for Further Research**

Future studies should provide a specific definition of parent involvement. Varying levels of parental involvement within an intervention protocol would make it possible to compare the possible beneficial treatments effects of several degrees of parental involvement within one intervention protocol.

### **5.4. Limitations**

Some of the measures of parent involvement used in this study were self-report measures. This heavily relied on the assumption that parents would accurately document their involvement as well as submit the parent logs, which was not always the case. Other limitations of this were lack of a control group and limited sample size. A lack of a direct parent involvement measure and a more structured definition of the parents' role in and out of the therapy session are also limitations.

### **5.5. Conclusions**

The findings of this study expanded the work of previous researchers in the area of parent involvement and outcomes for children with CP. As so many children have CP, it is unfortunate that so little research exists. As children and families often wait months for therapy, providing them with the best and most efficient care is imperative. Parents play a key role in the lives of their children and this study suggests that a careful examination of the role they play in the outcomes of intervention for their children warrants

careful study. The unexpected findings in this study suggest that it is important to find out what, how, when, where, and with whom parent involvement in interventions can be optimized.

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# Appendix

## Appendix A

## Study Procedures

1. Children will be recruited from either Bloorview Kids Rehab or Erinoak. Once families are identified, the Research Coordinator (RC) will contact the family by phone to conduct an initial screen for intake prerequisites and will provide an initial overview of the study. An appointment will be made for the RC to administer the intake assessments (KBIT-2, GMFCS).
2. Intake documents will be mailed to the parent/ caregiver (i.e., letter of information for parent and child with consent forms, demographic information form, daily activity log, ASK).
3. At the intake assessment visit, the RC will obtain informed consent for participation and videotaping and will collect demographic information forms and the ASK (note: child should bring Daily Activity Log to the first treatment session).
4. RC will connect each child with a therapist. Session schedule and location will be decided collaboratively by the treating therapist and the family (i.e., frequency = 1 or 2 / week; location = home, BKR, Erinoak, community).
  - ★ Therapist will notify RC of start date, frequency and location of visits.
5. Sessions begin (see protocol on next page).
  - ★ We anticipate 2 introductory sessions, 9 treatment sessions, and 1 consolidation session per child.
  - ★ At approximately the halfway point in treatment sessions, one session will be videotaped.
  - ★ After each session, the therapist will complete a Session Log that captures key thoughts. Please feel free to take a copy.
6. Therapist will notify RC of treatment completion date and forward all treatment logs (parent & therapist), outcome measures, and videotapes with appropriate labelling/ coding to U of T.
7. Data collection needs to be completed by \_\_\_\_\_, 2008 (excluding the 4 month follow-up visit). If the family is cancelling frequently, or the child is ill and not progressing well, please let us know as soon as possible.
8. Four months after the completion of treatment, we will be completing a follow-up visit to see if the results have been maintained. We will notify you of this visit and would like to have you come, however, if this is not possible, that is fine.

## Study Procedures

1. Children will be recruited from either Bloorview Kids Rehab or Erinoak. Once the families have been identified the Research Coordinator (RC) will contact the family by phone and complete a screen for inclusion/exclusion criteria as well as provide an initial overview of the study. An appointment will be made for the RC to administer the intake assessments (KBIT-2, GMFCS).
2. Intake documents will be mailed to the parent/ caregiver (i.e., letter of information for parent and child with consent forms, demographic information form, daily activity log, and ASK questionnaire).
3. At the intake assessment visit, the RC will obtain informed consent for participation and videotaping and will collect demographic information forms and the ASK (note: child should bring Daily Activity Log to the first treatment session).
4. RC will connect each child with a therapist. Session schedule and location will be decided collaboratively by the treating therapist and the family (i.e., frequency = 1 or 2 / week; location = home, BKR, Erinoak, community).
  - ★ Therapist will notify RC of start date, frequency and location of visits.
5. Sessions begin (see protocol on next page).
  - ★ We anticipate 2 introductory sessions, 9 treatment sessions, and 1 consolidation session per child.
  - ★ At approximately the halfway point one session will be video taped.
  - ★ After each session, the therapist will complete a Session Log that captures key thoughts. Please feel free to take a copy.
6. Therapist will notify RC of treatment completion date and forward all treatment logs (parent & therapist), outcome measures, and videotapes with appropriate labelling/ coding to RC at U of T.
7. Data collection needs to be completed by \_\_\_\_\_, 2008 (excluding the 4 month follow-up visit). If the family is cancelling frequently, or the child is ill and not progressing well, please let us know as soon as possible.
8. Four months after the completion of treatment, we will be completing a follow-up visit to see if the results have been maintained. We will notify you of this visit and would like to have you come, however, if this is not possible, that is fine.

## Appendix B

Investigating Best Practices for Children with Cerebral Palsy: A Pilot Study of Two Approaches

### Child and Family Demographic Form

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\_\_\_\_\_  
Child's Name

\_\_\_\_\_  
Name of person completing questionnaire:  
relationship to child (e.g., mother, father)

\_\_\_\_\_  
Child's date of birth (dd/mm/yy)

\_\_\_\_\_  
Address

\_\_\_\_\_  
Today's Date (dd/mm/yy)

\_\_\_\_\_  
City Prov. Postal Code

(\_\_\_\_)\_\_\_\_-\_\_\_\_ (\_\_\_\_)\_\_\_\_-\_\_\_\_  
Home Phone # Work Phone #

\_\_\_\_\_  
Therapist's Name

---

*We would like you to complete the following background questions about your child with fine motor difficulties and your family. This information will be used only to describe the group of families participating in this study. Your individual responses will not be identified in any way.*

---

1. How old is the child who is in this study?

\_\_\_\_ years and \_\_\_\_ months.

2. What is this child's sex?

Male  Female

3. In our family, this child is:

First-born  Second-born  Third-born  Other \_\_\_\_\_

4. How many children are in your family? \_\_\_\_\_

5. What is your child's primary diagnosis?

\_\_\_\_\_

6. Does your child have any **additional** problems? **Choose (X) all that apply.**

Visual impairment

Hearing impairment

Learning difficulties

Behavioral disorder

Other, please specify: \_\_\_\_\_

Specific Learning Disability (SLD)

Speech & Language Impairment (SLI)

Epilepsy or seizure disorder



7. Please identify your child's leisure interests (e.g., Cubs/Brownies, watching TV, colouring, reading, sports, etc.)

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---

8. Considering all aspects of your child's development (e.g., motor, language, social, learning) please indicate:

1. Areas of greatest strength

---

---

2. Areas of weakness/ concern

---

---

9. What type of services has your child received over the past 6 months? **Check all that apply.**

Occupational Therapy

Physiotherapy

Pediatrician

Psychology/ psychometry services

Special education

Other, please specify: \_\_\_\_\_

10. What language is spoken most often in your home? **Choose one only.**

English

French

Other, please specify \_\_\_\_\_

9. Please indicate if you are living in a two parent (parents living together in the same house) or single parent family. **Choose one only.**

Two parent family

Single parent family

10. What is your relationship to the child with cerebral palsy?

Birth mother

Birth father

Stepmother

Stepfather

Adoptive mother

Adoptive father

- Other guardian, please specify: \_\_\_\_\_

---

The following two questions are about education and employment. Your responses to these questions will be used to see whether the parents participating in this study are similar to families in general. All responses are confidential.

---

11. What is the highest level of education that you (and your spouse) completed? Check one level for each parent. Answer only for yourself, if you are a single parent.

	<i>Yourself</i>	<i>Your spouse/partner</i>
Elementary school (grades 1-8)	<input type="radio"/>	<input type="radio"/>
High school (grade 12 or 13)	<input type="radio"/>	<input type="radio"/>
College or technical training	<input type="radio"/>	<input type="radio"/>
University degree	<input type="radio"/>	<input type="radio"/>
Graduate university degree(s)	<input type="radio"/>	<input type="radio"/>

12. Are you currently employed?  Yes  No  
If a two parent family, is your spouse currently employed?  
 Yes  No

Please provide a brief description of what you do (eg. bus driver, civil engineer, accountant)

Mother: \_\_\_\_\_

Father: \_\_\_\_\_

***The following questions ask about your child's typical school environment.***

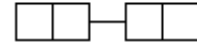
13. What is the highest grade your child has completed? Check one only.
- |                                    |                               |  |
|------------------------------------|-------------------------------|--|
| <input type="radio"/> Preschool    | <input type="radio"/> Grade 4 | <input type="radio"/> Ungraded         |
| <input type="radio"/> Kindergarten | <input type="radio"/> Grade 5 | → if ungraded, how many years attended |
| <input type="radio"/> Grade 1      | <input type="radio"/> Grade 6 |  |
| <input type="radio"/> Grade 2      | <input type="radio"/> Grade 7 |  |
| <input type="radio"/> Grade 3      | <input type="radio"/> Grade 8 |  |

14. My child receives most of his/her academic instruction in the following setting:

regular classroom  special education classroom

***Thank you very much for your time!***

## Appendix C



### Parent Weekly Log Book

#### Time Spent Reviewing or Using CO-OP or CTA Principles

Date: \_\_\_\_\_

Please check off the days that you were able to review activities/ ideas/ exercises learned in treatment this week. Also, indicate underneath how much time you spent (in minutes).

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	_____	_____	_____	_____	_____

#### Quality of time:

Please answer each question by circling the number that matches your level of agreement with the statement.

- I felt that I was skilful in carrying out the home programme:
  - I strongly disagree
  - Disagree
  - Undecided
  - Agree
  - Strongly Agree
- I feel that the time I spent integrating or practicing the treatment principles contributed to my child's learning of those principles.
  - I strongly disagree
  - Disagree
  - Undecided
  - Agree
  - Strongly Agree

# Appendix D

Investigating Best Practices for Children with Cerebral Palsy: A Pilot Study of Two Approaches

## Session Log

Child \_\_\_\_\_ ID Code #   -

Goals 1. \_\_\_\_\_  
2. \_\_\_\_\_  
3. \_\_\_\_\_

Therapist \_\_\_\_\_

Session # \_\_\_\_\_ Date \_\_\_\_\_ Length \_\_\_\_\_ Location \_\_\_\_\_

Videotaped? Yes No

	Approx Time Spent On Task (min)	Comments
Warm-up: (rapport)	_____	_____ _____ _____
Review of Homework/ Bridging	_____	_____ _____ _____
Goal 1	_____	_____ _____ _____ _____
Goal 2	_____	_____ _____ _____ _____
Goal 3	_____	_____ _____ _____ _____

## Appendix E

### SELF-EFFICACY PROBE OPERATIONAL DEFINITIONS

Kristen Huard  
(Revised from Mendes (2004))

#### Categories of Self-Statements

1. Child comments on his or her own *ability to perform* the *goal* occupation by commenting on whether or not they were successful performing the goal activity during or following trial and/or whether or not they made any mistakes during performance. Example phrases include:

<u>Positive</u>	<u>Negative</u>
"I can"	"I can't"
"I got it"	"I didn't get it"
"I did it right"	"I did it wrong"
"There you go"	"I made a mistake"
"Tada"	"Woops," "Shoot,"
"Yes!"	"No!"

2. Child comments on the *ease or difficulty* of the *goal* occupation by describing whether their experience performing the occupation was easy, hard, fun or frustrating. Example phrases include:

<u>Positive</u>	<u>Negative</u>
"This is easy"	"This is hard"
"I like (doing) this"	"I hate (doing) this"
"This is fun"	"This is frustrating"
"That was no problem"	"Oh, man!"

3. Child comments on their *future performance* of the *goal* occupation by describing whether or not they will participate and/or be successful in future attempts. Example phrases include:

<u>Positive</u>	<u>Negative</u>
"Next time I'll do better"	"I won't be able to do this again"
"I'm going to do it even faster (next time)"	"I'm never doing this again"
"If I practice I'll be great at this"	"I'm never going to get it"

4. Child comments on *knowledge of his or her own skills* by describing whether or not they are good at performing an activity and/or whether their performance has improved or declined over time. Example phrases include:

<u>Positive</u>	<u>Negative</u>
"I'm good at this"	"I'm not good at this"
"I'm the best"	"I've never been able to do it"
"I've mastered it"	"I can only get the first part"
"I'm a lot better than I was before"	"I've gotten worse at this"

5. Child demonstrates *non-verbal statements or gestures* while performing occupations. Examples include:

<u>Positive</u>	<u>Negative</u>
Big smile following successful trial	Exhale/sigh of frustration
Raises arms in air following successful trial	Slaps hand down, throws object
"Wooo...!"	"Grrr..." "Ahhh..."

Appendix F

**Daily Activity Log**



**THE THINGS I DO IN MY DAY (fill out for one day)**

My Name: \_\_\_\_\_

**MORNING**

6:00-7:00 am

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7:00- 8:00 am

---

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8:00-9:00 am

---

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9:00-10:00 am

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10:00-11:00 am

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11:00-12:00 am

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**AFTERNOON**

12:00-1:00 pm

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## Appendix G

Investigating Best Practices for Children with Cerebral Palsy: A Pilot Study of Two Approaches

### Research Protocol

#### Contemporary Treatment Approach (CTA)

<p><b>Prior to Therapy</b> (Research Coordinator)</p>	<p><b>Intake/ Preparation</b></p> <ol style="list-style-type: none"> <li>1) Referral to Best Practice Study from BKR or Erinoak</li> <li>2) RC to contact parents: will conduct initial screen (check for child/parent and therapist prerequisites); obtain verbal consent for participation in study; arrange appointment to visit family to complete intake assessments (KBIT-2 &amp; GMFCS)</li> <li>3) Mail intake documents (information letters, consent forms, demographic form, Daily Activity Log, Activity Scale for Kids (ASK #1))</li> <li>4) Intake assessment visit by research OT to administer KBIT-2 &amp; GMFCS</li> </ol>
<p><b>Session 1</b> (child, parent)</p>	<p><b>Assessment (Pre-Test) – 90 minutes</b></p> <ol style="list-style-type: none"> <li>5) Review child’s completed Daily Activity Log</li> <li>6) Administer Canadian Occupational Performance Measure (COPM) with child; identify and score 3 goals             <ul style="list-style-type: none"> <li>- Parent also scores child-chosen goals</li> <li>- Parent also identifies and scores 2 additional performance issues for generalization/transfer purposes</li> </ul> </li> </ol>
<p><b>Session 2</b> (videotaping) (child, parent)</p>	<p><b>Introduction of Treatment – 60 minutes</b></p> <ol style="list-style-type: none"> <li>7) Complete session 1 protocol if necessary</li> <li>8) Videotape child’s <b>baseline</b> performance (“make a movie”)</li> <li>9) Additional assessment as required</li> <li>10) Introduce treatment plan             <ul style="list-style-type: none"> <li>▪ Parent observes session</li> </ul> </li> </ol>
<p><b>Session 3-11</b> (videotape one session mid-way through, around session 7-8) (child, parent, student)</p>	<p><b>Treatment – 60 minutes</b></p> <ol style="list-style-type: none"> <li>11) Conduct contemporary treatment approach             <ul style="list-style-type: none"> <li>▪ Provide parent Session Log at each visit</li> <li>▪ Record parent involvement at each visit</li> <li>▪ Complete Therapist session log after each session</li> </ul> </li> </ol>
<p><b>Session 12</b> (videotape) (child, parent)</p>	<p><b>Consolidation (Post-Test) – 90 minutes</b></p> <ol style="list-style-type: none"> <li>12) Re-administer COPM scoring with child (3 goals) and parent (3 child-chosen goals + 2 additional performance issues)</li> <li>13) Re-administer COPM scoring with parent (3 child-chosen goals + 2 additional performance issues)</li> <li>14) Re-administer baseline videotaping</li> <li>15) Provide ASK #2 to parents (to be completed and mailed back to RC)</li> <li>16) Review and reinforce any key learning and/or home programming with parents/caregivers</li> <li>17) Give certificate</li> </ol>
<p><b>Follow-up</b> (4 months later) (student /RC)</p>	<p><b>Generalization and Transfer</b></p> <ul style="list-style-type: none"> <li>- Re-administer COPM scoring for both child and parent goals</li> <li>- Re-administer baseline videotaping of 3 goal activities</li> <li>- Interview for generalization of skills to home, school, community environments</li> <li>- Collect ASK #3</li> </ul>

(Adapted from Polatajko et al., 2000)

**Research Protocol |**  
**Cognitive Orientation to daily Occupational Performance (CO-OP)**

<b>Prior to Therapy</b> (Research Coordinator)	<b>Intake/ Preparation</b> 1) Referral to Best Practice Study from BKR or Erinoak 2) RC to contact parents: will conduct initial screen (check for child/parent and therapist prerequisites); obtain verbal consent for participation in study; arrange appointment to visit family to complete intake assessments (KBIT-2 & GMFCS) 3) Mail intake documents (information letters, consent forms, demographic form, Daily Activity Log Activity Scale for Kids (ASK #1)) 4) Intake assessment visit by research OT to administer KBIT-2 & GMFCS
<b>Session 1</b> (child, parent)	<b>Assessment (Pre-Test) – 90 minutes</b> 5) Review child's completed Daily Activity Log 6) Administer Canadian Occupational Performance Measure (COPM) with <u>child identify</u> and score 3 goals <ul style="list-style-type: none"> <li>• Parent also scores child-chosen goals</li> <li>• Parent also identifies and scores 2 additional performance issues for generalization/transfer purposes</li> </ul>
<b>Session 2</b> (videotaping) (child, parent)	<b>Introduction of Global Cognitive Strategy – 60 minutes</b> 7) Complete session 1 protocol if necessary 8) Videotape child's <b>baseline</b> performance ("make a movie") 9) Introduce Global Cognitive Strategy: Goal-Plan-Do-Check <ul style="list-style-type: none"> <li>▪ Therapist introduces the puppet: GoalPlan DoCheck</li> <li>▪ Therapist maps Goal-Plan-Do-Check (GPDC) to a familiar task</li> <li>▪ Child maps Goal-Plan-Do-Check to a familiar task</li> <li>▪ Parent observes session</li> </ul>
<b>Session 3-11</b> (videotape one session mid-way through, around session 7-8) (child, parent, student)	<b>Acquisition (Treating Therapist) – 60 minutes</b> 10) Conduct Dynamic Performance Analysis: (Ongoing) 11) Facilitate the child's acquisition and application of the Global Cognitive Strategy: Goal-Plan-Do-Check 12) Guide discovery of Domain Specific Strategies (DSS) and mediate their application to skill acquisition 13) Apply Enabling Principles 14) Teach parents/caregivers about Goal-Plan-Do-Check and applicable DSS 15) Educate parents/caregivers about their ongoing role in facilitating cognitive strategy use to promote skill acquisition <ul style="list-style-type: none"> <li>▪ Provide parent Session Log at each visit</li> <li>▪ Record parent involvement at each visit</li> <li>▪ Complete Therapist session log after each session</li> </ul>
<b>Session 12</b> (videotape) (child, parent)	<b>Consolidation (Post-Test) – 90 minutes</b> 16) Re-administer COPM scoring with child (3 goals) and parent (3 child-chosen goals + 2 additional performance issues) 17) Re-administer COPM scoring with parent (3 child-chosen goals + 2 additional performance issues) 18) Re-administer baseline videotaping 19) Probe child for generalization and transfer of Global and Domain Specific Strategies: GPDC and DSS 20) Review and reinforce CO-OP approach, and cognitive strategy use with parents/caregivers 21) Provide ASK #2 to parents (to be completed and mailed back to RC) 22) Give certificate
<b>Follow-up</b> (RC/ student)	<b>Generalization and Transfer</b> <ul style="list-style-type: none"> <li>- Re-administer COPM scoring for both child &amp; parent goals</li> <li>- Re-administer baseline videotaping of 3 goal activities</li> <li>- Collect ASK #3</li> <li>- Interview for transfer of GPDC to home, school, community environments</li> </ul>

(Adapted from Polatajko et al., 2000)



## Appendix H

Investigating Best Practices for Children with Cerebral Palsy: A Pilot Study of Two Approaches

### THERAPIST TRACKING SHEET

Therapist Name: \_\_\_\_\_ Client ID #: -

Child Name: \_\_\_\_\_

Parent/ Caregiver Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

---

**VISITS 1 and 2** → complete the following tasks:

#### **With the Child:**

- Review Daily Activity Log  \_\_\_\_\_  
( day/month/year)
- Administer COPM  \_\_\_\_\_  
- identify 3 goal activities ( day/month/year)
- Complete baseline Videotaping  \_\_\_\_\_  
( day/month/year)

#### **With Parents:**

- Administer COPM  \_\_\_\_\_  
- score child-chosen goals ( day/month/year)  
- choose and score 2 additional goals

**VISITS 3 → 11**

- Complete Therapist session log after each session

#### **With the Child:**

- Conduct Dynamic Performance Analysis: (Ongoing)
- Facilitate the child's acquisition and application of the Global Cognitive Strategy: Goal-Plan-Do-Check
- Guide discovery of Domain Specific Strategies (DSS) and mediate their application to skill acquisition

- Apply Enabling Principles

**With Parents:**

- Provide parent Session Log at each visit
- Record parent involvement at each visit (recorded on therapist session log)

**VISIT 12**

**With the Child:**

Re-administer COPM  \_\_\_\_\_  
( day/month/year)

Re-administer baseline videotaping  \_\_\_\_\_  
( day/month/year)

- Probe child for generalization and transfer of Global and Domain Specific Strategies: GPDC and DSS
- Give certificate

**With Parents:**

- Review and reinforce CO-OP approach, and cognitive strategy use with parents/caregivers

**FINAL SUBMISSIONS**

To Research Coordinator:  \_\_\_\_\_  
(day/month/year)

Assessments:

- COPM Time 1
- COPM Time 2
- Video Tape (baseline, middle session, final session)

Forms:

- Daily Activity Log
- Parent Session Logs
- Therapist Session Logs
- Study Completion Form

- Record parent involvement at each visit (recorded on Therapist Session Log sheet)

### **VISIT 12**

#### **With the Child:**

Re-administer COPM  \_\_\_\_\_  
( day/month/year)

Re-administer baseline videotaping  \_\_\_\_\_  
( day/month/year)

- Give certificate

#### **With Parents:**

- Review and reinforce any techniques taught or home programming provided

### **FINAL SUBMISSIONS**

To Research Coordinator:  \_\_\_\_\_  
(day/month/year)

#### Assessments:

- COPM Time 1  
 COPM Time 2  
 Video Tapes (baseline, middle session, final session)

#### Forms:

- Daily Activity Log  
 Parent Session Logs  
 Therapist Session Logs  
 Study Completion Form

## Appendix I

Correlations for Parent Involvement Variables and Parent Demographic variables.

	PQRS Time 1 - 2 Change Score	PQRS Time 2 - 3 Change Score	Positive Self Statements Time 1-2	Positive Self Statements Time 2-3	Negative Self Statements Time 1-2	Negative Self Statements Time 2-3	COPM P Time 1 - 2 Change Score	COPM P Time 2 - 3 Change Score	COPM S Time 1 - 2 Change Score	COPM S Time 2 - 3 Change Score	ASK C Time 1 - 2 Change Score	ASK C Time 2 - 3 Change Score	ASK P Time 1 - 2 Change Score	ASK P Time 2 - 3 Change Score	COPM P Par Time 1 - 2 Change Score	COPM P Par Time 2 - 3 Change Score	COPM S Par Time 1 - 2 Change Score	COPM S Par Time 2 - 3 Change Score	COPM P Par Transfer Goals Time 1 - 2 Change Score	COPM P Par Transfer Goals Time 2 - 3 Change Score	COPM S Par Transfer Goals Time 1 - 2 Change Score	COPM S Par Transfer Goals Time 2 - 3 Change Score
<b>Total Amount of Time Parents Practiced In Session</b>	0.21	-0.25	0.13	0.39	-0.18	0.25	0.2	-0.03	0.11	-0.03	0.2	-0.52	0.27	0.27	0.02	-0.22	0.45	-0.2	-0.03	-0.64	-0.34	-0.26
<b>Total Percentage of Days Parent Practiced In Session</b>	0.23	0.03	0.43	-0.12	-0.11	-0.09	0.11	-0.09	0.22	0.09	0.13	-0.33	0.27	-0.04	-0.15	-0.01	-0.1	-0.13	-0.17	-0.24	-0.29	0.14
<b>Total Amount of Time Parents Practiced Out Session</b>	0.41	-0.49	-0.03	0.33	-0.25	0.36	0.18	0.11	0.39	-0.25	-0.13	-0.37	-0.03	0.13	0.14	-0.1	0.12	-0.38	-0.22	-0.37	-0.35	0.05
<b>Total Number of Days Parent Practiced Out Session</b>	0.59	-0.61	0	0.33	-0.3	0.44	0.16	-0.05	0.23	-0.29	-0.19	-0.32	-0.18	0.21	0.18	-0.11	0.27	-0.17	-0.36	-0.42	-0.48	0.23
<b>Parents self report of perceived skill</b>	0.2	0.11	-0.09	-0.21	-0.1	-0.31	-0.37	0.38	0.02	0.12	0.05	0.07	-0.01	-0.45	-0.14	0.34	-0.44	0.17	-0.44	0.41	-0.39	0.45
<b>Parents self-report of perceived contribution</b>	0.16	-0.04	-0.06	-0.09	-0.15	-0.22	-0.35	0.38	0.02	0.1	0.04	-0.05	0.02	-0.49	-0.15	0.27	-0.3	0.2	-0.41	0.21	-0.44	0.34

