Embracing the Context of Pediatric Rehabilitation Programs: Investigating the Role of Family-Centred Service Philosophy in Program Evaluation

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Abstract

Program evaluation is becoming increasingly important in pediatric rehabilitation settings that adhere to FCS philosophy. This philosophy recognizes that each family is unique, that parents know their children best, and that optimal child functioning occurs within a family context. However, researchers know little about the specific evaluation activities occurring in these settings or the extent to which evaluators uphold FCS philosophy in their activities. The primary goal of this study is to examine the strengths, limitations, and consequences of current evaluation practice, including its compatibility with FCS philosophy. As a secondary goal, the study aims to understand the promise and prospects of alternative evaluation approaches that, in theory, are compatible with FCS philosophy. To address these goals, this study uses a mixed-methods approach and includes three phases. Phase 1 involves a survey of staff members involved with program evaluation at 15 Canadian pediatric rehabilitation centres. It determines the level of program evaluation occurring in these settings, verifies on the motivation for evaluation, and describes the degree to which evaluation activities are consistent with the FCS philosophy. Phase 2 involves interviews with staff members and explores the values, factors, and conditions that support and inhibit the evaluation of family-centred programs in pediatric rehabilitation settings as well as the benefits and limitations of using mainstream practices for evaluating these programs. Phase 3 then uses focus groups with staff members and interviews with parents to explore how the evaluation of family-centred programs can be improved as well as to identify the compatibility and practicality of using alternative evaluation approaches within these settings. Overall, the findings show that the amount of evaluation activities occurring within these centres is variable; that the majority of individuals working in program evaluation do not have formal training in it; and that the centres have limited resources for evaluation. The findings also demonstrate that participatory evaluation approaches are more compatible with FCS

philosophy but that it might be difficult to implement such approaches given the limited resources and diverse characteristics of rehabilitation settings. In light of these circumstances, the study notes ways for improving program evaluation activities.

Keywords: program evaluation, participatory program evaluation, family-centred service, Canadian rehabilitation centres

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Chapter 1: Introduction

Statement of Problem

The demand for systematic data on the performance of publically funded programs is increasing (Newcomer, Hatry, & Wholey, 2004). To make evidence-based decisions[1] about resource allocation, program improvements, or continued program involvement, government officials and foundations, as well as program managers, service providers, and recipients, want to know if programs are working and what they are achieving. With growing demands for data, program evaluation is becoming more important, especially in health-care settings such as pediatric rehabilitation.

Offering a wide range of medical, social, service coordination, educational, therapeutic, and recreational programs, pediatric rehabilitation centres provide care to children and youth with physical, developmental, or communicative disabilities. Program evaluation within these centres is particularly important for examining the extent to which programs are reaching their target audiences and anticipated outcomes (Woodward, 2010). Program evaluation can provide answers to questions about access to care, programming costs, quality of care, and program effectiveness. Although a literature review of published evaluations in this sector shows that some providers have engaged in evaluation to assess program outcomes (Conant, Morgan, Muzykewicz, Clark, & Thiele, 2008; Davies et al., 2005; Swaine, Pless, Friedman, & Montes, 2000) and report on program process (Goldbeck & Babka, 2001), researchers know little about the specific evaluation activities or their strengths, limitations, and consequences (Moreau & Cousins, 2011). The paucity of empirical evidence concerning evaluation is not necessarily

[1] *Evidence-based decisions* refer to decisions guided by research or evaluation rather than custom or ideology (Cooper, Levin, & Campbell, 2009).

restricted to the rehabilitation and health care fields. For some time now, contributors have been calling for more and better quality research *on* evaluation (Cousins & Earl, 1999; Henry & Mark, 2003; Mark, 2008; Smith, 1993). Yet, despite increased demands for program evaluation in rehabilitation as well as research on evaluation, only one other empirical study by Flynn, Glueckauf, Langill, and Schacter (1984) has examined program evaluation practices in rehabilitation centres for children and adults with disabilities. Almost 30 years ago, these authors surveyed 67 facilities and found that almost none had fully developed program evaluation systems. They also found that the amount of evaluation activities occurring in these centres varied substantially (Flynn et al., 1984). Since no additional studies on evaluation have been conducted within the last 30 years, it is now time to re-examine the evaluation practices in rehabilitation settings to see how program evaluation has evolved and where improvements are needed. Ultimately, this research on program evaluation will help guide future evaluation activities and contribute to researchers and evaluators' understandings of important evaluation issues (Mark, 2008). Furthermore, by documenting and understanding the current state of program evaluation in this field, this research will establish what types of resources and activities are needed to advance program evaluation.

The evaluation literature suggests some general areas for advancement that are applicable, but investigators have yet to verify these suggestions within pediatric rehabilitation. For example, the literature shows that professionals involved in program evaluation often find it challenging to select appropriate, efficient, and effective evaluation approaches and methods, especially when resources for evaluation are limited (Newcomer et al., 2004). In light of this challenge, researchers recommend that evaluators acknowledge the information needs of stakeholders and recognize the complexities of the programs under evaluation and of the settings

in which these programs are being implemented (Pawson, 2006). Although these complexities have implications for program evaluation, evaluators often rush into the design of evaluations with minimal consideration or understanding of them. They also frequently neglect the contexts of the programs that they are evaluating; these include program philosophies, which are instrumental in the daily operations and overall successes of programs (Race, Hotch, & Packer, 1994).

Within pediatric rehabilitation settings, programs typically follow the philosophy of family-centred service (FCS) or family-centred care (FCC). This philosophy recognizes that each family is unique, that parents know their children best, and that optimal child functioning occurs within a supportive family context (Rosenbaum, King, Law, King, & Evans, 1998). Academics have documented that FCS affects the outcomes of program recipients. They have shown that the family-centred concept of supporting families in meeting the needs of their children enhances adherence to interventions and treatments (Dunst, Trivette, Davis, & Cornwell, 1988) and thus improves children's health and developmental outcomes as well as family well-being (Reva, Allen, & Petr, 1998). Moreover, investigators have demonstrated that family-centred environments, which involve families in health-care decisions, often enhance both children's and families' sense of competence and understanding of conditions, illnesses, and the care provided. Furthermore, since children with chronic conditions and disabilities use, and will continue to use, health programs more frequently than their peers (Angst & Deatrick, 1996; Young et al., 2005), their families should be able to evaluate service options effectively in order to make informed decisions about the care that best fits their own and their children's needs and priorities. In light of this evidence, as well as the above-mentioned beneficial effects of FCS, service providers, evaluators, and researchers should explore the role of FCS philosophy in program evaluation.

The push to incorporate FCS philosophy into all aspects of professional practice, including program evaluation is continuing to develop. There is also a growing body of research by prominent organizations such as, the Institute for Patient- and Family- Centered Care (2012) and the Committee on Hospital Care (2003) on behalf of the American Academy of Pediatrics, that highlights the importance of involving clients, patients, and families in health care decisions and providing them with access to evidence about treatment and programming options. Of particular importance, the Committee on Hospital Care (2003) developed a policy statement for family-centred care in pediatrics, which includes specific recommendations for how pediatricians as well as other health professionals should integrate it in hospitals, clinics, and community settings. Many of these recommendations relate to program evaluation and thus, help to establish the need for the present study. First, the Committee on Hospital Care (2003) suggests that health professionals should collaborate with families to evaluate systems of care, their interactions with patients/clients and families, and patient/client flow and then make necessary improvements to enhance families and children's care experiences. They also advocate that health professionals should invite families to collaborate in pediatric research and evaluation. They emphasize that families should play a role in and define the scope of inquiries, determine how children and families participate in research and evaluation, and decide how findings are disseminated. Similarly, the Institute for Patient- and Family-Centered Care reiterates that FCS is a novel approach for the planning, delivery, and evaluation of health care. However, despite these recommendations, many experts working in the health and rehabilitation field believe that the push for accountability and evidence-based practice results in, for example, families being seen as sources of data rather than collaborators in evaluation processes (Humphries, 2003; Kitson, 2002). Moreover, both the Institute for Patient- and Family-Centered Care and the Committee on

Hospital Care provide minimal guidance on how to uphold the FCS philosophy in evaluation. This lack of direction may be because the mechanisms for facilitating family involvement are often dependent on, for example, prior family involvement in a given organization or the availability of resources to support family participation (Jivanjee & Robinson, 2007). The idea of engaging families in evaluation may also be challenging for some service providers because it requires them to rethink the approaches and methods used, to capture families' voices, values, and perspectives in the evaluation, and to hear and involve families in the evaluation design and implementation (Long, 2006). Service providers, especially those trained in traditional research and evaluation approaches, might also hesitate to collaborate with families because they believe that their active involvement might affect the rigour of the evaluation and result in role ambiguity (Jivanjee & Robinson, 2007). That said, the extent to which FCS philosophy is integrated into evaluation practices within pediatric rehabilitation has not yet been investigated.

Given this gap in the research as well as the above-mentioned shortcomings and problems in terms of the documentation and understanding of current program evaluation activities in the rehabilitation sector, the present three-phase, mixed-methods study aims to describe and analyze current program evaluation practice in family-centred pediatric rehabilitation settings. The primary goal of the study is to examine the strengths, limitations, and consequences of current practice, including its compatibility with the philosophy of FCS. As a secondary goal, the study aims to understand the promise and prospects of alternative evaluation approaches that, in theory, are more compatible with the FCS philosophy than traditional ones.

Contributions to the Field

Recently, researchers working in program evaluation have advocated for improving evaluation practice through research. Smith (2011) notes, "Research on evaluation is seen as a

means of providing a shared, nomothetic grounding that can move the field beyond ideologically-based theory, *ad hoc* methods, and ideographic practice" (p. xi). Through documenting and reflecting on evaluation, this study contributes to the growing body of research on program evaluation and builds on the very limited body of empirical research on evaluation activities within rehabilitation. Despite increased demands for program evaluation, researchers and practitioners have minimal information on the types of evaluation activities occurring in pediatric rehabilitation centres. Apart from the survey of Canadian rehabilitation facilities conducted by Flynn and colleagues (1984), no other researchers have examined program evaluation activities in the rehabilitation field and thus, the present study provides insight into the evaluation activities occurring in this sector.

This study also allows other researchers to compare the current state of evaluation in this specific field to other family- or patient-centred environments. Most important, the findings help to identify potential challenges for evaluation within these unique, resource-limited environments as well as possible ways for improving evaluation capacity, which is the ability to conduct evaluation and the aptitude within organizations to use evaluation results and processes (Cousins et al., 2008). Since minimal research has explored the relevance of collaborative and participatory evaluation to the philosophy of FCS, this study also fills a void and completes the initial steps in the development of a family-centred approach to evaluation. By generating awareness about family involvement in the evaluation of family-centred programs, the level of FCS in pediatric rehabilitation settings will increase, allowing service providers to improve the health and well-being of program recipients and their families as well as evaluation activities.

Overview of Study

To provide the aforementioned contributions to theory and practice, I have organized this sequential mixed-methods study into seven chapters. Following this introduction, Chapter 2 provides a comprehensive literature review that establishes the theoretical foundation for the study. This review integrates literature on program evaluation and FCS to explain and justify the conceptual framework, design, and research questions. Next, Chapter 3 describes the sequential mixed-methods design and philosophical assumptions of the study. Included in this chapter, is an overview of the context of the inquiry, my position within the research environment, a description of the mixed-methods approach used, and an overview of the ontology, epistemology, and axiology of the study[2]. Chapters 4 to 6 describe the study findings. Chapter 4 highlights the results of Phase 1, which surveyed individuals involved with program evaluation at Canadian pediatric rehabilitation centres to obtain insight into their evaluation practices. Chapter 5 explicates the findings of Phase 2, which used one-on-one interviews with staff members to explore the values, factors, and conditions that support and inhibit program evaluation in family-centred rehabilitation environments. Chapter 6 then documents Phase 3, which was made up of staff focus groups and one-on-one parent interviews. It also presents findings that suggest areas for improving the evaluation of family-centred programs as well as the compatibility, feasibility, and practicality of using participatory and collaborative evaluation approaches within family-centred pediatric rehabilitation settings. Finally, Chapter 7 integrates and discusses the key findings of all the study phases with reference to the published literature. It

[2] Ontology is concerned with the nature of reality whereas epistemology deals with the origin, nature, and limits of knowledge. Axiology is the study of values and value judgments (Guba & Lincoln, 1989). I will say more about these concepts when I situate myself within the research environment in Chapter 3.

also highlights study limitations, areas for future research, and some concluding thoughts on program evaluation within the family-centred pediatric rehabilitation context.

Chapter 2: Literature Review and Conceptual Framework

The purpose of this chapter is to draw on and integrate the program evaluation, health care, and FCS literature that supported the development of the research questions, conceptual framework, and design of this study. Since research on program evaluation within rehabilitation is limited, this review focuses on defining general concepts in program evaluation as well as explaining specific issues related to FCS and evaluation in health-care settings. In doing so, it demonstrates the interconnections between evaluation practice, contexts, purposes, and consequences, it reveals the gaps in current program evaluation and FCS research, and it justifies the need for the present study.

This chapter begins with a brief synopsis of evaluation practice within health-care environments, followed by definitions and a description of different types of program evaluation. Next, it describes the impact that organizational and political contexts as well as evaluators' characteristics have on evaluation practice. It then details the purposes of evaluation (accountability and learning), differentiates between traditional and participatory evaluation approaches, and discusses the consequences of evaluation, including the use of findings and process use. In closing, the chapter presents and explains the conceptual framework and research questions for the present study.

Evaluation Practice in Health Care

Although first witnessed in the 17th century, systematic program evaluation is a somewhat recent development of the 20th century (Rossi, Lipsey, & Freeman, 2004), especially within the health care field. Prior to 1960, the formal evaluation of health programs was rare, and professionals working in these areas did not typically hold specific evaluation positions (Shadish, Cook, & Leviton, 1991). However, as health programs grew, so too did evaluation. Today, many

health-care organizations view program evaluation as a mechanism for systematically determining the effectiveness and efficiency of programs and ensuring that clients or patients receive high-quality and appropriate care (Health Services Research Group, 1992; Long, 2006). Evaluation, particularly in turbulent economic times, is a valuable tool for assessing organizational progress and providing vital information for program improvement, accountability, and organizational change (Love, 1983). Many decision makers in health care view evaluation as an essential aspect of health services research because it provides them with vital information about the types of programs needed, if programs are being implemented as intended, and whether certain programs should continue (Health Services Research Group, 1992).

Another trend promoting the use of evaluation within health care is the movement towards evidence-based practice (EBP) (Grembowski, 2001). Within a culture of EBP, service providers need to collect data continuously to prove that their programs are effective (Urban & Trochim, 2009). While the usefulness and value of various forms of data often vary by stakeholder group, most health-care decision makers adhere to hierarchies of evidence. These hierarchies list a variety of evaluation designs in order of decreasing internal validity (Petticrew & Roberts, 2003). With randomized control trials (RCTs) at the top (Evans, 2003), some individuals conceive that other evaluation designs lack scientific merit. As Droitcour and Kovar (2008) confirm, "…studies that randomly assign subjects to alternative conditions (classically, to treatment versus control) have recently been championed as the best design for assessing program impact" (p. 65). However, this demand for more rigorous designs might adversely affect evaluations and result in the neglect of important evaluation questions that are unanswerable via RCTs (E. Johnson, Kirkhart, Madison, Noley, & Solano-Flores, 2008).

Defining Program Evaluation

While EBP places responsibility on health professionals to design evaluations that have scientific rigour, researchers have shown that many of these individuals have inadequate training in evaluation and minimal understanding of what program evaluation is because of the high-level jargon used to describe it (Letts et al., 1999). This confusion is not surprising since authors define program evaluation in numerous ways. Table 1 presents some of the published definitions of program evaluation. Each definition emphasizes a specific component of evaluation. For example, Rossi, Lipsey, and Freeman (2004) emphasize the use of social science methods in evaluation; Patton (1997) highlights the use of evaluation findings; and Preskill and Torres (1999) stress the learning function of evaluation. Regardless of these differences, all of these definitions exemplify that evaluation is a systematic, planned, and purposeful activity that involves the systematic collection of data to answer or address specific questions or issues and enhance knowledge for specific purposes (Preskill & Russ-Eft, 2005). As such, the present study modifies Patton's (1997) definition and delineates program evaluation as the systematic collection of information to make judgments about the value of programs, to improve the acceptability and effectiveness of programs, and to inform decisions about future service delivery in rehabilitation. Essential to this definition is the term judgment, which implies the comparison of observations (i.e., data gathered for the evaluation) against something (e.g., control group, external standard, baseline observation). This differentiates evaluation from health research, which may or may not be judgment oriented.

Table 1

Definitions of Evaluation

Source	Definition
Patton (1997)	Program evaluation is the systematic collection of information about the activities, characteristics, and outcomes of programs to make judgments about the program, improve program effectiveness, and/or inform decisions about future programming. (p.23)
Preskill & Torres (1999)	Evaluative inquiry is an ongoing process for investigating and understanding critical organization issues. It is an approach to learning that is fully integrated with an organization's work practices, and as such, it engenders (a) organization members' interest and ability in exploring critical issues using evaluation logic, (b) organization members' involvement in evaluative processes, and (c) the personal and professional growth of individuals within the organization. (p.1-2)
Rossi, Lipsey, & Freeman (2004)	Program evaluation is the use of social research methods to systematically investigate the effectiveness of social intervention programs. It draws on the techniques and concepts of social science disciplines and is intended to be useful for improving programs and informing social action aimed at ameliorating social problems. (p.28)
Scriven (1991)	Evaluation refers to the process of determining the merit, worth, or value of something, or the product of the process….The evaluation process normally involves some identification of relevant standards of merit, worth, or value; some investigation of the performance of evaluands on these standards; and some integration or synthesis of the results to achieve an overall evaluation or set of associated evaluations. (p.139)

Note. Adapted from Preskill & Russ-Eft (2005, p.10).

To operationalize the concept of evaluation, the writings of Rossi, Lipsey, and Freeman (2004) are helpful. They suggest that there are five forms of program evaluation: needs assessment, assessment of program theory, assessment of program process, impact assessment, and efficiency assessment. Table 2 provides a brief explanation of each of these forms.

Table 2

Forms of Evaluation

Form	**Description**
Needs assessment	Answers questions about the social conditions a program is intended to address and the need for the program.
Assessment of program theory	Answers questions about the conceptualization and design of a program.
Assessment of program process	Answers questions about program operations, implementation, and service delivery.
Impact assessment	Answers questions about program outcomes and impact on the social conditions it is intended to improve.
Efficiency assessment	Answers questions about program costs in comparison to either the monetary value of its benefits or its effectiveness in terms of the changes brought about in the social conditions it addresses.

Note. Adapted from Rossi, Lipsey, & Freeman (2004, pp. 62-65).

Rossi and colleagues (2004) also suggest that evaluators should first consider the need for a program and then progress sequentially to assess program theory, process, impact, and efficiency. By moving through the various forms, evaluators can focus on questions suitable for the implementation stage and current situation of programs, avoiding premature, higher-order evaluations that will likely produce limited information (Rossi et al., 2004). Most important, they can use the information obtained from one type of evaluation to inform another, and thus design contextually appropriate evaluations that, for example, account for the organizational and political contexts that affect service delivery and outcomes.

Context and Program Evaluation

As laid out in the *Encyclopedia of Evaluation* (Mathison, (2005), context is the site, location, environment, or milieu that surrounds the evaluand. Although the context of a program should steer evaluation efforts, it is often multi-layered and made up of organizational, social, and political dimensions (Alkin, 2011), which can facilitate or hinder evaluation efforts. The literature, however, suggests that evaluators need to plan and conduct evaluations within the unique contexts of programs. According to Holden and Zimmerman (2009), evaluators should understand the organizational and political environment as well as define the evaluator and the sponsor relationship. Conversely, Johnson (2008) remarks that evaluators should adapt and validate data-collection tools and procedures for the contexts in which they are used. Yet, often times, the way evaluators handle the context of a program reflects their understanding of it. For instance, those who use RCTs or other positivistic approaches in their evaluations tend to view context as something that they need to control while others, who gravitate towards user-oriented or constructivist approaches, might view context as a valuable source of information about the evaluand (Vo, in press). While the context of many rehabilitation programs is now more user-oriented or family-centred rather than medically focused, it is still unknown how evaluators incorporate this context into evaluation activities.

Family-Centred Service Context

The literature on FCS shows that the integration of families into programming and care processes was slow, since health professionals initially viewed families as incapable of raising children who were ill, injured, or disabled (Rosenbaum et al., 1998). Some also considered families irrelevant to the intervention process (Allen & Petr, 1998) and viewed their presence in health-care settings as a nuisance because they asked questions and were critical of health

professionals (Lewandowski & Tesler, 2003). However, in the 1950s, Carl Rogers began practising and writing about client-centred therapy in mental health. Rogers advocated for the recognition of clients' capacities and rights to self-direction in treatment as well as for the importance of family dynamics in care processes. In the mid-1960s, the Association for the Care of Children in Hospital embraced and expanded his ideas from client- to family-centredness (Bamm & Rosenbaum, 2008). These actions, combined with other consumer-led movements in education, health, and child development, resulted in a shift away from health professionals controlling the destiny of children to families controlling the process in partnership with health professionals (Rosenbaum et al., 1998). Soon after, governments throughout North America began to develop federal legislation (e.g., *Education for All Handicapped Children Act*) that validated the importance of family-centred approaches as well as families' rights in general. Since then, international organizations, including the United Nations, have introduced political agendas (e.g., *The United Nations 1994 International Year of the Family*) on family rights and have helped to advance the strength of families as well as the importance of family-centred practices (Briar-Lawson, Lawson, Hennon, & Jones, 2001). Today, the concepts of FCS are common, as pediatric settings recognize the importance of supporting family relationships and families' rights as well as the benefits of active family participation in the care of and programming for children and youth. However, it is important to note that FCS does not remove control from children and youth who are competent to make decisions concerning their health services. Rather FCS recognizes that children, youth, and families' perspectives are important and that older youth have the capacity for independent decision making.

This FCS context has created new challenges for program development, implementation, and evaluation. Some may attempt to embrace the family-centred context of programs in their

evaluation practice, whereas others might be more likely to select approaches and methods that overlook this context. To embrace the family-centred context and implement FCS within a program or evaluation, Bamm and Rosenbaum (2008) argue that families and service providers must have a thorough understanding of the meaning and principles of FCS. They suggest that the explicit definition of FCS enables a common language for communication between families and professionals as well as the appropriate interpretation of ideas, policies, and practices (Bamm & Rosenbaum, 2008). However, a review of the literature reveals that many have struggled to agree on the definition and parameters of the term *family-centred* and that there is some confusion surrounding the term itself because researchers have used FCS and family-centred care interchangeably and have adopted various definitions for them.

Table 3

Definitions of FCS & FCC

Source	Context	Term	Definition
Brewer, McPherson, Magrab, & Hutchins, (1989)	American Pediatric healthcare	Family-centered care	Family-centered care is a philosophy of care in which the pivotal role of the family is recognized and respected in the lives of children with special needs. In this philosophy family should be supported in their natural caregiving and decision-making roles by building on their unique strengths as people and families. In this philosophy, (normative) patterns of living at home and in the community are promoted; parents and professional are seen as equals in a partnership committed to the development of optimal quality in the delivery of all levels of healthcare. (p.1056)
Dunst Johanson, Trivette, & Hamby, (1991)	Psychology	Family-centered	A combination of beliefs and practices that define particular ways of working with families that are consumer-driven and competency enhancing. (p.115)
Law et al., (2003)	Canadian Pediatric Rehabilitation; CanChild	Family-centered service	Family-centered service is made up of a set of values, attitudes, and approaches to service for children with special needs and their families. Family-centered service recognizes that each family is unique; that the family is the constant in the child's life; and that they are the experts on the child's abilities and needs. The family works with service providers to make informed decisions about the services and supports the child and family receives. In family-centered service, the strengths and needs of all family members are considered. (p.2)
Shields, Pratt, & Hunter, (2006)	Nursing	Family centered care	Family centered care is a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognized as care recipients. (p. 1318)
Viscardis, (1998)	Ontario Pediatric Rehabilitation; Parent group	Family-centered approach	The family-centered approach begins with the child's and family's strengths, needs and hopes, and results in a service plan which responds to the needs of the whole family. It involves education, support, direct services and self-help approaches. The role of the service provider is to support, encourage and enhance the competence of parents in their role as caregivers. (p.44)

As shown in Table 3, researchers from various disciplines and contexts have used different terminology and similar concepts such as family participation, partnership,

collaboration, respect, or joint decision-making to define FCS (Franck & Callery, 2004). Since this study focuses on the evaluation of family-centred programs within pediatric rehabilitation settings, the use of the term FCS and the definition developed by Law et al. (2003) seems most fitting. This term and definition are accepted and used widely within Canadian pediatric rehabilitation settings. To operationalize their definition and guide both service providers and families, Law et al. (2003), in partnership with nineteen Ontario children's rehabilitation centres, reviewed descriptive and research literature on FCS to develop a conceptual framework that outlines the premises, principles, and elements (PPEs) of FCS (see Appendix A). The premises outline the basic assumptions that form the backbone of FCS. Each premise is then followed by a set of guiding principles or "should" statements that help to guide service providers' interactions with families (Rosenbaum, et al., 1998). The elements then flow from the premises and principles and outline the responsibilities and expected behaviours of service providers as well as the rights of families according to FCS. Overall, this conceptual framework is used as a teaching tool that helps service providers and families understand and implement FCS.

In addition, Rosenbaum et al. (1998) state that it "provides service providers or programs with a basis on which to measure both the perceptions of parents and their own behaviours" (p. 15). Using this framework, researchers have developed tools (e.g., Measure of Processes of Care) to assess the level of FCS within selected programs, levels that can affect program evaluation. This means that service providers who work in programs with lower levels of FCS might not be as inclined to integrate the family-centred philosophy into their evaluation activities. Service providers who also lack various organizational supports, structures, and resources might also not be as motivated to integrate this philosophy into their evaluation activities.

Organizational Factors

The literature shows that organizational factors can affect evaluation. For example, Love (1983, 1991) identifies several factors that influence the capacity of organizations to conduct evaluations and use evaluation findings. These factors include organizational support and structure, psychological climate, and resource management. Likewise, in relation to health care, Brazil (1999) argues that policies, cultures, funding and staffing resources, information capabilities, and assigned role definitions for evaluators within organizations influence the development of evaluation practice. Both Brazil (1999) and Love (1983, 1991) suggest that organizational support, particularly in the form of dedicated policies, are essential for legitimatizing evaluation practices, promoting positive attitudes towards evaluation, facilitating resource allocation for evaluation, and promoting evaluation use. They state that, without this support, evaluation activities are at a high risk of being disorganized, ad hoc, and understaffed.

Moreover, Love (1983) and Majchrzak (1982) note that if evaluation staff have minimal evaluation training or are balancing evaluation activities with other full-time responsibilities, the development and implementation of successful evaluations may be challenging. This type of situation may lead to, as Brazil (1999) states, “superficial data or *post-hoc* designs, instead of evaluation plans that are an integral component of program development” (p.viii).

Both Love (1983) and Brazil (1999) also found that organizational structure is key in the development and implementation of evaluation as well as the use of findings. Factors encompassed in the organizational structure are information management systems that provide timely access to valid and reliable data, the number of departments within an organization, the number of management levels, and the roles and relationships of those involved in evaluation. Brazil (1999) discovered that organizations that establish direct lines of communication between

evaluators and senior-level administrators have a greater chance of their evaluation findings influencing organizational change. However, a common trend in the literature, especially in relation to the health sector, is that evaluators often hold various roles within organizations and as such, their relationships with senior administration and frontline staff vary.

Furthermore, it is evident from research on evaluation that there is a strong relationship between the psychological climate or organizational culture of organizations and the success of evaluations (Love, 1983). As Brazil (1999) notes, some organizations' climates or cultures may welcome the idea of evaluation whereas others may not. For example, at one end of the spectrum, a consultative-participatory organizational culture may view evaluation as a tool for guiding decisions and actions while, at the other end, an exploitative-authoritarian organizational climate may use evaluation as a means for identifying failures and punishing subordinates (Brazil, 1999).

Lastly, many of the above-mentioned organizational factors are also reiterated by Cousins et al. (2008), who describe a conceptual framework for the capacity of an organization to conduct and use evaluation. In their framework, they suggest that evaluation capacity and utilization depends on organizational learning capacity, organizational support structures, the capacity to conduct evaluation, the sources of knowledge, skill, and ability, evaluative inquiry, the capacity to use evaluation, and the mediating conditions. Some of these components are of particular relevance to the organizational factors that influence program evaluation. First, Cousins et al. (2008) suggest that the evaluation capacity of an organization is dependent on its organizational learning capacity. If, for instance, a centre can successfully translate knowledge into practice and work effectively as a team, its potential for developing evaluation capacity is greater than the potential of centres that cannot. Next, in relation to organizational support

structures, the capacity to conduct evaluation, and the sources of knowledge, skill, and ability, Cousins and colleagues (2008) advise that organizational learning, and thus, evaluation capacity, increase when there are minimal levels of management within an organization and employees have greater control over their own work. They also discuss how resources for conducting evaluations (e.g., personnel, funding, time), organizational support (e.g., rewards, follow-up), and professional development and skills (e.g., critical thinking, teamwork, evaluation, instrument development, data collection and analysis) are essential for both organizational learning and evaluation capacity. Thus, it is important for evaluators to assess the culture of organizations and determine if the current circumstances will allow for the development and implementation of effective evaluation practice and capacity building.

Evaluator Characteristics

Equally important to the influence of organizational context is the impact of evaluators' characteristics. Greene (1988) found that evaluator characteristics such as their responsiveness, listening skills, acceptance of diverse stakeholder views, ability to invoke trust and develop relationships, technical skills, and capacity to be objective and credible are important for the development of effective evaluation processes. Other authors also note that evaluators' characteristics can affect evaluation use. For example, Alkin, Daillak, and White (1979) and Cousins et al. (2008) identified that evaluation users must perceive the evaluator as credible in order to use the evaluation findings that they produce. Conversely, Siegel and Tuckel (1985) state that "evaluators should be highly trained and knowledgeable about the field they are investigating, [because] if they lack the necessary expertise or are not sufficiently grounded in the area under investigation, then their findings, however valid, can be conveniently dismissed" (p.316).

This notion of training is especially relevant to debates in the literature on competency development in and professionalization of evaluation. As Stevahn, King, Ghere, and Minnema (2005) state, professional fields usually have competencies for practice and use them for the development of training programs or for periodic reviews of the field and those working within it. With the growing need for competencies for evaluation, King, Stevahn, Ghere, and Minnema (2001) described a preliminary taxonomy of essential evaluator competencies that Stevahn, King, Ghere, and Minnema (2005) further developed to include the following six categories: (a) professional practice, (b) systematic inquiry, (c) situational analysis, (d) project management, (e) reflective practice, and (f) interpersonal competence. In terms of professional practice, evaluators should, for example, act ethically, respect clients, and contribute to the knowledge base of evaluation. For systematic inquiry, evaluators should understand evaluation terms and theories, and have knowledge of various evaluation designs and methods. When it comes to situational analysis, evaluators should be able to describe the program, respect its uniqueness, examine the organizational context of the evaluation, and address the needs of the intended users. Project management competencies then focus on conducting evaluation and, as such, evaluators should be able to, for example, budget and coordinate resources. Reflective practice, on the other hand, refers to individuals' awareness of self and their professional expertise. Lastly, interpersonal competencies focus on evaluators' communication, negotiation, conflict resolution, collaboration, and cross-cultural skills (Stevahn, King, Ghere, & Minnema, 2005).

Between 2008 and 2009, the Canadian Evaluation Society (CES), in consultation with its members, also developed a similar list of competencies. The list, which includes reflective, technical, situational, management, and interpersonal practice competencies, is used by CES as

part of its voluntary credentialing program for evaluators (The Canadian Evaluation Society, 2010).

These competencies and the development of credentialing programs for evaluators is moving evaluation into the realm of professionalization. However, as noted previously, the idea of professionalization is an area of contention. As Jacob and Boisvert (2010) point out, those in favour of professionalization think that it will add credibility and legitimacy to the field of evaluation, provide evaluators with a sense of professional identity, make evaluation practice more visible, and thus, lead to increased training opportunities in evaluation. Ultimately, these training programs could help individuals develop the necessary skills and competencies to be effective evaluators. Professionalization would require evaluators to remain current in their skills and knowledge (Jacob & Boisvert, 2010), which would bring them and their work additional credibility as well as improve the quality of evaluations conducted (Altschuld, 1999; Bickman, 1999). It would also provide those who are working in the field with a sense of identity (Cousins, Cullen, Malik, & Maicher, 2009) or belonging to a professional community (Bickman, 1999).

However, many proponents of professionalization also acknowledge its limitations. Inevitably, the professionalization of evaluation could discredit certain practices that are working well in specific contexts and reduce the amount of flexibility that certain evaluators have in terms of evaluation activities (Jacob & Boisvert, 2010). Evaluators within the health care field might also be impacted negatively because evaluation is often an informal or secondary part of their job and, as such, they may not have the time or the desire to achieve and maintain the necessary competencies.

This notion of being trained and knowledgeable also relates to the idea of evaluators being versed in, appreciative of, or supportive of the values and philosophies of evaluands and

their organizations. Discussed at length in the cultural competency evaluation literature, it is important for evaluators to recognize their own world views, biases, and assumptions. Botcheva, Shih, and Huffman (2009) state, "Evaluators should be aware that the lens by which they view and interpret the world may differ from the lens of those served by the evaluation; evaluators need to adjust to these differences" (p. 177). By recognizing and adjusting to these differences, evaluators might identify new or alternative evaluation goals, methods, or outcomes. Evaluators may also become more cognizant of how their reactions to and understandings of the evaluation environment influence evaluation designs, methods, and analyses (Hughes, Seidman, & Williams, 1993).

Political Factors

Political factors can also influence evaluation designs, methods, analyses, and use of evaluation findings. According to Weiss (1993), politics and program evaluation connect in three major ways. First, evaluands are often the direct results of political decisions and thus, their implementation and evaluation is subject to political support or hostility. Next, since political leaders make decisions based on evaluation findings, the evaluation process is inherently political. Third, evaluation is, by nature, political because it makes political statements about programs, which include accounts about the validity of program goals and activities as well as the role of researchers and evaluators in program development (Weiss, 1993). Programs are also evolving continuously for political reasons. For instance, there may be "budgetary battles," "debates about the purpose and/or accomplishments" (Patton, 1977, p. 152) of a program, changes in top government officials with different ideological values, pervasive dissatisfied voters, or critical media coverage about programs (Weiss, 1993), all of which can affect evaluation processes. Therefore, as stated by the American Evaluation Association (2006), it is

important for evaluators to have an understanding of the socio-political context, including the political environment in which the evaluation will be conducted (Holden & Zimmerman, 2009). By considering this environment and the factors associated with it, evaluators can recognize the explicit and implicit reasons for the evaluation and ensure the use of appropriate indicators and methods. For example, Holden and Zimmerman (2009) state that, if the purpose of an evaluation is to justify additional funding for a program, the evaluator should have some comprehension of the political investment and other political and societal issues surrounding the evaluand. Political bodies (e.g., ministries of health and child and youth services) that emphasize program accountability may put pressure on centres to assess program impact or efficiency. Conversely, organizational climates characterized by budget cuts and resource shortages may limit funds for program evaluation and encourage service providers to place other programming demands above program evaluation.

Purposes of Program Evaluation

The literature illustrates that there are two main purposes for program evaluation (i.e., accountability, learning), that the purposes for conducting evaluations are often multi-faceted, and that many evaluators favour one purpose over another (Chelimsky, 2006).

Accountability

As Chelimsky (2006) and Moran (1987) note, the increase of political and economic discourses has encouraged many service providers in public organizations to engage in program evaluation for accountability purposes. Limited program funding in the social and health services sectors has also increased interest in the use of evaluation to establish program accountability. Through what is commonly referred to as summative evaluation, service providers are able to assess effectiveness, identify best practices, and validate their programs within fiscally

competitive climates (Clarke, 2006). Evidence of program effectiveness can then be compared with programming costs and decisions can be made about the continuation of the program (Love, 1983).

Alkin (1972) and Alkin and Christie (2004) acknowledge that there are three types of accountability in program evaluation: goal accountability, process accountability, and outcome accountability. Each type of accountability refers to a specific aspect of a program and is the responsibility of a particular stakeholder group. Goal accountability focuses specifically on whether relevant program goals have been developed and is of particular interest to governing boards and upper-level management. Process accountability examines the implementation and appropriateness of the procedures used for obtaining program goals and is the responsibility of managers and service providers whereas outcome accountability explores the degree to which goals have been achieved and is also the responsibility of managers and service providers (Alkin & Christie, 2004). Demand for these three types of accountability is present within health settings; however, similar to other public sectors, the focus has recently shifted from process to outcome accountability.

While the literature reveals that few researchers and service providers have reflected on the purpose of program evaluation in the rehabilitation sector, those who have published in this area stated that increasing accountability demands, fiscal constraints, and more encompassing accreditation standards have resulted in the growth of program evaluation in both institutional and community rehabilitation environments (Schnelker & Rumrill, 2001). As Letts and Dunal (1995) and Schnelker and Rumrill (2001) note, funding and accreditation bodies, as well as family advocacy groups, place high expectations on rehabilitation programs to demonstrate quality performance and cost effectiveness. Professional groups such as the Canadian

Association of Occupational Therapists and the Canadian Association of Speech Language Pathologists and Audiologists have also endorsed program evaluation and promoted it as a professional responsibility because it enables service providers to understand their programs and determine if and how they are making a difference in clients' and their families' lives (Letts & Dunal, 1995). In this sense, the literature shows that program evaluation in the rehabilitation field is focused primarily on accountability rather than learning.

Learning

Evaluation for the purposes of learning is slowly emerging in the health sector. Long (2006) suggests that, in addition to exploring if programs work, there is interest in learning from the implementation and evaluation experience itself. Program evaluation for the purposes of learning allows individuals, teams, and organizations to grow and develop. As Preskill and Torres (1999) note, through participating actively in program evaluation, individuals may seek to increase their competencies in data collection, analysis, and communication (behaviourism). They may also begin to understand issues more completely and gain greater appreciation of issues (constructivism) or to increase their ability to think differently about problems or issues through the application of new cognitive clues (cognitive learning; Preskill & Torres, 1999). Individuals from various stakeholder groups can then come together as a team to collaboratively explore program issues or problems, thus obtaining a more diverse and complex understanding. Through teamwork, the various stakeholders are also able to learn about each other's perspectives. While individuals and teams share their learning with others, the organization is able to learn (Preskill & Torres, 1999), and, in this sense, evaluation can generate new knowledge and facilitate learning at many levels within an organization.

Program Evaluation Approaches

On another note, there is a broad range of evaluation approaches. Stufflebeam (2001) identified twenty-two approaches often used to evaluate programs and assessed the strengths, weakness, and best applications of each. He also divided the approaches into four categories: pseudo-evaluations (i.e., approaches that promote invalid or incomplete findings), question- or method-oriented approaches, improvement or accountability-oriented approaches, and social agenda/advocacy approaches. Instead of re-examining all these approaches and their corresponding categories, I will now provide a brief overview of the traditional evaluation approaches mentioned frequently in the health evaluation literature as well as of the participatory evaluation approaches that played a key role in the present study.

Traditional Evaluation

McCoy and Hagie (2001) and Schnelker and Rumrill (2001) provide an overview of commonly used evaluation approaches in the health sector, identifying objective-oriented evaluation (Tyler, 1942) and scientific evaluation (Campbell, 1969) as the most predominant.

Objective-oriented evaluation. Tyler's (1942) approach to evaluation entails the comparison of the performance of a program with its objectives. When using this approach, the goals and objectives of the evaluand must be defined in behavioural terms prior to evaluation (McCoy & Hargie, 2001). With objective-oriented evaluation, Tyler (1942) also introduced the idea of ongoing evaluation as programs are implemented. With that said, within the health sector, objective-oriented evaluation is used by evaluators primarily for outcome evaluation (McCoy & Hargie, 2001), where evaluators use pre- and post-test designs to assess the discrepancy between the performance of a program and its stated objectives (Schnelker & Rumrill, 2001). Although this approach is straightforward, Stufflebeam and Shinklefield (1985) argue that all objectives

cannot be evaluated at one time and, as such, the selection of specific objectives for a given evaluation introduces a sense of bias (McCoy & Hargie, 2001). Furthermore, Schnelker and Rumrill (2001) state that the emphasis of this approach on outcomes can provide "narrow, simplistic descriptions of programs and little information to account for discrepancies" (p. 172).

Scientific evaluation. As McCoy (2001) notes, scientific evaluation approaches emphasize the collection of scientific data, use experimental and quasi-experimental designs, and identify cause-and-effect relationships. The main advocate of this approach is Donald Campbell (1969), who thought the world should be seen as a laboratory for social experimentation. Individuals who follow this belief typically start the evaluation process with diagnoses or hypotheses, prescribe treatments or interventions to selected individuals, and then evaluate the successes of those treatments or interventions (Koroloff & Friesen, 1997). Guba and Lincoln (1989) and their followers have been the foremost critics of this approach. Many have stated that this approach negates opportunities to explore programming issues that may surface in more flexible evaluation processes and that, given the overemphasis placed on measurement tools and quantitative methods, this scientific approach is, at times, superficial and mechanistic (L. King & Appleton, 1999). Moreover, as Guba and Lincoln (1989) also note, evaluators and program managers who use this approach often have the sole authority in determining what questions the evaluation will pursue as well as how data will be collected and interpreted. In hopes of creating "objective" evaluations, including objective data-collection instruments, these evaluators and managers may, using this scientific approach, overlook the values of other selected stakeholders or consider them secondary to their own.

Participatory and Collaborative Evaluation Approaches

In contrast to scientific evaluation is participatory evaluation. Cousins and Earl (1995) suggest that participatory evaluation is conducted as a partnership between trained evaluators and program stakeholders who may or may not have evaluation training. By working as a team, different members of the partnership bring different knowledge and skills to the evaluation process. Evaluators bring expertise in evaluation logic and methods as well as an understanding of professional standards of practice. They may or may not have a good understanding of the program or the context in which it operates. Conversely, program stakeholders have a deep, implicit, or possibly explicit, understanding of the program, what it is expected to do, and how it will do it (i.e., program logic). They are also intimately familiar with the program context because this is where they live, work, or receive services.

With that said, the evaluation literature shows that many authors and evaluators use the terms participatory and collaborative evaluation interchangeably and define them in a variety of ways. For some, participatory evaluation means a practical approach for decision making and problem solving whereas, for others, it is an approach rooted in power reallocation and social change (Cousins & Whitmore, 1998). In terms of collaborative evaluation, some describe it as practices that engage stakeholders in evaluation and enable them to share responsibility for the evaluation and the decision-making process (O'Sullivan, 2004). Alternatively, Cousins and Whitmore (1998) use the term collaborative inquiry (i.e., inquiry involving stakeholders) as an overarching concept under which they include specific streams of participatory evaluation, various forms of collaborative evaluation, and collaborative inquiry (e.g., participatory action research, emancipatory action research). Specifically, Cousins and Whitmore (1998) describe how there are two distinct streams of participatory evaluation—practical participatory evaluation

(P-PE) and transformative participatory evaluation (T-PE)—as well as different types of collaborative evaluation that are associated, but not exclusively, with the P-PE or T-PE stream (see Table 4).

Table 4

Description of the Streams of Participatory Evaluation

Stream	**Purpose**	**Orientation**	**Associated forms of collaborative evaluation (examples)**
Transformative Participatory Evaluation (T-PE)	To empower community groups oppressed by dominating groups (Cousins & Whitmore, 1998)	Political	Empowerment evaluation (Fetterman, 1994); Democratic evaluation (McTaggart, 1991)
Practical Participatory Evaluation (P-PE)	To foster program decision making and problem solving and the use of evaluation findings and processes (Cousins, 2005)	Practical	School-based evaluation (Alvik, 1995; Nevo, 1993, 1994); Developmental evaluation (Patton, 1997); Stakeholder-based evaluation (Bryk, 1983; Mark & Shotland, 1985)

Note. Adapted from Cousins & Whitmore (1998, p.12-13).

Cousins and Whitmore (1998) also identified three fundamental dimensions of form or process in collaborative inquiry, including participatory evaluation, which have been validated by Daigneault and Jacob (2009). The first dimension, control of decision making, refers to the individuals who control the technical decision making about evaluation processes and conduct: evaluators, stakeholders, or a balanced mix of the two (Cousins & Whitmore, 1998). The second dimension, stakeholder diversity, refers to the individuals among the program community who are involved in carrying out the evaluation. The third dimension, depth of participation, describes the extent to which stakeholders are involved in the different stages of evaluation, including the

design, data collection, processing and analysis, and reporting and dissemination phases. Involvement can range from consultation, where stakeholders have no direct responsibilities, to deep participation, where stakeholders are involved in every aspect of the evaluation (Cousins & Whitmore, 1998).

I will now provide a brief overview of selected participatory evaluation approaches: empowerment evaluation, school-based evaluation, developmental evaluation, and stakeholder-based evaluation. I will also describe the general challenges in using participatory evaluation approaches.

Empowerment evaluation. Community-based participatory action research, which involves persons who are the subject of the research, provides the basis for empowerment evaluation (P. Conway et al., 2010). Fetterman (1994) describes empowerment evaluation as "the use of evaluation concepts and techniques to foster self-determination" (p. 1). Using both qualitative and quantitative methods, empowerment evaluation aims to teach people how to do their own evaluations and hence become more self-sufficient. The literature on empowerment evaluation describes the three steps used in it. These steps are (a) developing a program mission or vision statement, (b) taking stock of or determining the most significant activities in a program, including strengths and weaknesses, and (c) planning for future programming by establishing goals and strategies for accomplishing them (Fetterman, 2001). The overall focus of this approach is on training, facilitation, advocacy, illumination, and liberation.

School-based evaluation. Conversely, the literature on school-based evaluation shows that it is collaborative and allows organizations to develop their own evaluation systems. Originally designed for use in schools by teachers, administrators, students, and parents, school-based evaluation facilitates both internal and external evaluations, thereby assisting with decision

making both within and outside of an organization (Nevo, 1993). The school-based approach suggests that the composition of the evaluation team should change periodically to allow for the sharing of responsibilities and for interested individuals to participate actively in evaluation. Furthermore, the literature includes examples of school-based evaluation that demonstrate how this approach and its evaluation team can become a permanent component within an organization so that service providers gain the capacity and confidence to use evaluative information for decision-making purposes and engage in dialogue with external organizations (e.g., funding bodies) who request program data, information, and evaluation for accountability purposes (Nevo, 1993).

Developmental evaluation. Patton (1997) defines developmental evaluation as "evaluation processes and activities that support program, project, product, personnel and/or organizational development" (p. 317). In developmental evaluation, the evaluator is part of a team that works together, conceptualizes, designs, and assesses new approaches using a long-term, continuous process (Patton, 1997, 2011). Patton (1997) emphasizes that developmental evaluation is not for summative evaluation, as he believes that developmental programs never reach the steady state required for this type of evaluation. He also describes the insignificant role that formal evaluation reports and timelines play in this evaluation approach.

Stakeholder-based evaluation. Finally, as Mark and Shotland (1985) describe, stakeholder-based evaluation "involve[s] stakeholder groups, other than sponsors, in the formulation of evaluation questions and in any other evaluation activities" (p. 606). With a stakeholder-based evaluation approach, many stakeholders are involved (i.e., primarily in a consultative role) in defining evaluation goals and selecting outcomes for evaluation. As described in the literature, the involvement of stakeholders in the evaluation process increases

the relevance and utilization of evaluation data and findings (Mark & Shotland, 1985). Used in a variety of program settings, including several community-based health programs (e.g., Mercier, 1997; Naylor et al., 2002), stakeholder-based evaluation allows for dialogue between various stakeholder groups and evaluators as well as for the inclusion of a wide variety of values. With that said, research on stakeholder-based evaluation noted that, in most circumstances, these approaches cannot incorporate the interests of everyone in evaluation processes, and therefore, additional questions arise around the prioritization of interests (i.e., whose interests should be included in the evaluation).

Challenges in using participatory evaluation approaches. Despite differences in the above-mentioned participatory evaluation approaches, they share some common challenges in terms of implementation. The evaluation literature commonly describes two interconnected challenges in using participatory evaluation approaches. First, many researchers note how, in most case, it is not feasible for all relevant stakeholders to participate in an evaluation and thus, participatory evaluators or those who commissioned the evaluation need to identify and select representatives from various stakeholder groups who might be interested in actively participating in evaluation processes. This selection of stakeholders for evaluations can be difficult as there are there are no definitive procedures for choosing stakeholders as well as a lack of research on stakeholder selection (Daigneault & Jacob, 2009). In fact, some researchers have commented that minimal guidance and research exists on stakeholder selection because evaluators have minimal control over the selection process (House & Howe, 2000). They suggest that evaluation sponsors commonly direct the selection process and thus, evaluators might encounter difficult situations where evaluation sponsors are influencing the focus of the evaluation intentionally or unintentionally (Chelimsky, 2008). Next, despite the advantages of having a highly diverse

group of stakeholders involved in the evaluation, critics of participatory evaluation approaches comment on how evaluators can experience difficulties in managing multiple stakeholders (Cullen, Coryn, & Rugh, 2011; Weaver & Cousins, 2000) and that conflict among stakeholders can sometimes arise because of power differentials and differences in viewpoints or values. Evidently, these conflicts and inclusion of multiple stakeholder groups can result in the need for increased time and resources to mediate differences, solve logistical problems, and complete the evaluation (Stufflebeam & Shinkfield, 2007). Nevertheless, while this diversity can add complexity to participatory evaluation, it is manageable if the evaluators have good group facilitation skills (Burke, 1998) and are able to balance power differentials and encourage trust among the various stakeholders (J. A. King, 1998). In this regard, both Burke (1998) and J.A. King (1998) emphasize the need for evaluators to have strong interpersonal, communication, and conflict management skills.

Participatory and Collaborative Evaluation and Family-Centred Environments

While a review of the evaluation research literature reveals that others have not explored the applicability or use of the above-mentioned alternative evaluation approaches within the rehabilitation family-centred context, some have applied and used collaborative and participatory approaches for evaluating family support programs as well as family-oriented children's mental health services.

Reflecting on the evaluation of family support programs, Weiss and Greene (1992) emphasize that the goal is not to completely abandon traditional or experimental evaluation approaches, but rather to select and design evaluation methods that give voice to the stories and views of the program participants and their families. They also highlight the benefits of various participatory approaches grounded in empowerment, collective dialogue, and social change as

well as comment on the role that evaluation can play in strengthening the intent, activities, and values of family support programs. Similarly, in their initial development of an evaluation approach for family support programs, Green et al. (1996) advocated for a strength-based, collaborative, comprehensive, and flexible evaluation approach that promoted the use of participatory and collaborative approaches and supported the values of the programs being evaluated.

In terms of collaborative and participatory evaluation approaches for evaluating family-oriented children's mental health services, Vander Steop and colleagues (1999) describe how family advocates worked collaboratively with evaluators to design and implement an evaluation of selected family services provided by the King County Blended Funding Project. Their described evaluation approach yielded relevant knowledge for families and elicited candid responses through parent-to-parent interviews. Overall, Vander Steop et al. (1999) state that family-driven evaluation approaches such as theirs require all stakeholders to extend beyond their traditional research comfort zones, to explore new approaches and methods, to allow time for the formation of trusting relationships, and to be willing to enter into unchartered program-planning, implementation, and evaluation areas.

Consequences of Program Evaluation

As suggested in the literature, the primary consequence of evaluation is knowledge production. Depending on the processes used, program evaluation can lead to the production of relevant, credible, and timely forms of knowledge (Cousins, Goh, Clark, & Lee, 2004). Based on the work of Alkin and Taut (2003) and Cousins et al.(2004), the key consequences of program evaluation are the use of evaluation findings and process use.

In terms of use of evaluation findings, Leviton and Hughes (1981) described three broad categories of utilization: instrumental, conceptual, and symbolic. Instrumental use refers to instances where stakeholders use evaluation findings to support decision-making or problem-solving processes (Shulha & Cousins, 1997). This type, therefore, uses evaluation findings for direct actions. Conceptual use refers to the use of evaluation findings to influence stakeholders' thinking about a program. In this sense, it can influence individuals' cognitive processing. However, conceptual use differs from instrumental use in that no action is expected. Symbolic use happens when people use the sheer existence of the evaluation, rather than its results, to persuade, convince, or simply comply with reporting demands (Shulha & Cousins, 1997). Regardless of these different types of use, Patton (1998) suggests that the use of findings is typically a short-term consequence of evaluation because findings are relevant only for specific and limited times.

In opposition to this, process use can have an ongoing influence on specific settings. While there may be similarities between process use and instrumental and conceptual uses, process use does not require changes in programs or direct actions because of evaluation findings (Shulha & Cousins, 1997). Instead, as defined by Patton (1997, 2007), process use leads to changes in stakeholders' attitudes, thought processes, and behaviours as a result of their involvement in program evaluation. There are six types of process use: (1) facilitating stakeholders' understanding of the evaluand, (2) supporting and reinforcing program intervention, (3) increasing stakeholders' engagement as well as their evaluation and critical-thinking skills, (4) facilitating program and organizational development, (5) infusing evaluation thinking into the organization's culture, and (6) promoting instrumentation effects and thus keeping stakeholders focused on program priorities (Patton, 2007). By being involved in the

evaluation processes, stakeholders are able to enter the evaluation culture and learn how to think and look at things through an evaluative lens. They can also use the skills (e.g., methodological and facilitation skills) they obtain to build the evaluation capacity of their organizations. King (2007) suggest that evaluation capacity building (ECB) strengthens and sustains program evaluation activities by developing the setting's abilities to design and implement evaluations as well as stakeholders' abilities to gain and use their evaluation knowledge and skills. In this sense, process use can be useful in various settings regardless of whether or not the evaluation findings or recommendations are unfavourable or not used. However, it is important to note that research on this process use is still in its early stages (Amo & Cousins, 2007).

In the previous sections, I have reviewed: (a) the various forms of evaluation, (b) how context influences evaluation, (c) the purposes for doing evaluation, (d) the various approaches for evaluation, and (e) the consequences of evaluation. I will now explain how I combined these items into a coherent framework to guide the study.

Conceptual Framework

In light of this reviewed literature, I developed a conceptual framework (see Figure 1) to guide this study. This framework provided a certain degree of structure to the study and steered the development of the data-collection tools and analyses. However, the fluid characteristics of the framework as well as the inclusion of general evaluation concepts offered some flexibility to account for unanticipated relationships between concepts or emergent ideas not captured in the literature. As shown in the review above, there is no empirical research on program evaluation within family-centred pediatric rehabilitation settings. There is, however, general research on FCS and evaluation practice, which includes the purposes, approaches, and consequences of evaluation. Given the existence of these bodies of literature, the present study is pre-ordinate in

nature and as such, I developed the aforementioned conceptual framework based on what is known in the field and in advance of data collection.

Context ↔ **Purposes** ↔ **Nature of Practice** ↔ **Consequences**

Family-Centred Service

Organizational Factors

Evaluators' Characteristics

Political Factors

Accountability

Learning

Traditional Evaluation

Participatory Evaluation

Process Use

Use of Findings

Figure 1. Visual diagram of conceptual framework.

The conceptual framework consists of five primary components: program evaluation practice, context, purposes, nature of practice, and consequences. The large vertical rectangles depict four of these components that influence the central component, program evaluation practice (bottom small rectangle), in pediatric rehabilitation settings. Double-headed arrows along the top of the model illustrate the recursive influence of the various components. Additionally, to understand and operationalize these major components, the framework includes a variety of sub-components (dashed rectangles) that align with each major component; the presumed relationship between them (Venn diagram & cycle diagram) is included where applicable.

Summary and Research Questions

This literature review provides a synopsis of various program evaluation, health, and FCS concepts that frame my perspective on program evaluation within family-centred pediatric rehabilitation centres. Nonetheless, it also exposes a number of voids in the relevant literature. First, while this review demonstrates that program evaluation is increasingly important in health care, it also shows that there is little information available on the types of evaluation activities used in specific health-care environments such as pediatric rehabilitation. Second, despite the predominance of FCS in pediatric health-care settings, minimal evidence exists on the degree to which evaluation processes in these settings are consistent with it. Third, the literature shows that context, which includes organizational factors, evaluator characteristics, and political factors, can influence evaluation processes. However, it is unknown how these factors affect the evaluation of family-centred programs within rehabilitation. Fourth, although there are two main purposes for or underlying functions of evaluation (i.e., accountability, learning), the literature suggests that evaluations in health care may be done more for accountability purposes. Again, this idea

has not yet been confirmed by researchers. Similarly, while discourses in the health evaluation literature imply that the use of findings may be higher than process use, investigators have not validated this notion. Finally, the evaluation literature demonstrates that there are various approaches to evaluation, including traditional, collaborative, and participatory, but that researchers have not investigated the benefits and limitations of using these approaches within family-centred rehabilitation environments.

The present study seeks to address these gaps and to advance our knowledge about program evaluation activities in pediatric rehabilitation settings and the role of FCS philosophy in them. It is important to note that the mixed-methods design includes three sequential phases, each with its own guiding research questions. Through this design, the scope of the inquiry increases because each phase provides more information on the evaluation of family-centred programs in pediatric rehabilitation settings. The research questions are as follows:

Phase 1 (Chapter 4)

1.1 To what extent are pediatric rehabilitation settings engaged in the evaluation of family-centred programs?

1.2 Why do pediatric rehabilitation settings engage in the evaluation of family-centred programs? To what extent are the purposes oriented towards accountability versus learning?

1.3 To what extent are the evaluations of family-centred programs consistent with FCS philosophy and logic?

1.4 Does evaluation practice vary as a function of organization size, location, resources, participant characteristics, and beliefs?

Phase 2 (Chapter 5)

2.1 What values, factors, and conditions support or inhibit the evaluation of family-centred programs? How do these values, factors, and conditions affect the evaluation?

2.2 What are the benefits and limitations of mainstream practices in the evaluation of family-centred programs?

Phase 3 (Chapter 6)

3.1 How can the evaluation of family-centred programs be improved?

3.2 (a) Are alternative evaluation approaches likely to be more compatible with FCS philosophy and logic?

3.2 (b) How feasible and practical would it be to implement such approaches?

As shown in the subsequent chapters, the answers to these questions add to the limited body of research on program evaluation within rehabilitation. They also aid in understanding the current evaluation activities in these settings and highlight the current gaps between FCS philosophy and evaluation practices.

Chapter 3: Overview of Study Design and Philosophical Assumptions

This chapter provides a general overview of the design and philosophical assumptions of the present mixed-methods study. It begins with a description of the research context, which includes a synopsis of Canadian pediatric rehabilitation settings, and of my position as an "insider-researcher" or active member of the study group (Dwyer & Buckle, 2009). Next, it discusses some common definitions, philosophies, and justifications for mixed-methods research. Using the information from this discussion, the chapter then explains the research design and philosophical assumptions underlying the study. Finally, it highlights the ethical considerations of the study.

Research Context

This study focuses on program evaluation activities in Canadian pediatric rehabilitation centres. These centres offer a range of rehabilitation and treatment services to children and youth under 19 years of age who have developmental-behavioural conditions, neuromotor/neurological conditions, physical disabilities, musculoskeletal diagnoses, or sensory impairments (Canadian Network for Child and Youth Rehabilitation, 2012). While the programs offered at each pediatric rehabilitation centre vary, they all provide a broad range of assessment, treatment, and community programs to children and youth. For the purposes of this study, I defined a program as a set of planned systematic activities (Yarbrough, Shulha, Hopson, & Caruthers, 2011) that recognize the philosophy of FCS and are designed to achieve specific outcomes or results. Common programs offered at these centres include: (a) augmentative communication programs, (b) blind and low vision program, (c) seating and mobility programs, (c) respite programs, (d) recreation programs, (e) child development programs, (f) acquired brain injury programs, (g) autism programs, and (h) early childhood education programs. As such, these centres employ a

range of service providers, including behaviour consultants, dietitians, early childhood educators, family resource workers, nurses, occupational therapists, psychologists, physicians, physiotherapists, recreation therapists, social workers, and speech-language pathologists. Since evidence suggests that the majority of individuals who work in these educational and health-related occupations are female (Statistics Canada, 2010), the majority of individuals working in these centres are presumably also female.

Of the 29 centres associated with the Canadian Network of Child Youth Rehabilitation (CN-CYR), 28[3] received an invitation to participate in the study. The CN-CYR is a group of organizations and members within the Canadian Association of Pediatric Health Centres (CAPHC)[4] who share an interest in the delivery of child development and rehabilitation services. Twenty-one of the invited centres are located in Ontario and freestanding rather than departments within health-care organizations. In Ontario alone, rehabilitation centres provide services to more than 58,000 children and youth each year (Ministry of Children and Youth Services, 2102). The Ontario Ministry of Children and Youth Services funds these centres, but some also receive additional funding from the Ministry of Education as well as the Ministry of Health and Long-Term Care, depending on the specific services that they provide. Similarly, provincial ministries of health fund the other seven Canadian centres, but some receive additional funding from other ministries, contingent on the types of services that they offer.

As mentioned in the preceding chapters, these Canadian rehabilitation centres have formally adopted the philosophy of FCS. While this philosophy has been widely implemented

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[3] One centre was excluded because it is my place of employment.
[4] The Canadian Association of Pediatric Health Centres is a leader and advocate for advancing the improvement of health care for Canada's children and youth. It provides its member and partner organizations with education, research, and quality improvement initiatives to improve health service delivery for Canadian children and youth (Canadian Association of Pediatric Health Centres, 2011).

across the centres, the level of FCS in the individual centres or programs may vary. Despite this potential variation, it is important to note that CAPHC and CN-CYR also endorse this philosophy through their strong partnerships with the Canadian Family Advisory Network[5] and their commitment to the health and well-being of children, youth, and families (Canadian Association of Paediatric Health Centres, 2011). Moreover, CAPHC and CN-CYR are committed to program evaluation and the improvement of evaluation methodology across Canadian rehabilitation centres (Canadian Association of Paediatric Health Centres, 2011). In fact, in 2011, they launched a new rehabilitation initiative that focuses solely on the improvement of health-care service delivery for children and youth with disabilities. Recognizing that these children and youth depend on several different services and that costs of services for this group can be high, CAPHC and CN-CYR established a national committee to explore ways of developing and collecting process and outcome indictors. Through the development of these indictors, they hope to facilitate program planning and evaluation to ensure the effective management of care and care costs as well as equitable access to high-quality services.

Researcher's Position

As both a researcher and an employee in a pediatric health-care centre and rehabilitation department, I too have a stake in the effective management of care and service delivery. In developing this study, I recognized the need to acknowledge my particular viewpoints and experiences within this context to enhance the methodological rigour of the study (Ritchie, Zwi, Blignault, Bunde-Birouste, & Silove, 2009). For the purposes of the study, I am self-identifying

[5] The Canadian Family Advisory Network (CFAN) was formed in 2002 to link family advisory groups that are involved with pediatric acute care, rehabilitation, and hospices across Canada. It encourages and facilitates the participation of families in health care (Canadian Association of Pediatric Health Centres, 2011).

as an insider-researcher because I was involved with the group being studied prior to the commencement of the research (Louis & Bartunek, 1992; Ritchie et al., 2009). At the time of study inception, I had worked here as a research associate for six years, and I was involved in seven internal program evaluations of family-centred pediatric rehabilitation programs. In this role, I became a proponent of participatory program evaluation and thereby encouraged the clinicians that I worked with to involve representatives from key stakeholder groups, including clients and families, in evaluative activities and knowledge production. I was also a member of both the Operations Committee and the Knowledge Translation and Research Committee for CN-CYR, where I collaborated with representatives from the various centres that participated in this study. It is essential to recognize that these roles created a shared identity, language, and experiential base between the study participants and me (Asselin, 2003). As such, the participants trusted me and were more open in some of their responses. My position also provided me with easy access to centres that might otherwise have been closed to "outsider-researchers" or those with no connections to or little knowledge of the various centres (Dwyer & Buckle, 2009). Regardless, I needed to be aware of the how these roles affected the data-collection processes (e.g., the questions I asked) as well as my interpretation of the findings. I therefore kept a study journal to track and reflect on my subjective research processes, including the reasoning behind my specific research decisions. The contents of this journal were instrumental in helping me interpret the data and develop Chapter 7 (*Discussion, Implications, and Future Directions for Research*). To minimize the risk of bias, I also excluded my centre of employment from the study. By doing this, I was able to use my centre as a pilot site for the various data-collection tools and also to minimize any role confusion where I might have

responded to the participants or data from a perspective other than that of the researcher of this mixed-methods study (Dwyer & Buckle, 2009).

Mixed-Methods Research

There are various definitions, philosophies, and justifications used to describe mixed-methods research. In the sections below, I will discuss some of these items as a way to explain the sequential mixed-methods design and pragmatic philosophical assumptions underlying the present study.

Defining Mixed-Methods Research

Researchers have assigned various definitions to mixed-methods research. Tashakkori and Teddlie (1998) describe it as a methodology and associate it with specific philosophical assumptions and values (Creswell & Plano Clark, 2007). They argue that mixed-methods research influences how researchers frame their research questions and choose their research methods (Tashakkori & Teddlie, 1998). Others characterize mixed-methods research as a method and view it as a doing tool or a way for collecting and analyzing data (Giddings & Grant, 2007). For instance, Greene, Caracelli, and Graham (1989) define mixed-method designs as "those that include at least one quantitative method (designed to collect numbers) and one qualitative method (designed to collect words), where neither type of method is inherently linked to any particular inquiry paradigm" (p. 256). Creswell and Plano Clark (2007), on the other hand, define mixed-methods research broadly as both a methodology and method and suggest the following explanation:

> As a methodology, it involves philosophical assumptions that guide the direction of the collection and analysis of data and the mixture of qualitative and quantitative approaches in many phases in the research process. As a method, it focuses on collecting, analyzing,

> and mixing both quantitative and qualitative approaches in a single study or series of studies. (p.5)

I adopted this aforementioned definition of mixed-methods research because of its comprehensiveness and clear focus. However, it is important to recognize that this given definition can influence the research approach used as well as the philosophical stance embraced.

Philosophies for Mixed-Methods Research

Researchers typically use either a pragmatic or a dialectical lens to guide their mixed-methods studies. Greene and Caracelli (1997), Rocco, Bliss, Gallagher, and Perez-Prado (2003), and Teddlie and Tashakkori (2003) are among the supporters of the dialectical approach whereas Creswell and Plano Clark (2007), Johnson and Onwuegbuzie (2004), Patton (1988), and I are advocates of pragmatism. While pragmatism recognizes that there are fundamental differences between paradigms of inquiry, it views philosophical assumptions as independent and mixable for the purposes of addressing specific research problems (Greene & Caracelli, 1997). Those who adopt this position view the research questions as more important than the methods used or their underlying paradigms (Greene & Caracelli, 2003). Conversely, those who opt for a dialectical position view philosophical paradigms as key in the research process and as factors that must be honoured rather than ignored. Researchers who hold this view juxtapose methods from different paradigms to enhance their understanding of the research problems. In their studies, there is a conscious and explicit back and forth between their quantitative and qualitative components in order to gain a complete understanding of their given topic (Rocco et al., 2003).

Justifications for Mixed-Methods Research

It is, however, important to note that both pragmatic and dialectic theorists and practitioners see important benefits of mixed-methods research. Greene (2007) describes how mixed-methods research provides "fresh insights, [and] new perspectives" (p. 103).
Teddlie and Tashakkori (2003) argue that one of the practical benefits of mixed-methods research is that it provides stronger inferences than those of purely qualitative or quantitative methods. By using mixed-methods, researchers are able to draw on the strengths of both types of approaches, thereby minimizing the weaknesses of each.

Greene and colleagues (1989) also discuss five purposes of mixed-methods research. First, they suggest that mixed-methods research enables triangulation, which is the use of different methods to offset biases in a study and strengthen the validity of the results. Next, they argue that mixed-methods research is excellent for complementarity purposes. That is, researchers can use various methods to investigate different components or dimensions of the same phenomenon (Greene, 2007). Third, they state that mixed-methods research has developmental purposes in that by using qualitative and quantitative methods sequentially, researchers can use the results of the first method to help develop the second method. Fourth, they note that mixed-methods research can have an initiation purpose. In this regard, Greene (2007) describes how researchers can implement different methods to assess various components of the same phenomenon and thus, increase the breadth and depth of the findings and interpretations. Lastly, they argue that mixed-methods research serves an expansion purpose where researchers can use different methods to assess various phenomena and expand the range of their study.

Furthermore, with mixed-methods, researchers are able to answer complex questions that they might not have been able to address using solely qualitative or quantitative approaches. With this type of approach, they, explore how relationships occur, generate theories, and verify theories in the same study. In this sense, mixed-methods research is reflective of practical problem-solving skills, whereby investigators can use both numbers and words, combine inductive and deductive thinking, and employ observation and documentation to answer complex questions (Creswell & Plano-Clark, 2007).

Philosophy of Present Mixed-Methods Study

Given my pragmatic approach, I recognized the existence and value of both the natural and social worlds (Johnson & Onwuegbuzie, 2004) and had an interest in what is and what might be. Using my conceptual framework as well as the inclusion of a quantitative research phase, I held assumptions about the nature of the world that are more of a realist ontology—in which it is assumed that there are things that one can know about the world that are fact or reality. Dewey (1998) describes this realist position as the acceptance of things and events that are independent of thought. However, through the inclusion of qualitative research phases, I also held an ontology that is somewhat relativist—in which the nature of being is dependent on individual or group perspectives and interpretations. In this sense, I contended that thought sometimes leads to distinct acts that can change facts and events (Dewey, 1998). By holding this pragmatic view, it is possible to locate phenomenon in several realms including humans' inner worlds (i.e., knowledge, intentions, feelings), actions, symbolic signs, or the natural environment (Goldkuhl, 2004). Moreover, using a pragmatic epistemology, I was able to draw on multiple approaches from qualitative and quantitative assumptions to understand the problem. As such, I assumed that knowledge could be both constructed and based on the reality of lived experiences (Johnson &

Onwuegbuzie, 2004). Lastly, in terms of axiology, I used a value-oriented approach and recognized that my values affected what I choose to investigate, what I saw, and how I interpreted it (Johnson & Onwuegbuzie, 2004). My values were especially important in developing the questionnaire survey and the interview and focus group guides. They were also significant in my understanding, description, and interpretation of the participants' perspectives. However, it is important to note that I acknowledged my values at the onset of the study and in the interviews and focus groups. During the interviews and focus groups, I also encouraged the participants to discuss their values in relation to FCS and program evaluation.

Design of Present Mixed-Methods Study

A mixed-methods approach is appropriate for this study because there is minimal information on the evaluation activities at these centres as well as a desire to explore several aspects of the phenomenon. Following a sequential mixed design, this study had both developmental and expansion purposes, as defined by Greene, Caracelli, and Graham (1989). In terms of development, it used the results from one method to inform the development of the data-collection tools for subsequent methods. In terms of expansion, it included multiple phases or components, each with their own guiding research questions; as such, the scope of the inquiry increased and provided more information on the evaluation of family-centred programs in pediatric rehabilitation settings. Table 5 provides an overview of the purpose and questions for each phase as well as the sample and instruments used in each.

Table 5

Overview of Methodological Framework

Phase	Purpose	Research questions	Sample	Instruments
Phase 1	To determine and document the level of program evaluation occurring in rehabilitation settings, to verify and elaborate on the motivation for evaluation, to identify and describe salient approaches and methods, including the degree to which they are consistent with FCS philosophy, and to explore whether evaluation practice varies with organization classification, location, and participant characteristics.	1.1. To what extent are pediatric rehabilitation settings engaged in the evaluation of family-centred programs? 1.2. Why do pediatric rehabilitation settings engage in the evaluation of family-centred programs? To what extent are purposes oriented towards accountability versus learning? 1.3. To what extent are the evaluations of family-centred programs consistent with FCS philosophy and logic? 1.4. Does evaluation practice vary as a function of organization classification, location, and participant characteristics?	▪ Staff involved with program evaluation at 15 participating centres	▪ Questionnaire survey
Phase 2	To explore the values, factors, and conditions that support and inhibit the evaluation of family-centred programs in pediatric rehabilitation settings and to describe the benefits and limitations of using mainstream practices for evaluating these programs.	2.1. What values, factors, and conditions support or inhibit the evaluation of family-centred programs? How do these values, factors, and conditions affect the evaluation? 2.2. What are the benefits and limitations of mainstream practices in the evaluation of family-centred programs?	▪ Selected staff involved with program evaluation at 15 participating centres	▪ One-on-one telephone interviews
Phase 3	To suggest how the evaluation of family-centred programs can be improved and to identify the compatibility, feasibility, and practicality of using alternative evaluation approaches within family-centred programs.	3.1. How can the evaluation of family-centred programs be improved? 3.2. (a) Are alternative evaluation approaches likely to be more compatible with FCS philosophy and logic? 3.2 (b) How feasible and practical would it be to implement such approaches?	▪ Selected staff involved with program evaluation at two participating centres ▪ Selected family members involved with two centres	▪ Focus groups ▪ One-on-one telephone interviews

I considered several factors when developing and deciding on this three-phase mixed-methods design. Following the advice of Creswell and Plano Clark (2007), I considered the problem under study, my own level of expertise in quantitative and qualitative data collection and analyses, and the amount of time I had to conduct the study. These factors influenced the timing, weighting, and mixing of the various phases.

Timing. Timing, also known as implementation or sequence, refers to the time and order in which the researcher collects, interprets, and analyzes the quantitative and qualitative components (Creswell & Plano Clark, 2007; Greene et al., 1989). The timing within a mixed-methods study can be either concurrent or sequential. Concurrent timing means that the researcher collects, analyzes, and interprets the quantitative and qualitative data at the same time (Creswell & Plano Clark, 2007). Conversely, sequential timing means that the researcher collects and analyzes one type of data before collecting and analyzing the second type (Creswell & Plano Clark, 2007). Given the sequential nature of the design of this study, I first collected and analyzed the quantitative data and then the qualitative data. By collecting and analyzing the data one phase after another, I was able to use the results from the preceding phase to inform the development of the data-collection tools for the subsequent phase. More specifically, I was able to identify gaps, trends, or ambiguities in the results from one phase and then follow-up on them in the next phase.

Weighting. In addition to timing, I also considered the weighting of the quantitative and qualitative approaches within the study. Weighting refers to the priority that the researcher gives to each research method in answering the research questions (Creswell & Plano Clark, 2007). Both quantitative and qualitative methods can have equal priority or one can have priority over the other in terms of importance in addressing the research problem. Morse (1991) notes that

researchers' decisions with regards to weighting can be theory driven and dependent on whether the study is positivistic, naturalistic, or pragmatic. The decision can also depend on the researchers' interests, goals, and their intended audience. In this study, both the quantitative and qualitative methods were equally important; however, given that the primary goal of the study was to examine the strengths, limitations, and consequences of current practice, along with its compatibility with FCS philosophy, I prioritized Phases 1 and 2 over Phase 3. While still important, Phase 3 addressed the secondary goal of this study, which was to understand the promise and prospects of alternative evaluation approaches that, in theory, are more compatible with FCS philosophy than traditional ones.

Mixing. The last item that I considered in selecting the design for this study was how to mix the quantitative and qualitative data sets and methods (Creswell & Plano Clark, 2007). Creswell and Plano Clark (2007) provide three mixing strategies. First, merging of the data sets can occur during the interpretation or the analysis of the data. Alternatively, mixing can occur by embedding one type of data within the design of the other type. Lastly, mixing can occur when the analysis of one type of data influences, for example, the research questions, selection of participants, or development of data-collection instruments for a subsequent phase. In the current study, I mixed the types of data in two ways. As mentioned earlier, the results of each phase guided the development of the data-collection tools for the subsequent phase. Additionally, I merged the findings from the quantitative and qualitative phases in the discussion section of this dissertation to draw meta-inferences (Creswell & Plano Clark, 2007).

Overview of research process. Figure 2 provides a visual overview of the research process and includes the timing, weighting, and mixing procedures used in the study. The

capitalized words denote the prioritized items, and the arrows depict the sequence of the various components.

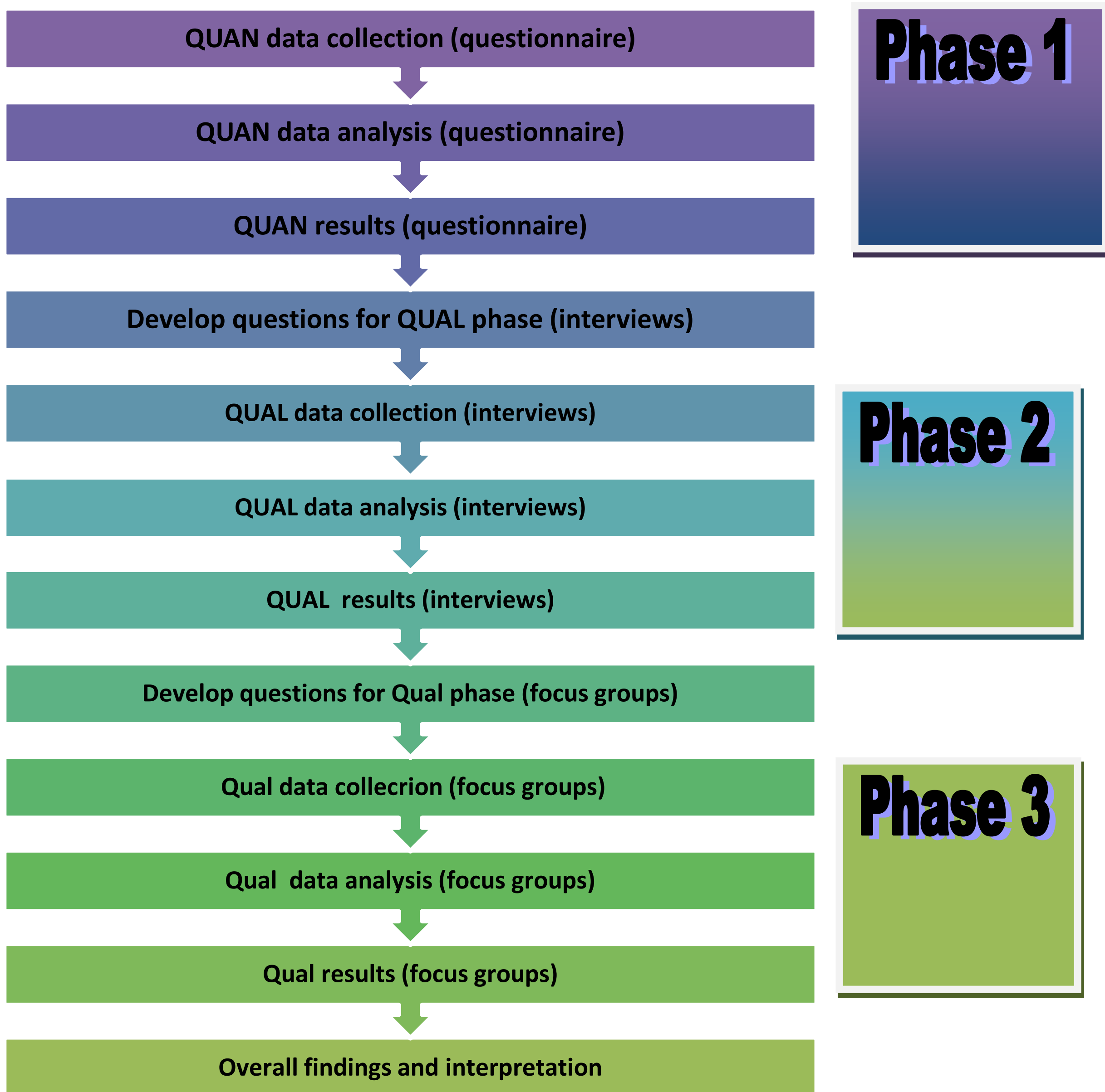

Figure 2. Visual representation of procedures used in three-phase mixed-methods study.

Given the nature of the three phases, I adopted three different strategies for analyses. Although the strategies for Phases 2 and 3 were similar, I tailored each approach to suit the purpose, form, content, and data of its corresponding phase. The next three chapters (Chapters 4,

5, 6), which describe each phase and its respective findings, provide more detail on these strategies for analyses.

Ethical Considerations

I obtained approval for this study from the Social Sciences and Humanities Research Ethics Board at the University of Ottawa, the Toronto Academic Health Sciences Network Research Ethics Board, the Horizon Health Network Research Ethics Board, and two research review committees at participating rehabilitation centres. In addition, chief executive officers (CEOs) at the participating centres provided formal letters of support for the study prior to study recruitment. All oral and written communication with the CEOs and study participants detailed the purpose of the research and discussed confidentiality, anonymity, as well as participants' rights to withdraw from the study. Participants in the study also consented to participation by returning their completed questionnaires (Phase 1) or by signing informed consent forms (Phases 2 and 3).

Summary

In this chapter, I described the ethical considerations for and research context of the present study as well as some of the key definitions and philosophies surrounding mixed-methods research. I also explained the research design and philosophical assumptions that guided this pragmatic, three-phase, sequential mixed-methods study. The main purpose of Phase 1 was to survey staff involved in program evaluation at the participating pediatric rehabilitation centres to determine and document the extent and type of program evaluation occurring in this context. Drawing on the results from Phase 1, Phase 2 consisted of one-on-one telephone interviews with individuals involved in program evaluation at the participating centres. In these interviews, I explored the values, factors, and conditions that support and inhibit the evaluation of family-

centred programs in pediatric rehabilitation settings and exemplified the benefits and limitations of using mainstream practices to evaluate these programs. Lastly, using the results from Phase 2, Phase 3 consisted of focus groups with selected staff members and one-on-one telephone interviews with families to suggest how the evaluation of family-centred programs could be improved. This phase also identified the compatibility, feasibility, and practicality of using alternative evaluation approaches within family-centred programs. As noted above, the next three chapters (Chapters 4, 5, and 6) describe each of these phases in more detail, including the sample, instrument development, procedures, data analyses, and findings of each.

Chapter 4: Phase 1

This chapter describes the methods and results of Phase 1, which surveyed staff members involved with program evaluation at various Canadian pediatric rehabilitation centres. The purpose of this phase was fourfold. It aimed to determine and document the level of program evaluation occurring in these rehabilitation settings, to verify and elaborate on the motivation for evaluation, to identify and describe salient approaches and methods, including the degree to which they are consistent with FCS philosophy, and to explore whether evaluation practice varies with organization classification, location, and participant characteristics. The following research questions guided this phase:

1.1 To what extent are pediatric rehabilitation settings engaged in the evaluation of family-centred programs?

1.2 Why do pediatric rehabilitation settings engage in the evaluation of family-centred programs? To what extent are purposes oriented towards accountability versus learning?

1.3 To what extent are the evaluations of family-centred programs consistent with FCS philosophy and logic?

1.4 Does evaluation practice vary as a function of organization size, location, resources, participant characteristics, and beliefs?

Overall, the answers to these questions highlighted the types of evaluation conducted in family-centred pediatric rehabilitation centres and helped to inform the development of the data-collection tool (i.e., staff member interview guide) for Phase 2.

Sample

For Phase 1, the intention was to obtain a representative sample of the invited 28 pediatric rehabilitation centres associated with CN-CYR. As described in Chapter 3, CN-CYR is

a group of organizations and members within CAPHC who share an interest in the delivery of child development and rehabilitation services. As an initial step in the recruitment for this phase and in obtaining support for the overall study, I contacted the CEOs of these 28 centres by email to seek their permission to survey staff members involved in program evaluation. Fifteen CEOs responded positively and provided formal letters of support for the study and subsequent questionnaire. Of the 15 centres that responded, two were from the Western provinces (i.e., British Columbia, Alberta, Saskatchewan, Manitoba), 11 were from Ontario, one was from Quebec, and one was from the Atlantic provinces (i.e., New Brunswick, Nova Scotia, Prince Edward Island, and Newfoundland). Four of the centres were from small to medium sized cities (population 10, 000-100, 000) and 11 were from large cities (population greater than 100, 000). This sample was representative of the CN-CYR membership because the majority of the 28 organizations associated with CN-CYR are located in Ontario (N=21) and situated in large Canadian cities (N=22). Moreover, the number of pediatric rehabilitation centres in Quebec (N=1) and the Western (N=4) and Atlantic (N=2) provinces is minimal, as they serve large catchment areas. In total, site representatives from the participating centres distributed 682 questionnaires to individuals who were potentially eligible for the study. Given that these organizations vary in size, the number of questionnaires distributed at each ranged between 3 and 250.

Instrument Development

I used the conceptual framework for the study to guide the development of the questionnaire. Although this framework consists of five basic components, I focused mainly on four components for the questionnaire: program evaluation practice, context, purposes, and consequences. To operationalize these components and generate dimensions and items for the

questionnaire, I used a combination of existing tools that measure program evaluation activities and FCS.

In terms of the tools that I used for measuring program evaluation activities, Smith, Ryan, and Cousins (2007) conducted an Ontario-wide survey to explore program evaluation activities for anti-bullying programs in schools. I modified the wording of their survey items, which focused on purposes for evaluation, the kinds of information collected, and the consequences of evaluation, to fit the rehabilitation context of the present study and used them to quantify the extent to which pediatric rehabilitation settings are engaged in program evaluation and why they are doing it. Next, to help develop the items and scales for assessing the extent to which the evaluations of family-centred programs are consistent with FCS philosophy and logic, I used items from the *Measure of Processes of Care for Service Providers* (MPOC-SP) developed by Woodside, Rosenbaum, King and King (2001) and the *Patient- and Family-Centered Pediatric Ambulatory Care: Self-Assessment Inventory* (Institute for family-centered care, 2006). The MPOC-SP consists of 27 items and is a self-assessment questionnaire for health professionals working with children who have chronic health or development problems. It is designed to measure pediatric service providers' reported implementation of FCS along four scales (i.e., Showing Interpersonal Sensitivity, Providing General Information, Communicating Specific Information about the Child, Treating People Respectfully). Studies (Siebes et al., 2006; Woodside, Rosenbaum, King, & King, 2001) have shown that it is both reliable and valid as a measure of the provision of FCS in rehabilitation settings. I also used items from the *Patient- and Family-Centered Pediatric Ambulatory Care: Self-Assessment Inventory* designed by the Institute for Patient- and Family-Centered Care (2006). While the validity and reliability of this inventory is unknown, staff working in outpatient clinics, hospitals, and health systems use it to

reflect on how well they are operationalizing patient- and family-centred care. Overall, I used the three aforementioned instruments in conjunction with the conceptual framework to develop the dimensions and items for the questionnaire.

Table 6

Description of Dimensions for Questionnaire

Component Dimension Sub-dimension	**Survey item numbers**
Screening	1
Program evaluation type	
Needs assessment[a]	6.1, 6.2, 6.3
Assessment of program theory[a]	6.4, 6.5, 6.6
Assessment of program process[a]	6.7, 6.8, 6.9
Impact assessment[a]	6.10, 6.11, 6.12
Efficiency assessment[a]	6.13, 6.14, 6.15
Design & methods	6.16, 6.17, 6.18, 6.19
Context	
Participant characteristics	11, 12, 13, 14, 15, 16, 17
Participant beliefs	10.1, 10.2, 10.3
Resources	2, 3, 4, 5, 14
Family-centred	
Collaboration[a]	7.1, 7.2, 7.3, 7.4
Interpersonal sensitivity[a]	7.5, 7.6, 7.7, 7.8
Respect[a]	7.9, 7.10, 7.11, 7.12
Communication[a]	7.13, 7.14, 7.15, 7.16
Organization location	18
Organization classification	19
Purposes of program evaluation	
Accountability[a]	8.1, 8.2, 8.3
Learning[a]	8.4, 8.5, 8.6, 8.7, 8.8
Consequences	
Conceptual use	9.1, 9.2
Instrumental use	9.3, 9.4
Symbolic use	9.5, 9.6
Process use	9.7, 9.8

[a] Scale scores were calculated for these dimensions and sub-dimensions.

Table 6 provides a description of the questionnaire dimensions and the numbered references for the items that fall under each of the dimensions. Conversely, Table 7 illustrates how these dimensions relate to the specific research questions for Phase 1.

Table 7

Relationship between Research Questions and Dimensions for Questionnaire

Research questions		Dimensions
1.1)	To what extent are pediatric rehabilitation settings engaged in the evaluation of family-centred programs?	- Needs assessment - Assessment of program theory - Assessment of program process - Impact assessment - Efficiency assessment - Design & methods - Resources
1.2)	Why do pediatric rehabilitation settings engage in the evaluation of family-centred programs? To what extent are purposes oriented towards accountability versus learning?	- Accountability - Learning - Conceptual use - Instrumental use - Symbolic use - Process use
1.3)	To what extent are the evaluations of family-centred programs consistent with FCS philosophy and logic?	- Family-centred - Participant beliefs
1.4)	Does evaluation practice vary as a function of organization classification, location, and participant characteristics?	- Organization location - Organization classification - Participant characteristics - Accountability - Learning - Family-centred - Needs assessment - Assessment of program theory - Assessment of program process - Impact assessment - Efficiency assessment

It is important to note that for this questionnaire the FCS dimensions included collaboration, interpersonal sensitivity, respect, and communication. Table 8 provides the definitions for these FCS dimensions.

Table 8

Definitions of FCS Dimensions

FCS Dimension	Definition
Collaboration	Service providers or evaluators working in partnership with families in the evaluation of their children's programs, particularly in decision-making processes and the development of ways to elicit families' inputs and concerns.
Interpersonal sensitivity	Service providers or evaluators supporting and enabling families in the evaluation of their children's programs in a manner that will contribute positively to their parental roles and the raising of their children.
Respect	Service providers or evaluators treating families as individuals and equals with valuable insights during evaluation.
Communication	Service providers meeting families' information needs in terms of evaluation.

Presented in booklet format, the questionnaire (see Appendix B) was seven pages in length and consisted of 19 closed-ended questions, each with multiple items. For question 1, respondents confirmed their eligibility for the study by indicating if they were or are involved in a variety of program evaluation activities at their centre. If they were not or are not involved, the questionnaire thanked them for their participation and instructed them to return it in the designated envelope. Questions 2 to 5 focused on the resources that the respondents' centres have for program development and evaluation. Question 6 examined the extent to which the respondents' centres engaged in a variety of activities related to needs assessments, assessments of program theory, assessments of program process, impact assessments, and efficiency assessments. Question 7 explored the extent to which the evaluation activities are consistent with

FCS philosophy and logic while question 8 investigated the accountability and learning purposes of evaluations. For questions 6 to 8, respondents rated the degree to which their centres performed various activities or behaviours on a 5-point scale, where 1 meant *Never* and 5 meant *Always*. For question 9, respondents indicated their level of agreement with statements related to evaluation consequences using a 4-point scale, where 1 indicated *Strongly Disagree* and 4 indicated *Strongly Agree*. Lastly, questions 10 to 19 concentrated mainly on the respondents' beliefs about FCS, their formal training in program evaluation and research methods, as well as their ability to make decisions about the type of evaluation activities used at their centres. For these questions and items, I used a variety of scales and response options. In the hopes of minimizing the number of missing responses, I also included a *Don't know* option for the majority of the questions.

It is also important to note that I included definitions for the terms "program evaluation" and "program evaluation activities" at the top of the questionnaire. My intention was to be as general as possible, but specific enough to differentiate the assessment that occurs solely for clinical purposes at the client level from the evaluation that occurs at the overall program level. Furthermore, the instructions for the questionnaire directed respondents to reflect on their experiences with program evaluation at their centres over the past five years. I selected this timeframe in an attempt to elicit responses that reflected current practice.

Ten reviewers from the Children's Hospital of Eastern Ontario Research Institute, who have knowledge of program evaluation activities and the health sector, reviewed a draft of the questionnaire for content validity. This review ensured that the contents were appropriate and relevant to the topic and that the questionnaire was not missing any pertinent items or dimensions (Litwin, 2003). I also piloted the questionnaire with 30 program administrators and

service providers working at the Children's Hospital of Eastern Ontario Rehabilitation Patient Service Unit. I used the data obtained from this pilot to perform an internal consistency analysis to assess the homogeneity of the items within each of the 11 scale variables of the questionnaire. Using Cronbach's coefficient alpha,[6] I demonstrated that each item belonged in its corresponding scale variable (see Table 9). Since all items demonstrated high internal consistency, I did not remove any.

Table 9

Internal Consistency for 11 Scale Variables

Scale variable	N	Numbers of scale items	Cronbach alpha
Needs assessment	30	3	.968
Assessment of program theory	29	3	.867
Assessment of program process	30	3	.945
Impact assessment	28	3	.945
Efficiency assessment	30	3	.928
Collaboration	12	4	.871
Interpersonal sensitivity	29	4	.880
Respect	29	4	.942
Communication	29	4	.791
Accountability	30	3	.966
Learning	29	5	.961

[6] Cronbach's coefficient alpha is a measure of internal consistency. Alpha values usually vary between 0 and 1. The closer the alpha statistic is to 1, the greater the internal consistency of the items (George & Mallery, 2006).

As part of this pilot, I also asked each respondent to complete a debriefing questionnaire that focused on the appropriateness, comprehensibility, and feasibility of the questionnaire (see Appendix C). Their responses to this debriefing questionnaire helped to refine the general format of the questionnaire and the instructions for it.

Procedure

Once the CEOs of the participating centres endorsed the study and the distribution of the questionnaire, I worked with each of them to identify a site representative to support the data-collection activities. These representatives provided me with the approximate number of individuals who were involved with program evaluation at their centres. Based on these numbers, I sent pre-packaged envelopes to the representatives for distribution. Each envelope contained an information letter (see Appendix D), a blank and anonymous questionnaire, and a pre-addressed and stamped return envelope. The site representatives placed the pre-packaged envelopes in the mailboxes of the potential respondents. While Dillman's (2000) Tailored Design Method (2000) recommends a five-contact strategy (i.e., a pre-notice letter, a questionnaire, a thank-you postcard, a replacement questionnaire, a final contact) to obtain a high response rate, this study used a modified Tailored Design Method (see Table 10) with only two reminder letters (see Appendix E). This modified approach did not overburden the site representatives or potential respondents, but still made them aware of the importance of the questionnaire and their participation in Phase 1.

Table 10

Modified Version of Tailored Design Method

Type of mailing	Contact time point	Procedure
First mailing	Day 1	Distribute copy of anonymous questionnaire with information letter and return envelope.
Second mailing	Day 14	Distribute postcard reminding all participants that they should have received a questionnaire two weeks ago and asking them to please return the questionnaire if they have not already done so.
Third mailing	Day 28	Distribute replacement questionnaire with cover letter with different message as well as original information letter and return envelope.

Consent to participate in this portion of the study was implied by the respondents' submission of their completed questionnaire. The questionnaire took the respondents approximately 15 to 25 minutes to complete.

Data Analysis

The research questions for Phase 1 and the format of the data were the primary criteria used to select the general analytical procedures described below. Questionnaire data were analyzed using descriptive and inferential statistics in IBM SPSS (version 19) software. Descriptive statistics were used to calculate frequencies, percentages, means, standard deviations, medians, and minimum to maximum values. Each respondent's data yielded 11 scale variables (i.e., averages of the item-variables). Using Cronbach's alpha, the internal consistency of each scale variable was calculated. Next, regression analyses were used to explore if

evaluation practice (i.e., needs assessment, assessment of program theory, assessment of program process, impact assessment, efficiency assessment, collaboration, interpersonal sensitivity, respect, communication) varied as a function of selected variables related to organization classification (i.e., freestanding or sub-centre), location (i.e., large or small to medium city), and participant characteristics (i.e., evaluation training, research methods training, ability to make decisions, primary discipline, primary role, length of employment). As described below, both simple linear regression[7] and standard multiple regression[8] were used. Initially, to prepare for these regression analyses, zero-order correlation coefficients were calculated to describe the strength and direction of the linear relationships between the independent and dependent variables and to identify potentially significant predictors for each of the evaluation practice variables. More specifically, Spearman's *r* was used as the measure of association because the variables used different scale types. All correlation coefficients were interpreted using Davis (1971) descriptors (i.e., negligible = .00 to .09; low =.10 to .29; moderate = .30 to .49; substantial = .50 to .69; very strong = .70 to 1.00). Correlations between the various predictor variables were also checked to ensure that the assumptions of non-multicollinearity were met for the multiple regression analyses. If any independent variables were very strongly correlated (i.e., r = .70 to 1.00), it was assumed that multicollinearity existed (Allison, 1999). To facilitate data reduction, only the most relevant independent and dependent variables were selected for the regression analyses; to ensure that there was a minimum of ten cases for each predictor variable (Brace, Kemp, & Snelgar, 2006), only variables with statistically significant correlations were selected for the analyses. As such, both simple and multiple regressions were

[7] Simple linear regression measures the amount of influence one independent or predictor variable has on a dependent or criterion variable (George & Mallery, 2006).
[8] Multiple regression shows the amount of influence two or more independent or predictor variables have on a dependent or criterion variable (George & Mallery, 2006).

used. Simple linear regression analyses were used if only one independent variable showed a statistically significant relationship with the designated dependent variable. Conversely, standard multiple regression analysis was used if two or more independent variables demonstrated statistically significant correlations with the criterion variable. With this standard approach, the selected independent variables were entered into each equation simultaneously. This approach was the safest to use given the relatively low number of cases for analyses and the lack of strong theoretical predictions (Brace et al., 2006). For all regression analyses, dummy variables were created for nominal variables with more than two categories (see Appendix F), the alpha level was set at .05, and listwise deletion[9] was used. Given the exploratory nature of this study, in which data were collected based on objectives rather than pre-specified hypotheses, multiple test adjustments for the regression analyses were not strictly required (Bender & Lange, 2001). All results were viewed as descriptive and exploratory and thus, must be tested in future confirmatory studies (Bender & Lange, 2001).

Findings

Characteristics of Questionnaire Respondents

In total, I received 204 completed questionnaires, constituting a response rate of 29.9%. While Church and Waclawski (1998) report that response rates between 30% and 85% are typical for organizational surveys of employees, this response rate is on the lower end of this range and as such, the data would have yielded results that are more reliable if the response rate was higher. Moreover, because the questionnaires were anonymous, I was unable to investigate the possibility of a non-response bias or determine the response rates from each of the participating centres. As such, the survey respondents may not be a true representation of all

[9] Listwise deletion means that if one or more missing value(s) exist for a subject, all data for that subject are removed prior to analyses (George & Mallery, 2006).

those involved in program evaluation at the 15 participating pediatric rehabilitation centres. Moreover, at four centres, the site representatives did not know who was involved in program evaluation activities and therefore, they distributed the surveys to all staff members whose departments were active in terms of program development and delivery and potentially engaged in program evaluation. This wide distribution may have contributed to the lower response rate.

Based on the responses to question 1, which confirmed respondents' eligibility, 188 of the 204 respondents were involved in program evaluation and thus eligible for the study.

Table 11

Respondents' Involvement in Program Evaluation Activities (N = 188)

Item	**n (%)**
Involved in or responsible for the:	
Design of program evaluation activities	118 (62.8)
Selection of data-collection instruments for program evaluation activities	115 (61.2)
Collection of data/information for program evaluation activities	170 (90.4)
Analyses of data from program evaluation activities	92 (48.9)
Interpretation of results from program evaluation activities	97 (51.6)
Preparation of reports for program evaluation activities	93 (49.5)
Formulation of recommendations generated from program evaluation activities	96 (51.1)
Dissemination of results and recommendations from program evaluation activities	92 (48.9)

As shown in Table 11, these respondents were involved in a variety of program evaluation activities. Approximately one-third (33.0%) were involved in all listed aspects of evaluation—from design to dissemination. While the majority (90.4%) of participants indicated involvement in data collection, only 22.3% reported being involved solely in this aspect of

evaluation. Moreover, 79 (42.0%) indicated that they were able to make decisions about the type of program evaluation activities used in their centres.

Additional demographic data about the respondents and their centres revealed that the respondents were also somewhat diverse, especially in terms of primary discipline (see Table 12).

Table 12

Respondents' Demographics

Item	N	n (%)
Primary discipline	180	
Medicine		4 (2.2)
Nursing		11 (6.1)
Business administration/Management		14 (7.8)
Occupational therapy		41 (22.8)
Social work		7 (3.9)
Audiology		5 (2.8)
Education		8(4.4)
Psychology		19 (10.6)
Recreational therapy		9 (5.0)
Speech-language pathology		29 (16.1)
Physiotherapy		33 (18.3)
Primary role	185	
Clinician/Service provider		148 (80.0)
Director/Manager		37 (20.0)
Time worked at centre	185	
1 to 10 years		115 (62.2)
11 or more years		70 (37.8)
Gender	185	
Female		179 (96.8)
Geographical context of centre (Location)	185	
Large city (population 100, 000+)		144 (77.8)
Small to medium city (population 10, 000-100, 000)		41 (22.2)
Classification of centre	185	
Freestanding centre		142 (76.8)
Sub-centre		43 (23.2)

The next section explores the extent to which these participants thought that their pediatric rehabilitation centres engaged in the evaluation of family-centred programs.

1.1 To what extent are pediatric rehabilitation settings engaged in the evaluation of family-centred programs?

The results demonstrate that the participating centres do not engage frequently or always in all activities relate to needs assessments, assessments of program theory, assessments of program process, impact assessments, and efficiency assessments. In terms of noteworthy responses for the 19 items related to these forms of assessment, more than half (50.6%) of the respondents stated that their centres frequently or always assess if programs will address their clients' or patients' needs; 31.0% noted that their centres frequently or always create or obtain written plans on how programs are supposed to work; 39.0% said that their centres investigate frequently or always how well programs are operating; 34.0% said that their centres frequently or always evaluate the outcomes and impacts of programs; and finally, 42.0% were unsure whether or not their centres examined if the effects of programs are attained at reasonable costs.

In an attempt to reduce the amount of data and better understand the extent to which pediatric rehabilitation settings engage in the evaluation of programs, a series of scale variables were also created. As illustrated in Table 13, each scale variable demonstrated high internal consistency.

Table 13

Internal Consistency for Program Evaluation Scale Variables

Scale variable	**N**[a]	**Number of scale items**	**Cronbach alpha**
Needs assessment	141	3	.877
Assessment of program theory	122	3	.878
Assessment of program process	133	3	.806
Impact assessment	136	3	.903
Efficiency assessment	102	3	.903

[a]The N values decreased because the *Don't know* options were removed for the purpose of creating the scale variables.

Based on these scale variables, the respondents indicated that their pediatric rehabilitation centres more commonly conduct need assessments (*M*= 3.6, *SD* = 0.7) and assessments of program process (*M*= 3.5, *SD*= 0.7) rather than assessments of program theory (*M*= 3.3, *SD*= 0.8), impact (*M*=3.3, *SD*=0.9), or efficiency (*M*=3.2, *SD*=0.9). In terms of study design and data collection for these assessments, the respondents' answers were variable; as such, it is unclear what types of designs and methods their centres use on a regular basis (see Table 14). Moreover, roughly one-third of the respondents did not know if their centres used any of the listed study designs or data-collection methods.

Table 14

Methods Used to Evaluate Pediatric Rehabilitation Programs

Method	n (%)					
	Never	**Rarely**	**Sometimes**	**Frequently**	**Always**	**Don't know**
Pre- and post-tests	11 (5.9)	22(11.7)	55 (29.3)	36 (19.1)	10(5.3)	54(28.7)
Experimental/Quasi-experimental	43(22.9)	41(21.8)	20 (10.6)	8 (4.3)	2 (1.1)	74 (39.4)
Standardized measures	13(6.9)	21(11.2)	47(25.0)	31(16.5)	10(5.3)	66 (35.1)
Focus groups or interviews	12 (6.4)	31(16.5)	63(33.5)	22 (11.7)	8 (4.3)	52 (27.7)

In light of this methodological uncertainty, it is important to recognize that few (18.1%) respondents indicated that their centres have an employee whose primary responsibility is program evaluation and even less (8.5%) confirmed that their centres receive funding for program evaluation. Furthermore, although 42.6% of respondents reported formal training in research methods, only 19.1% have formal training in program evaluation. Three of these respondents obtained their evaluation training through continuing education programs and workshops, while the reminder received training as part of their professional graduate degree programs (e.g., PhD in Psychology, Masters in Social Work, Masters of Occupational Therapy)

Summary for Question 1.1

Overall, respondents indicated that their pediatric rehabilitation centres sometimes or frequently conduct need assessments and assessments of program process and that they more commonly conduct these forms of assessment rather than assessments of program theory, impact, or efficiency. In terms of study design and data collection for these assessments, the respondents' answers were variable; as such, it is unclear what types of designs and methods their centres use

on a regular basis. The respondents also reported that their centres have minimal resources (e.g., employees, funding) for program evaluation and a small percentage of employees with formal training in program evaluation. The questionnaire also examined why pediatric rehabilitation settings engage in the above-mentioned evaluation activities. I now turn to an examination of the reasons for doing evaluation.

1.2 Why do pediatric rehabilitation settings engage in the evaluation of family-centred programs? To what extent are purposes oriented towards accountability versus learning?

The respondents suggested that their centres, in varying degrees, engage in evaluation for purposes of both accountability and learning (see Table 15). However, of particular interest is the amount of respondents who did not know the extent to which their centres engaged in evaluation for the given purposes.

Table 15

Reasons for Engaging in the Evaluation of Family-Centred Rehabilitation Programs (N = 188)

Purpose	n (%)					
	Never	Rarely	Sometimes	Frequently	Always	Don't know
Accountability						
To satisfy accountability demands	4 (2.1)	10 (5.3)	45 (23.9)	58 (30.9)	26 (13.8)	45 (23.9)
To produce evidence of program effectiveness	6 (3.2)	17 (9.0)	57 (30.3)	57 (30.3)	18 (9.6)	33 (17.6)
To make decisions about programs	4 (2.1)	14 (7.4)	65 (34.6)	54 (28.7)	18 (9.6)	33 (17.6)
Learning						
To develop evaluation and inquiry skills	10 (5.3)	29 (15.4)	50 (26.6)	34 (18.1)	6 (3.2)	59 (31.4)
To understand programming issues more fully	6 (3.2)	16 (8.5)	66 (35.1)	36 (19.1)	14 (7.4)	50 (26.6)
To stimulate changes in clinical practice	6 (3.2)	15 (8.0)	67 (35.6)	47 (25.0)	14 (7.4)	39 (20.7)
To learn about other people's perspectives of programs	3 (1.6)	24 (12.8)	61 (32.4)	42 (22.3)	13 (6.9)	45 (23.9)
To improve overall practices and service	2 (1.1)	10 (5.3)	60 (31.9)	65 (34.6)	23 (12.2)	29 (14.9)

Both the accountability and learning scale variables demonstrated high internal consistency, with Cronbach's alphas of .861 and .911, respectively. They also revealed that the respondents' pediatric rehabilitation centres conduct evaluation slightly more for accountability purposes (*M*= 3.5, *SD*= 0.8) than learning (*M*= 3.3, *SD*= 0.8). Furthermore, when asked to rate the degree to which they agreed with selected statements regarding the consequences of program

evaluation at their centres, the respondents agreed that their pediatric rehabilitation centres use evaluation to better understand their programs and practices (*M*=3.0, *SD*=0.7), to learn from their experiences (*M*= 3.0, *SD*= 0.6), to comply with reporting demands (*M*= 3.1, *SD*= 0.6), and to justify decisions previously made about programs (*M*= 3.0, S*D*= 0.7). Conversely, respondents disagreed that their centres base decisions about programs on evaluation results (*M*=1.8, *SD*= 0.7), use evaluation results to influence changes in program policies and procedures (*M*=2.0, *SD*=0.7), use evaluation to develop their research and inquiry skills (*M*= 1.5, *SD*= 0.8), or use evaluation to change their behaviour and thinking (*M*=1.9, *SD*= 0.7).

Summary for Question 1.2

Although several respondents did not know why their centres engaged in evaluation, the findings show that pediatric rehabilitation centres conduct evaluation slightly more for accountability purposes rather than learning. In addition, use of findings is more frequent than process use in these centres. More specifically, the centres are using evaluation findings to better understand their programs and practices or comply with reporting demands rather than to develop their research and inquiry skills or change their behaviour and thinking. I now turn to an examination of the extent to which the evaluations of family-centred programs are consistent with FCS philosophy and logic.

1.3 To what extent are the evaluations of family-centred programs consistent with FCS philosophy and logic?

The results demonstrated that the evaluations of family-centred program are somewhat consistent with FCS philosophy and logic, but that improvements are still necessary to incorporate certain family-centred behaviours into program evaluation activities. On the four FCS scales (i.e., collaboration, interpersonal sensitivity, respect, communication), the

respondents' ratings of their pediatric rehabilitation centres were mainly in the *sometimes* to *frequently* extent range, with lower mean scores for collaboration and interpersonal sensitivity (see Table 16).

Table 16

Means, Standard Deviations (SD), Median (Min-Max), and Cronbach Alphas of Family-Centred Evaluation Scales

Scale variable	N[a]	Mean (SD)	Median (Min-Max)	Cronbach alpha
Collaboration	103	2.9 (1.0)	3.0 (1-5)	.868
Interpersonal sensitivity	104	2.9 (1.1)	3.0 (1-5)	.933
Respect	140	3.8 (0.9)	4.0 (1-5)	.939
Communication	106	3.4 (1.0)	3.3 (1-5)	.877

[a]The N values decreased because the *Don't know* options were removed for the purpose of creating the scale variables.

Collaboration. In terms of collaboration, 17% of respondents said that their centres work in partnership with families to identify evaluation priorities; 8% noted that their centres frequently or always work in partnership with families to select program evaluation designs and data-collection tools; 15% reported that their centres frequently or always allow families to choose their level and type of involvement in program evaluation activities; and 37% indicated that their centres commonly view families as members of the evaluation team.

Interpersonal sensitivity. The respondents also suggested that their centres, in most cases, are not engaging in specific behaviours that may enhance interpersonal sensitivity in evaluation. The results showed that 25% of respondents stated that their centres frequently or always take the time to establish relationships with families during evaluation; 17% indicated that their centres discuss and explore each family's feelings about participating in program

evaluation activities; only 11% noted that their centres frequently or always select program evaluation designs and methods that fit with families' needs and lifestyles; and finally, 18% said that their centres typically help each family secure a stable relationship with at least one individual who works with them throughout the evaluation process.

Respect. Next, responses with regards to respect were slightly more positive but still showed room for improvement. The majority of respondents indicated that their centres did ensure, frequently or always, that families were (a) treated as the true experts on their children during evaluation (59.0%), (b) given opportunities to say what was important to them during evaluation activities (62.2%), and (c) treated as people rather than as "data sources" during evaluations (62.2%).

Communication. Lastly, in relation to communication, 37.3% of respondents stated that their centres encourage communication among families, service providers, and evaluators during evaluation. More than half (55.3%) of the respondents also indicated that their centres commonly use language that families can understand when communicating about program evaluation activities, but less than one-third (27.1%) stated that their centres routinely offer information about program evaluation activities to families in a variety of ways.

It is also important to note that several respondents did not know the extent to which their pediatric rehabilitation centres engaged in the various family-centred behaviours with regards to program evaluation activities. However, 79.0% believed that their centres highly valued FCS, 61.0% indicated that their centres promoted FCS to a great extent, and 88.1% stated that they were moderately or greatly interested in a family-centred approach to evaluation.

Summary for Question 1.3

To summarize, the findings showed that evaluation activities are somewhat consistent with FCS philosophy and logic, but that improvements are needed, especially in terms of collaboration and interpersonal sensitivity. It is also important to note that several respondents did not know the extent to which their pediatric rehabilitation centres engaged in the various family-centred behaviours in terms of program evaluation. Nevertheless, the majority stated that their centres highly valued FCS, that their centres promoted FCS, and that they are interested in a family-centred approach to evaluation.

Responses from this questionnaire were also used to determine if evaluation practice varies according to organization classification, location, and respondent characteristics.

1.4 Does evaluation practice vary as a function of organization classification, location, and participant characteristics?

As shown in Table 17, five independent variables showed statistically significant correlations with some of the dependent evaluation practice variables. The data demonstrated low to moderate statistically significant positive correlations between the location of the organization and needs assessment, impact assessment, and efficiency assessment as well the four FCS evaluation activity variables and two evaluation purpose variables. In particular, respondents from pediatric rehabilitation centres located in small to medium cities reported that their centres engaged more often in needs assessments, impact assessments, efficiency assessments, FCS evaluation activities, and evaluation for both accountability and learning purposes than those situated in larger cities. Moreover, the analysis highlighted a low statistically significant negative association between formal training in evaluation and efficiency assessment, meaning that, in comparison to those with formal training in evaluation, respondents with no

training reported that their centres do more efficiency assessments. Similarly, the findings showed low statistically significant negative correlations between formal training in research methods and assessment of program process, efficiency assessment, and communication. As such, those with no formal training in research methods tended to state that their centres do more assessments of program process and efficiency than those with formal training in research methods. They also reported higher levels of communication with families during evaluation activities. Next, the results demonstrated low statistically significant positive correlations between respondents' abilities to make decisions about evaluation and needs assessment as well as both evaluation purpose variables (i.e., learning and accountability). Specifically, those with the ability to make evaluation decisions noted that their centres engaged more often in needs assessments and evaluation for both learning and accountability purposes than those who could not make evaluation decisions. The data also illustrated low statistically significant negative correlations between respondents' length of employment and efficiency assessment as well as communication and interpersonal sensitivity. In general, newer employees stated that their centres did more efficiency assessments and scored higher in terms of collaborating with and showing interpersonal sensitivity to families during evaluation activities than those with long-time employees. Lastly, the correlation matrix (see Table 18) established that the bivariate relationships between the independent variables was not too high, and thus, there was only a low to moderate probability that the assumption of non-multicollinearity may be violated in the regression analyses. The largest correlation was 0.35, which is below the recommended maximum of 0.60 (Allison, 1999).

Table 17

Bivariate Correlations between Type of Evaluation, FCS Evaluation Activities, Evaluation Purpose (Dependent Variables) and Organization Classification, Location, and Participant Characteristics (Independent Variables)

Variable	**Classification of organization** (0= Freestanding 1= Sub-centre)	**Location of organization** (0= Large city 1= Small to medium city)	**Formal training in evaluation** (0= No training 1= Yes training)	**Formal training in research methods** (0= No training 1= Yes training)	**Ability to make decisions about evaluation** (0= No decision-making ability 1= Yes decision-making ability)	**Primary discipline** (0= Other professional 1= Rehab Science professional)	**Primary role** (0=Clinician/ Service Provider; 1= Manager /Director)	**Length of employ-ment** (0= 0-10yrs 1= 11 + yrs)
				Type of evaluation				
Needs assessment	.030	.230**	-.153	-.069	.164*	-.106	.058	-.081
Assessment of program theory	-.092	.109	-.005	-0.11	.074	-.099	-.084	-.074
Assessment of program process	-.131	-.032	-.013	-.164*	.148	-.138	.043	-.043
Impact assessment	-.016	.206**	.068	-.077	.120	-.016	.018	.004
Efficiency assessment	.069	.196*	-.217*	-.182*	-.073	-.003	-.068	-.202*
				FCS Evaluation Activities				
Collaboration	-.023	.155*	-.080	-.141	-.118	-.006	-.136	-.188**
Interpersonal sensitivity	-.035	.318**	-.075	-.157	.015	-.015	-.067	-.189*
Respect	.007	.235**	.035	-.075	.058	-.019	-.095	-.014
Communication	-.018	.168*	-.055	-.177*	-.062	.027	-.082	-.096
				Evaluation Purpose				
Accountability	-.063	.195*	-.008	-.046	.180*	-.056	-.034	-.003
Learning	.013	.202**	.098	-.036	.191*	-.047	-.074	.056

* $p < 0.05$. ** $p < 0.01$

Table 18

Inter-Correlations among Predictor Variables

Variable	**Classification of organization** (0= Freestanding 1= Sub-centre)	**Location of organization** (0= Large city 1= Small to medium city)	**Formal training in evaluation** (0= No training 1= Yes training)	**Formal training in research methods** (0= No training 1= Yes training)	**Ability to make decisions about evaluation** (0= No decision-making ability 1= Yes decision-making ability)	**Primary discipline** (0= Other professional 1= Rehab Science professional)	**Primary role** (0=Clinician/Service Provider; 1= Manager /Director)	**Length of employment** (0= 0-10yrs 1= 11 + yrs)
Classification of organization								
Location of organization	-.201**							
Formal training in evaluation	.003	-.018						
Formal training in research methods	.042	-.040	.350**					
Ability to make decisions about evaluation	.003	-.002	.244**	.226**				
Primary discipline	.075	.051	-.081	-.074	-.110			
Primary role	-.064	.080	.092	-.020	.281**	-.168*		
Length of employment	.151	-.148*	.004	0.18	.178	-.026	.200**	

* p < 0.05. ** p <0.01

Based on the findings of the correlations analysis, 10 regression analyses were conducted—specifically three simple regressions and seven multiple regressions. Overall, two significant regression models emerged, both from the multiple regression analyses. Results indicated a moderate correlation (R = .346) between the level of efficiency assessment and the four predictor variables—location of organization, formal training in evaluation, formal training in research methods, and length of employment—existed. The linear combination of these independent variables significantly predicted the level of efficiency assessment ($F = 4.685$, $p < .001$)[10] and accounted for 9% (adj. $R^2 = .094$)[11] of the variance in the level of efficiency assessment.

Table 19

Contribution of Predictor Variables for Level of Efficiency Assessment (N = 143)

Predictor variable	**Beta**[12]	**t Value**[13]	**p**
Context	.159	1.841	.068
Formal training in evaluation	-.176	-2.086	.039
Formal training in research methods	-.084	-.992	.323
Time at centre	.195	-2.409	.017

[10] The F statistic tests the overall significance of the regression model. It is the mean square regression divided by the mean square residual (George & Mallery, 2006).
[11] Adj. R^2 indicates the proportion of the variance in the criterion variable accounted for by the model. It takes into consideration the number of variables in the model and the number of observations the model is based on.
[12] The Beta value is a measure of how strongly the predictor variable influences the criterion variable.
[13] The t Value refers to the ratio of the slope coefficient (b) to its standard error. When samples are larger than 100, a t statistic greater than 2 (or less than -2) means that the coefficient is statistically significant at the .05 level (Allison, 1999).

Table 19 describes the relative influence of the selected predictor variables. There was a significant negative influence from both formal training in evaluation and length of employment on the level of efficiency assessment, with length of employment having the greatest influence. This means that newer employees, as well as those without formal training in evaluation, were more likely to report that their centres do efficiency assessment. However, since these two predictor variables account for a small amount of variance in the criterion variable, these findings have limited explanatory power.

The results also demonstrated a moderate correlation between the level of interpersonal sensitivity shown to families during program evaluation activities and both the location of organization and the length of employment (R = .361). The combination of these two variables significantly predicted the amount of interpersonal sensitivity shown to families during program evaluation (F = 10.896, $p < .001$) and accounted for 11.9% (adj. R^2 =.119) of the variance in it.

Table 20

Contribution of Predictor Variables to Level of Interpersonal Sensitivity (N = 143)

Predictor variable	Beta	t Value	P
Context	.311	3.959	< .001
Time at centre	-.138	-1.762	.080

Table 20 describes the relative influence of the selected predictor variables. At the variable level, there was a significant positive influence in terms of location of organization on interpersonal sensitivity. Thus, respondents from centres in small to medium cities reported their centres as being more sensitive to families during evaluation activities.

Summary for Question 1.4

The correlation analysis demonstrated statistically significant positive correlations between the location of the centre and needs assessment, impact assessment, and efficiency assessment as well the four FCS evaluation activity variables and two evaluation purpose variables. Of particular interest, the data showed that respondents from pediatric rehabilitation centres located in small to medium cities reported that their centres engaged more often in needs assessments, impact assessments, efficiency assessments, FCS evaluation activities, and evaluation for both accountability and learning purposes than those situated in larger cities. Moreover, the regression analysis illustrated that newer employees, as well as those without formal training in evaluation, were more likely to report that their centres do efficiency assessment. It also showed that respondents from centres in small to medium cities reported their centres as being more sensitive to families during evaluation activities.

Summary for Phase 1

Overall, 188 staff members from Canadian pediatric rehabilitation centres participated in Phase 1. Their responses suggested that the amount of evaluation activities occurring within these centres is variable and that very few centres are engaging in all types of program evaluation, including needs assessments or assessments of program theory, process, impact, and efficiency. More specifically, the results demonstrate that many centres are engaging in needs assessments and assessments of program process more so than assessments of program theory, impact, or efficiency. This suggests that pediatric rehabilitation centres are particularly interested in establishing the need for their programs and answering questions about program operation, implementation, and service delivery rather than questions about program design, outcomes, or costs. However, it is important to note that many respondents were uncertain about why their

centres engage in these types of evaluations as well as the designs and data-collection methods commonly used. While many respondents also indicated that they were unsure if their centres examined the cost benefits of programs, newer employees as well as those without formal training in evaluation were more likely to report that their centres do efficiency assessment than those who were long-time employees or had formal training in evaluation.

In terms of training and resources, this phase revealed that the majority of individuals working in program evaluation within pediatric rehabilitation centres do not have formal training in it and that, within these centres, there are minimal resources (e.g., employees, funding) dedicated solely to evaluation. Lastly, the findings showed that evaluation activities are somewhat consistent with FCS philosophy, but that improvements are needed, especially in terms of collaboration and interpersonal sensitivity. In this regard, pediatric rehabilitation centres need to partner more often with families in evaluation decision-making processes and ask families for input and feedback on the evaluation designs and data-collection tools used to evaluate their children's programs. They also need to look for ways to better support and enable family participation in evaluation activities, as very few respondents noted that their centres frequently or always select program evaluation designs and methods that fit with families' needs and lifestyles. With that said, the results did show that respondents from centres in small to medium cities (defined as those with populations ranging between 10, 000 and 100,000) reported their centres as being more sensitive to families during evaluation activities in comparison to centres in large cities. Moreover, all respondents noted that their centres are doing a somewhat adequate job at communicating with and showing respect for families during evaluation, yet improvements could still be made in, for example, routinely offering information about evaluation activities to families in a variety of ways and treating families as the true experts on

their children during evaluation. Nonetheless, the findings from this phase were helpful in the development of the interview guide for Phase 2. As described in the next chapter, Phase 2 explored the values, factors, and conditions that support and inhibit many of the evaluation activities described in Phase 1 as well as the benefits and limitations of these activities.

Chapter 5: Phase 2

This chapter highlights the methods and results of Phase 2. The purpose of this phase was to explore the values, factors, and conditions that support and inhibit the evaluation of family-centred programs in pediatric rehabilitation settings. It also aimed to exemplify the benefits and limitations of using mainstream practices for evaluating these programs. The following research questions guided this phase:

2.1 What values, factors, and conditions support or inhibit the evaluation of family-centred programs? How do these values, factors, and conditions affect the evaluation?

2.2 What are the benefits and limitations of mainstream practices in the evaluation of family-centred programs?

Because I was interested in the personal insights of clinicians/evaluators, I used qualitative, one-on-one telephone interviews in this phase. As illustrated in the subsequent sections, these interviews provided substantial insight into program evaluation from practitioners' points of view.

Sample

I used purposeful or "purposive" sampling to identify and recruit individuals for Phase 2. Purposeful sampling is a common approach in qualitative research (Miles & Huberman, 1994; Patton, 1990). Patton (1990) explains that "the logic and power of purposeful sampling lies in selecting information-rich cases for study in depth" (p.169). For this phase, the purpose of purposeful sampling was to obtain a typical case sample of information-rich individuals who were involved in program evaluation at the participating pediatric rehabilitation centres. Given their experiences with program evaluation, these individuals helped me answer my central research questions (associated with Phase 2). All individuals invited to participate in Phase 1

were eligible to participate in a one-on-one interview for Phase 2. Participation in Phase 1 was not a prerequisite for participation in Phase 2. In an effort to ensure a good representation in the achieved sample and some potential participation from each participating centre, I aimed to interview one to two individuals from each rehabilitation centre. However, during the recruitment period (September 2011), a competing study[14] as well as accreditation activities were occurring in most of these centres, and thus, interest in this phase was somewhat low. To increase participation and locate additional interviewees, I then used snowball sampling. I asked each interviewee if they had colleagues, at their centre or at another participating centre, who were versed in the topic area and potentially interested in participating in an interview. If the interviewees identified colleagues, I asked them to forward the information letter to these individuals by email. In the end, all individuals who contacted me and expressed interest in an interview participated in Phase 2. In total, 15 individuals from eight different rehabilitation centres participated.

Instrument Development

I used the conceptual framework as well as the findings from Phase 1 to inform the development of the interview guide (see Appendix G). I piloted the interview guide with two program administrators and two service providers from a rehabilitation department at a pediatric health-care centre not participating in this study. This pilot involved mock interviews and debriefing sessions, where I asked the pilot interviewees about the quality and clarity of the interview questions. I used the information from this pilot to improve the wording and flow of the interview guide.

[14] This competing study was being conduct by researchers from an Ontario University and focused on levels of FCS with rehabilitation settings.

The interview guide included questions about interviewee characteristics and those of their centres in terms of program evaluation. It included questions about their centres' rationale(s) for doing program evaluation and the types of evaluations conducted, including the processes used, the justification(s) for these processes, as well as their benefits and limitations. Table 21 details the dimensions included in the guide and the question numbers that fall under each dimension while Table 22 shows how the various dimensions relate to the specific research questions for Phase 2. Although the interview guide consisted of 17 questions, I used these questions only as ideas to simulate discussion between the interviewees and myself. Essentially, this conversational approach enabled me to follow up on emerging patterns and themes in subsequent interviews.

Table 21

Description of Dimensions for Interview Guide

Dimension	**Interview question number**
Program evaluation type	5
Context	1-3, 11-15
Purposes	4
Nature of practice	6-9, 17
Consequences	10, 16

Table 22

Relationship between Research Questions and Dimensions for Interview

Research question	Dimensions
2.1) What values, factors, and conditions support or inhibit the evaluation of family-centred programs? How do these values, factors, and conditions affect the evaluation?	Program evaluation type Context Purposes
2.2) What are the benefits and limitations of mainstream practices in the evaluation of family-centred programs?	Nature of practice Consequences

Procedure

Once ethics approval for Phase 2 was obtained from the University of Ottawa and selected research ethics boards or review committees at the participating centres, the site representatives at each centre distributed information letters (see Appendix H) to all potential interviewees who were involved with program evaluation at their centres. In the information letter, I instructed those who were interested in participating in an interview to contact me to obtain additional information. As mentioned, I also asked the interviewees to forward a copy of the information letter to colleagues who were knowledgeable in the topic area and potentially interested in participating in an interview. Each interview took place over the telephone, at a time that was convenient for the interviewee. I conducted the interviews over a two-month period, from September to October 2011. All individuals chose to participate during their lunch hour or after work. This scheduling worked well because the interviewees were uninterrupted during the interviews and able to participate from the privacy of their offices or homes. The interviewees signed an informed consent form (see Appendix I) prior to the interview. The average length of the interviews was 37 minutes (range: 22 to 61 minutes). Each interview was audio-recorded and

transcribed verbatim for analyses. After transcription, I matched each transcript against the audio recording to ensure its accuracy.

Data Analysis

Patton (1990) describes how the challenge of qualitative data analysis "is to make sense of massive amounts of data, reduce the volume of information, identify significant patterns, and construct a framework for communicating the essence of what the data reveal" (pp. 371-372). To meet this challenge, I analyzed the interview data using QSR International NVivo 9®, a well-known and popular qualitative analysis software program. Through NVivo, I reliably tracked pieces of data, queried and reflected on emerging concepts, and graphically modeled trends and relationships among the various codes and sources in visual displays (Bazeley, 2007).

I also used Miles' and Huberman's (1994) three concurrent activities—data reduction, data analysis, and conclusions/verifications—to inform my cyclical and iterative analytic process. Immediately following each interview, I summarized key points and identified additional questions or probes for subsequent interviewees using memos in NVivo. These memos documented my research process and allowed me to track the development of my insights and ideas (Bazeley, 2007). Upon completion of the data collection, I began data reduction. First, I created a starter coding system based on my conceptual framework, research questions, and key themes and variables from the reviewed literature as well as the results from Phase 1 (Miles & Huberman, 1994). Miles and Huberman (1994) describe a code as "an abbreviation or symbol applied to a segment of words – most often a sentence or paragraph…to *classify* the words" (p.56). Within NVivo, coding involves the creation of *nodes* that provide storage areas for accessing coded text (Bazeley, 2007). For the purpose of this initial analysis, I used *free nodes*, which do not assume relationships with any other concepts, as labels for

assigning units of meaning to the information compiled during the interviews (Bazeley, 2007; Miles & Huberman, 1994). Next, I read each interview several times, annotated phrases within the text, and coded the data using my starter coding system. At this point, I also allowed for nodes that I did not identify a priori to emerge from the data (Glaser & Strauss, 1967). This mix of deductive and inductive coding ensured that I did not miss any key ideas or force-fitted the data into pre-existing nodes. After coding the first two interviews, I discovered that I had too many nodes; as such, I revised my coding structure (see Appendix J) by merging nodes and creating *tree nodes*, which are hierarchical structures with categories, sub-categories, and sub-sub-categories. Throughout this coding process, I developed additional memos, which were dated and time stamped, to note my coding decisions as well as other important information that helped me contextualize my results. Essentially, this activity provided a timeline of when and why I made various coding decisions. I then ran matrix queries (i.e., qualitative cross-tabulations) and used data displays (i.e., models, charts, coding stripes) in NVivo to understand the results of the above-mentioned data reduction. More specifically, I created models to explore the relationships between the nodes and sources to identify patterns and themes across sources, and thus, verify the concluding results for this phase. I reached data saturation of the nodes or themes following the analyses of the first 10 interviews; the remaining five interviews did not contribute any additional nodes or themes.

Trustworthiness of Analysis

Qualitative researchers use the concept of trustworthiness to evaluate the quality of their research and to ensure that their findings represent the experiences of the individuals under investigation (Lincoln & Guba, 1985). Four criteria used to assess trustworthiness include

credibility, dependability, confirmability, and transferability. Below, I describe these criteria as well as how I established the trustworthiness of my analyses.

Credibility

Credibility in qualitative research is concerned with the appropriateness and accuracy of the data sources as well as the interpretation of the data. Lincoln and Guba (1985) assert that ensuring credibility is one of the most important factors for establishing trustworthiness. While there are several techniques for enhancing the credibility of qualitative research, I focused solely on peer debriefing and member checks.

Peer debriefing involves meeting with objective peers to review and explore various aspects of the study. I used peer debriefing throughout my data analyses. I met regularly with four research colleagues[15] to review various aspects of the analyses and to discuss areas where I was experiencing challenges. This peer debriefing process was particularly helpful in terms of selecting appropriate wording for the themes that emerged from the data.

Another useful technique that I used to establish credibility was member checks or feeding back transcribed interview texts and interpretation summaries to participants for comment. Through member checks, I was able to solicit participants' reactions to their transcripts as well as my findings and interpretations of the interviews. Following the recommendation of Merriam (1998), I used member checks throughout Phase 2. Initially, the participants had the opportunity to review their transcripts and clarify any statements that were unclear or inaccurate. They also reviewed a summary of my preliminary interpretations to verify emerging themes and provided additional information (e.g., names of governing bodies,

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[15] These research colleagues worked in program evaluation or qualitative research at a pediatric health-care centre not involved in this study. As research assistants, coordinators, and program evaluators, they had a vested interested in this project because they regularly conduct research and evaluations within family-centred environments.

meanings of acronyms used during the interviews) that helped me expand upon the findings. Once I completed the data analyses, the participants received another summary of the findings and interpretations. All participants responded and affirmed the accuracy of the interview transcripts. They also provided affirmative comments supporting my initial interpretation of the findings.

Dependability

Lincoln and Guba (1985) suggest that there can be no credibility without dependability. Dependability in qualitative research is similar to reliability in quantitative research. To demonstrate dependability, I followed Miles' and Huberman's (1994) recommendation and had another independent researcher, with expertise in health program evaluation, code two randomly selected transcripts in NVivo using my existing coding system. I then ran a coding comparison query to determine the kappa coefficient and percentage of agreement between her coding and mine. Although I considered our inter-coder reliability of 72% appropriate (Miles & Huberman, 1994), we discussed the inconsistencies in our coding and I slightly revised the final coding system and analyses. Dependability is important to trustworthiness; however, I also thought that it was important to demonstrate confirmability.

Confirmability

Confirmability is the potential for congruence between two or more independent people about the accuracy, relevance, or meaning of the study (Lincoln & Guba, 1985). I used audit trails as a strategy to ensure confirmability. An audit trail is the systematic documentation of each decision made during the research process that allows an independent auditor to follow a researcher's steps and decisions and establish the same conclusions about the data. NVivo facilitated the establishment of this audit trail. As mentioned earlier, I created memos, which were dated and time stamped, to note my coding decisions as well as other important study-

related information. Therefore, someone could review my analysis and use my memos to understand the shifts and progressions in my thinking (Bazeley, 2007).

Transferability

Lastly, transferability refers to whether the findings from the data can be transferred to other settings or groups and is similar to the concept of generalizability (Lincoln & Guba, 1985) . Lincoln and Guba (1985) recommend two strategies that facilitate transferability: purposeful sampling and thick descriptions. As previously discussed, purposeful sampling involves the conscious selection of participants who can give rich information about the topic under exploration. Through purposeful sampling and information-rich interviewees, I was able to obtain thick descriptions of the contexts and experiences relevant to the topic area. I also included detailed descriptions of the research processes. This level of description allows others to judge the contextual similarity and transferability of my study findings.

Findings

Characteristics of Interviewees

Although 675 individuals received an invitation letter inviting them to participate in Phase 2, only 15 individuals were willing and able to participate. However, as mentioned in Phase 1, site representatives at four centres did not know who was involved with program evaluation activities, and thus, they distributed the information letters to all staff members whose departments were active in program development and delivery as well as potentially engaged in program evaluation. Again, this wider distribution may have contributed to the apparently low interest in Phase 2.

Of these 15 individuals, I identified three by snowball sampling. The 15 participants were from eight different rehabilitation centres; all were actively involved in program evaluation (i.e., evaluation design, data collection, analysis, dissemination of findings) and had been working in

the rehabilitation sector for more than two years. Nine of the interviewees held management or supervisory positions within their centres (e.g., clinical coordinator roles, program managers) whereas the remaining six were full-time clinicians, who provided programming to clients and their families. Two interviewees were from the Western provinces, nine were from Ontario, two from Quebec and two from the Eastern provinces. Eleven of the individuals' centres are located in large cities (population greater than 100, 000) and four of the interviewees' centres are in situated small to medium sized cities (population 10, 000-100, 000). Similar to the sample in Phase 1, this sample was reflective of the CN-CYR membership, given that the majority of its organizations are located in Ontario and found in large cities. With the exception of one participant, all participants were female. This gender divide is also representative of the staff population working in Canadian pediatric rehabilitation settings. Overall, this group of interviewees provided substantial insight into the program evaluation processes and activities used at various pediatric rehabilitation centres across Canada. The following are the answers to the major research questions that guided Phase 2.

2.1 What values, factors, and conditions support or inhibit the evaluation of family-centred programs? How do these values, factors, and conditions affect the evaluation?

Interviewees highlighted evaluator characteristics and organizational factors as supporting or inhibiting the evaluation of family-centred programs. To identify these items, all interviewees reflected on the implementation of specific program evaluations within their centres and situated their thoughts within their own experiences. The family-centred programs described in the interviews were geared towards children and youth with physical or developmental disabilities and involved high levels of collaboration with clients' families. The interviewees based their experiences on several different types of programs, including preschool, transition,

recreational therapy, speech therapy, physiotherapy, assistive technology, and respite programs. I now turn to a description of the characteristics and factors that facilitate and hinder the evaluation efforts of such programs.

Clinician/Evaluator Characteristics

Attitudes towards program evaluation. Some of the interviewees detailed how their positive perceptions towards evaluation as well as their desire to do it motivated them to engage in evaluation activities. These individuals saw evaluation as an important component of their clinical responsibilities and essential for ensuring that clients and their families received effective care. When asked about why she engaged in program evaluation, one individual stated, "Because I see the value and importance of having them [evaluations]. You need to evaluate programs for the children and their families." Similarly, another clinician/evaluator emphasized that for her "Program evaluation is part of my practice—to always be thinking of where the children are, and are those children meeting their milestones, and if not, how do we get them there? How do we get all the children in our program there?" By viewing program evaluation as "integral" to their roles as clinicians and as a way to "identify effective treatments and therapies" for their clients, these interviewees were keen to incorporate program evaluation into their daily practices. However, not all participants shared this positive outlook on evaluation. Some described that they were "intimidated" by program evaluation. Quotes that reflected this feeling included, "Others in my group know more than me in terms of evaluation and I never know if I am doing it right," "I am scared of seeing negative results for my program," and "I am always hesitant because I do not always choose the right outcome-measurement tools. There are so many to choose from, it can be very, very hard."

Moreover, other participants discussed their previous negative experiences with program evaluation. As one participant described, "There was a terrible rift among our team members in

terms of what each person wanted to do for the evaluation. It was terrible." Meanwhile, others detailed how they repeatedly saw "bad results" and, as such, were not overly motivated to do program evaluation. For instance, one clinician/evaluator stated,

> When I keep seeing results in the negative direction, it's hard to look, especially when you are evaluating your own program. It makes me not want to do evaluation… I see differences in my patients, but I might just not know how to show it on paper or in evaluation.

Others also reiterated this idea of not knowing how to do evaluation when prompted to elaborate on the causes of their negative evaluation experiences. Many described how their negative experiences may be linked to "no training in program evaluation," "not enough in-services on how to do it or what to look at," or "not knowing the right measurement tools."

Training in program evaluation. The interviewees' levels of training and experience in program evaluation varied. Some "learned it through practice," while others completed university-level training. Likewise, some reflected on 20 years of program evaluation experiences, while others drew on more limited, but recent experiences. Regardless of these differences, all interviewees suggested that they would like to receive additional training in program evaluation and viewed access to training as a key facilitator of evaluation activities.

When I asked about knowledge of and training in program evaluation, those in management-level positions stated that they had adequate knowledge and training in it but that their clinical teams had insufficient knowledge of evaluation. They elaborated that there was a lack of formal training opportunities for clinicians/evaluators and that the majority of the training received was ad-hoc or through first-hand experiences in specific program evaluations. As one individual stated,

> I would say that front line staff at this point have not really had that training unless they happened to be involved in a specific project like the client satisfaction team, where maybe that kind of training is required, and they have, you know, had to go out and get that.

Given the varying levels of evaluation skills among staff in the centres, some also commented on how evaluation activities were easier for some programs compared to others, depending on the composition of the program team. For example, one interviewee stated, "Psychologists have a stronger background, I think, than us with research and evaluation that sort of thing, they can do evaluation quicker." Furthermore, another participant disclosed, "I have to be honest, we have struggles and people are at different skill levels in terms of their comfort level and ability to set specific program evaluation goals and use specific evaluation tools. This really impacts our evaluations." Overall, these statements suggest that those with training in program evaluation or related and/or relevant research backgrounds may be more efficient and able to conduct evaluation activities than those with no training.

A desire to involve families in program evaluation. On a different topic, a few interviewees identified how they are beginning to look for ways to make evaluation processes more "family inclusive" or "family appropriate." To evaluate their family-centred programs, some believed that it was important to seek family feedback about the evaluation processes used and were exploring ways to do this. As one interviewee summarized, "It is something that I really wanted to do. We were considering how to exactly approach it; whether we approach a specific family or randomly select them. We were talking about a number of different things." Similarly, others expressed a desire to involve parents in the design phase of their evaluations. For instance, one clinician/evaluator stated, "I would like to ask one or two parents to come and

brainstorm with me in the evening. I mean, that would be great." Generally, those who brought up the idea of actively involving families in program evaluation activities viewed such involvement as a support mechanism for their evaluations, as it could potentially help them "ask the right questions" and "develop stronger relationships with families."

Organizational Factors

Funding for program evaluation. Regardless of their desire to involve families in program evaluation, all participants mentioned that insufficient funding affected the evaluation of their family-centred programs. Interviewees described the non-existence of funds for evaluation activities and the use of funds allocated for service delivery to fulfill their evaluation requirements. For example, one participant stated, "We are not going to see any more money for program evaluation." Another reported, "We don't receive any money from the Ministry to do evaluation. It is now just mandated. It is just part of what is expected for us to do because we are in the [Program A]." Moreover, some who did receive small amounts of funding for program evaluation from external grants commented that they do not typically have enough money to complete all aspects of the evaluation. More specifically, an interviewee explained,

> Everything is getting tighter as budgets change and all of that. What can sometimes happen is—I know from a particular program I am in—we get evaluations back regularly and we look at the subjective comments and we will make changes based on that, but the compilation and presentation of the data we got falls a little bit by the wayside because we have no funding to analyze the data.

As noted by the participants, this lack of funding for evaluation often means that staff members do not necessarily have protected support or time to do program evaluation; as such, evaluation activities are short-lived and superficial or done haphazardly.

Staffing and time for program evaluation. Participants mentioned staffing and time for evaluation as major factors that both inhibited and supported their program evaluation efforts. This included time available for staff to conduct evaluations as well as staff that had program evaluation responsibilities in their job descriptions. The clinicians/evaluators agreed unanimously that time issues were their biggest barriers to designing and conducting evaluations. Repeatedly, staff stated views such as, "It is a time factor, really, more than anything," "I think that the resources are such that they do not get around the time to do it," and "We just need more thinking time, to be perfectly honest. To kind of come up with how else—what else should we be evaluating and how else can do an evaluation piece."

However, interviewees who had access to research or rehabilitation assistants to support their centres' evaluation activities described how these individuals were instrumental in their program evaluation activities, especially in terms of analyzing the data. One person stated, "We use a research assistant because that person is helpful in taking the information and collating the information." Another noted, "Well, we have someone else, an assistant, who actually does the crunching of the data. It's great." However, many of those that I spoke with acknowledged that staffing was an impediment to their centres' program evaluation efforts. The interviewees who held this viewed mentioned that additional staff with devoted time for evaluation could enhance the type of evaluation conducted, the quality of data analyses, and the utilization of evaluation findings. As one clinician/evaluator expressed,

> If we had a designated rehab assistant to compile it [evaluation data] so that the therapists could sit down and have a look at it, once all of the kind of math has been done, the compilation has been done, that would be helpful.

Likewise, someone else stated, “We do not have a data analyst or anything like that. I think resources are certainly a limitation in terms of us doing anything, you know, more robust than what we are already able to do.”

In terms of staffing, many interviewees also discussed the importance of having evaluation formally incorporated into selected individuals’ job descriptions. The interviewees thought that when management designated this role to a specific individual or group, more evaluation occurred. Some reported how program evaluation is part of their team coordinators’ roles. Conversely, others commented on how program evaluation has “not been something that has historically been a role for somebody.” Few noted that the evaluation role has fallen to administrative assistants. However, as one stated, “It is busy and the admin assistants, I do not think, right now see it as their role to compile it [evaluation data]…Maybe if they were designated to do it.” To complement this delegation of evaluation responsibilities to selected individuals, the interviewees also suggested the need for policies and procedures for program evaluation.

Policies and procedures for program evaluation. Participants identified the necessity of policies and procedures that detailed “how to do evaluation,” “how often it needs to done,” as well as “guidelines for program evaluation.” They thought that such documents would facilitate and standardize their evaluation efforts and ensure that clinicians/evaluators within their centres were “making similar efforts in terms of evaluation.”

When asked to describe how the non-existence of these policies and produces affected their current program evaluations, one participant noted,

> We don’t have any policies or procedures for program evaluation that are written out. I think it has just been an assumption that people would have specific things they are

> working toward, but we do not do a good job at evaluation and it's because of this lack of documentation, nobody knows what is going on—it's a mess.

Similarly, another stated,

> We have nothing in terms of policies and procedures. We are very primitive in terms of program evaluation. We have no standards in place and this is a problem because some people are doing lots of evaluation and others are doing none.

Overall, the participants emphasized that this lack of policies and procedures results in a lack of clarity in terms of evaluation expectations, and thus, varying amounts of program evaluation.

Existence of family advisory committees. The existence of family advisory committees (FACs) also varied. Despite some interviewees' desire to involve families more routinely in the design and implementation of program evaluations, a few discussed how their centres no longer have FACs or councils that could advise them on how to engage families in the processes. This lack of infrastructure often stopped clinicians/evaluators from developing partnerships with and seeking input from families for evaluation activities. As the following participant explained,

> We had the family advisory committee for years and because—I actually was the centre rep that was involved with that. A number of years ago—I am going to say probably back in 2004—we lost a lot of interest from the people who were involved; people had gotten busy with other things. We put it on a hiatus at that time. We tried to reinstate it a number of times; it is very difficult. Our families just do not seem to have that interest to do that. Often, when we do need some family input on some things we cannot get it.

However, participants with operational family advisory groups within their centres expressed mixed results in terms of their accessibility to program evaluation and family-engagement advice. Some described how the process of involving family representatives in their evaluations

was simple and rewarding. As one individual explained, “We were looking at revising our program and its evaluation and we went to the family advisory committee for feedback on that. Their rep has been helpful in terms of program evaluation and what we should ask families on our survey.”

On the other hand, others stated that they had trouble working with their family forum to identify family representatives who had experiences with their programs and were interested in becoming involved in evaluation activities. Moreover, an interviewee suggested that the process for involving interested families was too complicated and time consuming, and thus, did not occur:

> We do have a process in place for parent advisors and it is a fairly—I think it is a fairly complicated process. They have to go through a lot of paperwork and screening and that came up in the decision making around what to use, that parents should be involved and we should get their input and then this whole process—it was investigated and this whole process came out that the Centre requires—definitely has parent advisors, but if we wanted to get some parents we knew—it was going to be a cumbersome, fairly long process to recruit some families and get them through that process, so we didn’t do it.

In general, the participants illustrated how the existence of FACs could facilitate the evaluation of their programs, but they also demonstrated how these same groups could deter family involvement because of the complicated processes and procedures that sometimes come with the creation of such committees.

Establishment of committees to assist with program evaluation. In terms of committees, the interviewees saw the establishment of committees to oversee evaluation activities as essential. They thought that these committees were symbolic of a “supportive evaluation

environment." They also thought that they were useful in providing valuable feedback to clinicians/evaluators on their evaluation plans, indicators, evaluation tools, analyses, and dissemination efforts. One participant commented, "We have a group who helps develop tools and looking at results and stuff like that." Another interviewee explained,

> We have a quality-management council here at our centre that is involved in all of our program evaluations. All of the coordinators of the programs as well as all of the managers are involved in that. All evaluations and indicators are brought to quality management and through quality management they are discussed, it is helpful.

Overall, the interviewees felt positive about these committees. They thought that it would be "constructive" and "helpful" to have these groups within their individual departments or centres. Nonetheless, they also mentioned that because these groups were responsible for many other activities in addition to evaluation, they were not always readily accessible or timely in terms of providing feedback.

Data-management systems for program evaluation. The interviewees also mentioned insufficient data-management systems within their centres as a barrier to program evaluation and timely access to evaluation data. Participants suggested that if they could extract several of their output and outcome measures from administrative databases or electronic client records, the data-collection processes in evaluations would run more efficiently. The development of these systems, as the interviewees noted, is in the "long-term goals" of their centres. As one person articulated, "I think better computerized data-collection systems will be a huge time saver in the long run, but that is in the long run." However, others pointed out that, some clinicians who may not be computer literate might see the inclusion of such data-management systems as an obstacle to evaluation:

> You know, we are in the process within the next six months or seven months—whatever—totally changing our information within our computer system. This could potentially help with program evaluation but some of our staff are older, like myself, and are not as computer literate as some of the younger people who are so keen.

In this sense, not all participants viewed the introduction of data-management systems as a facilitator of program evaluation activities.

Affiliations with academic centres. The interviewees also stated that collaborative partnerships between their pediatric rehabilitation centres and academic institutions (e.g., universities and hospital-based research institutes) facilitated their evaluation efforts. They felt that these partnerships provided them with opportunities to seek advice from experts in evaluation theory, data-collection tools, and analyses. Although the consultations with these academics typically involved only one-off meetings or occasional training workshops, the interviewees really appreciated the interactions and believed that academic input helped make the evaluation more "evidence-based" and "credible." As one individual described, "We have talked with some of the people at [University A] who are involved in the development and the ongoing research with various evaluation tools, just to see that we are using them with fidelity." Correspondingly, another expressed how "there are pretty close ties between our facility and [University B] and they do act as a resource for certain evaluation questions that we have." In sum, interviewees viewed these connections as highly beneficial for their evaluation processes.

Summary for Question 2.1

In sum, the 15 interviewees highlighted three evaluator characteristics and seven organizational factors that support and inhibit the evaluation of family-centred programs in pediatric rehabilitation settings. Given the large amount of data and findings for this question, I

have summarized these characteristics and factors and illustrated how they can hinder and support program evaluation in Table 23. I will then move on to detail the findings for the second research question for this phase that explored the benefits and limitations of the mainstream evaluation of family-centred programs.

Table 23

Evaluator Characteristics and Organizational Factors that Hinder and Support Program Evaluation in Pediatric Rehabilitation

Characteristic or factor	How it hinders evaluation	How it supports evaluation
Evaluator characteristics		
Attitudes towards evaluation	- Negative attitudes towards evaluation lead to decreased desire to do evaluation.	- Positive attitudes towards evaluation lead to increased desire to do evaluation.
Training in program evaluation	- Minimal training in evaluation makes it challenging to do evaluation.	- Additional training in evaluation enhances the ability to do evaluation efficiently.
A desire to involve families in evaluation	- Not knowing how to involve families in evaluation makes it challenging to do evaluation.	- Involving families in evaluation can lead to shared responsibilities and increased knowledge about the best ways to do the evaluation.
Organizational factors		
Funding for evaluation	- Insufficient funding leads to incomplete, short-lived, disorganized, or superficial evaluations.	- Funding for evaluation leads to completed, high-quality evaluations.
Staffing and time for evaluation	- Limited time to do evaluation and no dedicated personnel means that there is no help for data collection or analysis.	- A rehabilitation or research assistant means that there is help for data collection and analysis and more time to plan and do evaluations.
Policies and procedures for program evaluation	- Lack of policies and procedures leads to disorganized evaluation activities with no clear expectations as well as certain departments who do more evaluation work than others.	- Policies and procedures lead to clear expectations for evaluations and uniformity across departments and centres.

Characteristic or factor	How it hinders evaluation	How it supports evaluation
The existence of family advisory committees	- Lack of FACs means it is hard to involve families in evaluation activities - Some FACs have complicated processes for involving families, and thus, families are not involved.	- FACs can help obtain family input in evaluation activities.
The establishment of committees to assist with program evaluation	- Committees are involved in many activities and cannot always provide timely feedback about evaluations.	- Committees create a supportive environment for evaluation and provide valuable feedback to clinicians/evaluators about evaluations.
Data management systems for program evaluation	- Insufficient data-management systems lead to challenges in data collection for evaluation. - Computer literacy can lead to challenges in data collection for evaluation from data-management systems.	- High-quality data-management systems enable efficient extraction of outputs and outcomes for evaluations.
Affiliations with academic centres	- Lack of affiliations leads to less evidence-based and credible evaluations, which are not based on evaluation theory, standardized data-collection tools, or appropriate analyses.	- Collaborative partnerships between rehabilitation centres and academic institutions facilitate learning opportunities between clinicians/evaluators and advice, evaluation, and methodological experts.

2.2 What are the benefits and limitations of mainstream practices in the evaluation of family-centred programs?

Throughout the interviews, participants spoke mainly about outcome evaluations that were mainstream practice within their pediatric rehabilitation centres. Their evaluation interests focused primarily on knowing, understanding, or proving the impact of their programs on clients and families. Based on the ideas and experiences that they shared in the interviews, I concluded that the majority of the program evaluations in the interviewees' centres relied heavily on the collection of clients' physical and psychological outcomes. As one participant stated, "We try to do mainly outcome indicators rather than process indicators." This individual, along with others, described how they measured these outcomes by observing and rating their clients' performances on specific tasks. They then aggregated these ratings to demonstrate program effectiveness. The interviewees also mentioned their strong dependence on self-reported standardized measures for assessing families' satisfaction levels. The participants cited the Client Satisfaction Questionnaire-8 (Larsen, Attkisson, Hargreaves, & Nguyen, 1979) and the Measure of Processes of Care (S. King, King, & Rosenbaum, 2004) as commonly used data-collection tools for program evaluation.

Overall, the interviewees reported that these outcome-based, mainstream evaluation practices have minimal benefits and several limitations. As described below, the benefits relate to evaluation use whereas the limitations relate to bias in the evaluation processes, the inability to balance evaluation and clinical work, minimal collaboration with other departments, centres, and organizations, a lack of transparency among stakeholder groups, and limited family engagement in evaluation processes.

Benefits of Mainstream Practices

Evaluation use. The interviewees implied that they have effectively used their evaluation findings in a variety of conceptual, instrumental, and symbolic ways. All participants suggested that they used evaluation results for decision making and program improvement. However, they characterized the majority of these instrumental uses as minor and involving small changes to program content, procedures, or processes. As one participant stated, "We use the results to make small modifications in terms of the program content, sometimes it is about location or timing of the intervention." Similarly, another participant noted, "Based on the evaluation results, we had some conversations and made decisions just about some of the comments and how to slightly change what we did in that program." With that said, the participants acknowledged that limited funding sometimes prohibited them from using the evaluation findings to modify their programs. In these circumstances, the interviewees described how they used the evaluation findings to, instead, gain new perspectives on their programs. As one individual articulated, "Sometimes we cannot really make a change to the program, so we have to, perhaps, do an education piece about the program and evaluation can help us better understand the program and how to educate people about it." Others also reiterated the importance of this conceptual use by noting that the evaluation information "helps staff understand what is going on in the program."

Moreover, all interviewees emphasized the symbolic use of their evaluation findings. Some reported that they used evaluation findings to justify program development or continuation to provincial ministries. As one participant said, "We use evaluation to justify continuation of services or justify initiation of services. It is almost like defending ourselves that it is a good program." Many also reiterated the idea that they "did an evaluation to give the Ministry information for program continuation." Conversely, others spoke of how they used the mere existence of their evaluations to fulfill accreditation standards for their centres. One participant

noted clearly, "I think Accreditation Canada needs to see simply that we have mechanisms in place for program evaluation and that we are using them." In terms of accreditation, many interviewees further noted how their program evaluations enhanced the reputation and credibility of their centres.

In regards to process use, some participants articulated how their overall thinking and behaviour changed because of their involvement in program evaluation. One interviewee described how she began integrating her evaluation knowledge and skills into her clinical practice:

> I am using some of those evaluation questions with my other clients every day now and I am inviting much more feedback because I know what feedback can bring me. I am inviting much more feedback than I used to. I used to be open to feedback, but did not invite it; now I invite it, as a clinician, that is my difference.

This individual, along with others, also described how their program evaluation experiences helped them better understand themselves, as clinicians, as well as the activities and services that they deliver to clients and their families. It was evident from their responses that they, as individuals and team members, were eager to learn about evaluation. Moreover, all participants expressed how they and their colleagues used evaluation as a mechanism to keep their programs on track and to help them focus on specific program outcomes. The following participant expressed what others stated over the course of their interviews:

> I think the staff understands the importance of collecting evaluation data. I think it has been good for them to see, you know, the positives because I think a lot of times what stands out with a lot of teams is the frustrating families, right, "Oh, this client, they are not going anywhere. I feel like I am doing all of this work and nobody is implementing

> this stuff," and then when you actually look at the results from the overall program evaluation of specific outcomes, and we are showing a significant change for the clients and families. That is great and then we are motivated to keep the program going and to keeping aiming for those outcomes!

Some interviewees also noted improvements in their overall knowledge of evaluation as well as their evaluation skills. One participant specified, "I am now more knowledgeable about the evaluation process itself". Another felt that evaluation "is beneficial because my staff and I maintain that sort of working knowledge about why you need to evaluate and how you need to evaluate." Regardless of these benefits, the interviewees mentioned several limitations of their mainstream evaluation practices.

Limitations of Mainstream Practices

Bias in the evaluation processes. The interviewees raised concerns about the lack of independence between the evaluators and the programs under evaluation. They thought that by evaluating the effectiveness of their own programs, they biased the processes. Many noted how limited funding to hire internal or external program evaluators resulted in the creation of clinician/evaluator roles. While the interviewees recognized that this approach facilitated their utilization of evaluation findings and allowed them to use their first-hand knowledge of the program to focus evaluations on the issues and outcomes that were of direct concern to them, they acknowledged that the clinician/evaluator approach diminished the credibility and objectivity of the overall evaluations. Some also thought that they were, at times, investigating their program through "rose-coloured glasses" or they were "too close" to the participants to evaluate properly. The following quotations reflect these sentiments:

> It is also [because] you are so invested in what you are doing that you could be bias. You know, you are so invested and you do not want to hear that it, your program, is a bad

> program. You are going to read something and you are going to read, "Oh, that is good," when the person next to you says, "Are you kidding? It is really bad."
>
> When we say, "if you've ever seen a negative result?" Well no. We do not want to see a negative result. But, that is a liability of having people internally evaluating their own system, right?

Overall, the interviewees admitted that the clinician/evaluator approach often resulted in skewed evaluation findings and inaccurate descriptions of their programs. However, they emphasized that limited resources for program evaluation as well as pressure to do evaluations left them with no other option than to evaluate their own programs.

Inability to balance evaluation and clinical work. In light of this self-evaluation role, all interviewees discussed how they struggled to maintain both their program evaluation and clinical responsibilities. Several viewed their evaluation activities as separate or "add-ons" to their very busy clinical schedules. One manger stated, "We have, actually, had to reduce clinical direct time on a regular basis in order to allow for that extra time required to do that evaluation documentation." Many also stressed that "it is a lot of extra burden put on the staff" and "we know that staff are stretched to the max." Similarly, front-line clinicians noted that their evaluation efforts are often "falling by the way-side" because "if it is not part of what they are doing already or intimately linked to what they are doing already, it probably is not going to get done." Furthermore, one participant stated the following:

> Because we were so busy, some of the evaluation meetings were cancelled; some of the meetings were postponed. It was never made the top priority. If there was a patient there versus a meeting, the patient would have won and that is not necessarily right.

Generally, these participants acknowledged the potential benefits of evaluation on client care, but stated that they often had to choose between their clients and their evaluation activities because of their large caseloads. As one interviewee reiterated, “Because our caseloads are so large and people just keep churning them through, we do not get the luxury of being able to look at that evaluation.” In this sense, when forced to balance both their clinical and evaluation responsibilities, most interviewees viewed evaluation as an extra or bonus activity rather than an essential part of program delivery and implementation.

Minimal collaboration with other departments, centres, and organizations. All interviewees also suggested that there was a lack of collaboration between evaluators/clinicians within their own departments or centres. The following account summarized this limitation:

> It is interesting, you kind of work in this vacuum and you think that we are really focused on our survey and we are told that families are surveyed out. You know, that they are getting so many different surveys, I think, it made it very clear that even within our institution, that there probably is not a good list of surveys and evaluations being done.

As implied by this participant as well as other interviewees, this lack of internal communication and collaboration in terms of ongoing evaluation initiatives resulted in survey fatigue among families who participated in multiple programs within their centres. At times, participants thought that these multiple approaches to evaluation resulted in “a lot of energy being expended unnecessarily” when certain evaluations could have “maybe be done together.”

Moreover, the majority of the interviewees thought that their pediatric rehabilitation centres did not collaborate effectively with other external rehabilitation-oriented groups or organizations with stakes in program evaluation. Many suggested that they might have benefited from the development of a pediatric rehabilitation network or group whose sole purpose was the

facilitation of program evaluation activities. They suggested that this network could provide professional development activities on program evaluation and encourage dialogue amongst clinicians engaged in evaluation.

To date, interviewees stated that they did not share their program evaluation tools or procedures with other centres and, in most cases, operated in “silos” conducting site-specific evaluations with minimal knowledge of similar evaluations conducted in other centres. For instance, one participant expressed, “Right now, there is no sharing of the tools that others are using as well as the processes that they are using at different centres. That would help us.” Conversely, others talked about their rationale for and interests in collaborating with outside organizations. Like many others, one individual stated,

> I am sure, obviously, other people are doing it at other centres but I just don’t know where to start. It would be great to speak to them….to me, I would want to look at what my colleagues in physio are doing at [Hospital A]. I would, like to know how they are doing it.

By sharing their ideas, procedures, and resources, the interviewees thought that there might be more consistency in program evaluation at the national, provincial, or local levels. Participants discussed how this aligned approach could also facilitate the comparison of program outcomes across centres—something that Canadian pediatric rehabilitation centres are not doing well. Repeatedly, participants spoke of the benefits of such efforts for clients and their families as well as for clinicians/evaluators:

> It would be nice and I know this is something that we need to do and we are doing it probably at a higher level than me, but to have some consistency. I know we are trying to compare ourselves if we are looking at data from different health centres across the

> country and sometimes apples and oranges, just given their size and population and, you know, those different variables, but it would be nice to have--and again it could be happening just higher than me, but a bigger connection and some more consistency between centres so that we can be more consistent how we are doing things.
>
> It has been an interesting dialogue because there is such variability amongst what everybody does across the various centres. We need to standardize to compare outcomes and improve care for our clients.

With the above-mentioned comments, the interviewees demonstrated that their use of mainstream evaluation practices has been ineffective in terms of information- , resource-, and outcome-sharing between colleagues and departments. They also illustrated that they are placing an evaluation burden or survey fatigue on families who access multiple programs.

Lack of transparency among stakeholder groups. Another weakness of mainstream evaluation practices that evolved from the interviews pertained to issues of ambiguity between various stakeholder groups. The interviewees, especially those from Ontario, stated that there has been a lack of transparency in requests from the Ministry of Child and Youth Services for evaluation data. Many noted that this transparency is essential for maintaining trust between themselves and the political bodies who fund their programs. They thought that they needed to know, and had a right to know, the purpose(s) of the evaluation data. When I asked the respondents about government-initiated evaluation activities within their centres, one individual stated the following:

> I do not know what questions they think they are going to be looking at. We do not really know what is going to happen with the data at this point. At least, I do not. But, we are all

> putting that data in on a regular basis, as per their protocols. We are not getting any feedback on that.

Similarly, another said,

> I think as clinicians, we are not seeing the value in the time, you know, as a counter to the time that it is taking to actually fill out these forms and submit them. Maybe down the line we will get a different kind of information that will help to inform us, but right now it is not very meaningful and we don't know what it is being used for.

Overall, the participants highlighted that there is limited disclosure from the government regarding the purposes of evaluation and the use of evaluation data, which is a significant limitation in terms of the outcome evaluations that these clinicians are, at times, mandated to do from their provincial funding sources.

While stressing the importance of transparency, the participants also noted that, as clinicians/evaluators, they wanted to improve the level of transparency between themselves and the families involved with the evaluands. While participants noted that families "are informed in the sense that they sign a consent form" or know about the evaluation because "they answer questions and stuff like that," they are not always privy to the findings of the evaluation. As one participant explained clearly, "We do not close the loop, I guess, in a formal way. It is more informal in terms of reporting back to families." Essentially, the interviewees also believed that this lack of formal feedback to the families was another drawback of their current evaluation practices, as it limited family engagement in evaluation processes.

Limited family engagement in evaluation processes. The interviewees stated unanimously that their current evaluation practices provide families with minimal "ownership" in or commitment to the evaluation. Although the extent to which the clinicians/evaluators

involved families in evaluation processes varied from centre to centre, most described how families completed questionnaires and forms for various program evaluations. The interviewees noted that through families' completion of various self-reported measures, they were able to better understand the families' perceptions of services or therapies at one point in time, but that they were unable to foster ongoing communication with families regarding program development, implementation, or evaluation. As one participant summarized,

> We are asking for families' feedback in order to either modify our program or to say it is good right now, but there is no continuous communication between us and the families in regards to this type of feedback, it's only done once a year.

When I asked about who controls the technical decision making about evaluation processes and conduct, all interviewees indicated that control resided with them or with program review committees, of which they were members. Many interviewees echoed the idea that "all decisions were made at the Rehab Operations Committee." In terms of committee membership, only one participant stated that her centre had a family representative on the review committee. However, this interviewee noted that this family member's participation was intermittent because of the timing of the committee meetings, which occurred on "weekdays in the morning." The remainder of the participants indicated that family representatives were not involved in the decision-making processes and did not sit on the review committees.

Aside from describing their own involvement in their program evaluations, the interviewees provided minimal insight in terms of stakeholder diversity or who else was involved in carrying out the evaluations. One participant, however, mentioned that the operations review committee for her program involved a family member, but that this family representative

was not a participant in her program. Regardless, this interviewee noted that “having an input of a parent has been very informative.”

Lastly, when asked about the depth of participation and the extent to which families were involved in the evaluation design, data-collection, analyses, and dissemination phases, interviewees said that family involvement was, for the most part, limited because they “do not think we have a very good idea of how that is going to go in terms of getting input of families and getting them involved.” The involvement of families in this manner was “unknown territory” for the clinicians/evaluators. However, some stated how clinicians/evaluators have spoken on behalf of families about evaluation issues. As one participant stated, “In terms of family involvement, it is the clinician speaking with their individual families and then these clinicians sit on the working group and they translate the families’ thoughts to us.” Similarly, another participant indicated that for one evaluation “each discipline had a delegate who sought feedback from one or two of their own families and then brought the families ideas forward.” Nonetheless, many interviewees noted that, “we do not include the families as much as we should.” They also acknowledged the potential benefits of active family engagement in evaluation and stated, “It is probably good to consult with families when developing your measures.” Moreover they suggested that

> [They] would want that family person to be involved in all of the evaluation, from creating the questions, how many questions, what are the questions, how do we request parents answer or give us feedback to how do we collocate that, who do we disseminate it to and setting goals.

Conversely, another person described how their centre “is currently asking for families’ feedback of survey questions in order to modify the survey.”

While these interviewees were beginning to engage families in evaluation processes, the mainstream evaluation practices reported by others did not provide family members with opportunities to become a part of the evaluation teams or to voice their concerns or ideas about evaluation processes.

Summary for Question 2.2

Overall, the 15 interviewees identified one key benefit and five main limitations of their mainstream evaluation practices. In terms of the benefits, the participants explained how their current practices facilitated conceptual, instrumental, and symbolic uses of evaluation findings as well as some incidents of process use. For instance, the participants recounted how they used evaluation findings to support decision making, to make small program improvements, to gain program insights, to justify program development or continuation, and to fulfill accreditation standards. Some also commented on process use and how their evaluation practices helped them improve their evaluation skills and better understand both themselves as clinicians as well as the programs they deliver. In terms of limitations, the participants noted how their self-evaluation activities led to biased evaluations as well as inabilities to balance both clinical and evaluation responsibilities. They also commented on how there is no communication or collaboration between departments and other rehabilitation centres; as such, everyone is left to create their own evaluation processes and tools. Moreover, they described how there is a lack of transparency about the use of evaluation findings at two levels: between themselves and funding bodies and between themselves and program recipients. Lastly, they showed how there is limited family engagement in their current evaluation activities.

Summary for Phase 2

Taken as a whole, Phase 2 included interviews with 15 staff members from pediatric rehabilitation centres. The findings from the latter question combined with the findings from the other question for this phase highlight what characteristics and factors drive program evaluation within pediatric rehabilitation settings as well as the strengths and limitations of it. The overall results demonstrated that substantial improvements are needed to further support and capitalize on the benefits of program evaluation within these settings. However, it is still unclear what those specific improvements might look like or what types of evaluation approaches are most compatible and feasible within the family-centred pediatric rehabilitation context. Therefore, using some of the findings from Phase 2, I developed focus group and interview guides for Phase 3, which examines the approaches that these advancements might take.

Chapter 6: Phase 3

This chapter highlights the methods and results of Phase 3. The purpose of this phase was to identify how the evaluation of family-centred programs can be improved as well as to explore the compatibility, feasibility, and practicality of using alternative evaluation approaches within the family-centred pediatric rehabilitation context. As such, it addressed the secondary aim of the present study, which was to understand the promise and prospects of alternative evaluation approaches that, in theory, are more compatible with FCS philosophy than traditional ones.

Using qualitative methods, I gathered staff members' and parents' perspectives to answer the following overarching research questions:

3.1 How can the evaluation of family-centred programs be improved?

3.2 (a) Are alternative evaluation approaches likely to be more compatible with FCS philosophy and logic?

3.2 (b) How feasible and practical would it be to implement such approaches?

As described below, I conducted two focus groups with staff members and six one-on-one telephone interviews with parents from two participating rehabilitation centres. My rationale for using two different data-collection techniques in this phase was pragmatic, and the decision enabled participation from both staff members and parents. The focus groups allowed me to obtain multiple staff members' perspectives and shared insights on the topic area in an efficient manner (Gibbs, 1997). The group settings also helped me obtain high-quality data, as it provided checks and balances for the participants, thus eliminating any false or extreme views (Patton, 1990). Furthermore, the interactional, synergistic nature of the focus groups encouraged the participants to clarify or expand upon their discussion points in relation to those raised by others. The one-on-one telephone interviews, on the other hand, enabled parents with caregiving and

work responsibilities to participate in the study at times and locations that were most convenient for them. Providing parents and staff members with the opportunity to voice their experiences and express their views on this topic was important because the findings of this phase may, in the future, affect their level of engagement in program evaluation activities. I will now turn to a detailed description of the parent and staff member samples used in this phase.

Sample

I used a purposeful sampling approach to select the centres and information-rich parents and staff members for Phase 3. Participation in Phases 1 and 2 was not a prerequisite for participation in Phase 3. Although I invited all 15 participating centres to participate, only two centres expressed interest. Originally, I intended to conduct more focus groups at each centre. The general plan was to conduct homogeneous focus groups with service directors/program administrators, practice leaders/managers, other staff involved in program evaluation, family advisory committee members, and youth advisory committee members. Each group would have consisted of a different homogeneous sample (Krueger & Casey, 2000).

However, this strategy did not work out despite my best efforts. Due to staff availability, the non-existence of committees, or limited availability of committees, the CEOs at these two centres each decided that their centres could only commit to one heterogeneous focus group as well as interviews with selected parents actively involved in their centres. Thus, at each of the two centres I conducted one focus group and three interviews.

Focus Groups

The CEOs at each centre suggested that I use a heterogeneous focus group, made up of directors, managers, and front-line staff involved with program evaluation. Although this group composition could have resulted in some participants being unduly influenced by other

participants' managerial positions, I prefaced each focus group discussion by highlighting the participants' similar interests in program evaluation and invited them to individually follow up with me if they were uncomfortable sharing specific information in the focus group setting. In terms of the number of participants in each focus group, the literature demonstrated that there is no clear standard regarding the number of participants to include in each group (Krueger & Casey, 2000). It suggested that groups may range in size from 4 to 20 participants (Gibbs, 1997; R. Krueger & Casey, 2000; McLafferty, 2004), but that researchers should use smaller groups if they intend to gain an in-depth understanding of the participants' experiences (Krueger & Casey, 2000). Given these recommendations and the purpose of this phase, I aimed for 5 to 12 participants in each focus group.

One-on-One Interviews

The CEOs also suggested one-on-one telephone interviews as an alternative to focus groups for obtaining parents' input on the topic. One CEO recommended interviews with the family advisory committee members at her centre. This committee consists of parents who represent a cross-section of the rehabilitation centre's clientele. The committee meets monthly and provides the staff at the centre with ongoing feedback and a family perspective on how to achieve the best quality of service delivery. Given the limited frequency and timing of the committee's meetings, it would not have been conducive to a focus group.

Conversely, the other CEO indicated that the family advisory committee at her location was abolished one year ago because of organizational issues. As such, she suggested that the site representative for the study at her centre assist with the recruitment of family members who were actively involved with the centre and potentially interested in participating in a one-on-one interview for Phase 3. For the purpose of these interviews, the site representative defined this

active involvement as parents who volunteered at the centre or parents who were long-term clients (i.e., involved with the centre for more than three years).

Recognizing that the recruitment of parents within this context can be challenging, that this phase was forward looking in nature, and that some parents may be more articulate than others or more willing to share their opinions and perspectives on the topic, I did not predetermine an exact sample size for the interviews. Instead, my intention was to cease data collection when I thought the richness of the data was meaningful to report and when I obtained coherence on the subject matter; I did not collect any new information from subsequent interviews (Morse, 1991).

Instrument Development

Since I used two mechanisms to collect data for this phase, I needed to develop two different instruments: a focus group guide and an interview guide. The conceptual framework for the study and the findings from Phases 1 and 2 played instrumental roles in the development of both of these guides.

Focus Groups

I used Krueger and Casey's (2000) five general categories of questions—opening, introductory, transition, key, and ending—to develop the outline for the focus group guide. The opening question established a rapport between the participants and initiated conversations and interaction between them. This opening question was brief and easy to answer. The introductory questions introduced the topic of discussion and encouraged participants to think about the topic of interest. Transition questions then served as a bridge from the introductory to the key questions and helped to establish a connection between the participants and the topic of study. Next, the key questions served as the primary focus of Phase 3. Finally, the ending questions

brought closure to the interview and served as a reflection on and summary of what the participants discussed. To pilot the focus group guide, I conducted a mock focus group with five staff members involved with program evaluation at a pediatric rehabilitation department not participating in this study. At the end of this focus group, I asked the participants about the clarity, construction, and appropriateness of the questions and used their feedback to improve the guide.

The final focus group guide comprised 13 major questions, each with several probing questions that clarified the participants' answers or stimulated further discussion when needed (see Appendix K). Following the advice of Krueger (1994), the questions were unidimensional, conversation invoking, and "direct, forthright, comfortable, and simple" (p.3). Table 24 outlines the questions and dimensions included in the guide while Table 25 documents the relationship between these dimensions and the overarching research questions.

Table 24

Description of Dimensions for Focus Group and Interview Guides

Dimension	**Focus group & interview question number**
Nature of practice	1-5, 8
Context	6, 7, 9
Consequences	10, 11

Table 25

Relationship between Research Questions and Dimensions for Focus Groups and Interviews

Research question	**Dimensions**
3.1) How can the evaluation of family-centred programs be improved?	Nature of practice
3.2 (a) Are alternative evaluation approaches likely to be more compatible with FCS philosophy and logic? 3.2 (b) How feasible and practical would it be to implement such approaches?	Context Consequences

One-on-One Interviews

I developed the eleven questions for the interview guide (see Appendix L) with the above-mentioned focus group questions. This process allowed for a similar investigation of the topic area from both the staff members and parents' perspectives. In addition to the above-mentioned focus group guide, the interview guide provided parents with the opportunity to tell me about their experiences in providing data or being involved with the evaluation of services at their given centres. I piloted the interview guide with three parent members of a FAC from a pediatric health-care centre not associated with the present study. This pilot involved mock interviews and debriefing sessions, in which I asked the pilot interviewees about the quality and clarity of the interview questions. I used the information from this pilot to improve the wording and flow of the interview guide. Again, Table 24 outlines the questions and dimensions included in the guide while Table 25 documents the relationship between these dimensions and the overarching research questions. Similarly to the procedures used in Phase 2 and in the focus groups with staff members, I used these interview questions only as ideas to simulate conversation between the parents and me. I followed up on any emerging themes in subsequent interviews.

Procedure

Once ethics approval for Phase 3 was obtained from the University of Ottawa and the research ethics boards or review committees at the two participating centres, the site representatives for the study at each centre distributed information letters (see Appendices M & N) to all potential focus group and interview participants. In the information letter, I instructed those who were interested in participating to contact me to obtain additional information. The focus groups and interviews each followed slightly different procedures.

Focus Groups

The focus groups took place in meeting rooms at the participating rehabilitation centres. The site representatives selected the most appropriate day and time for the focus groups. Both focus groups occurred on Monday afternoons in January 2012, between 12:00 and 1:00, with lunch provided. Each participant signed an informed consent form prior to the focus group (see Appendix O). I moderated each group because I understood the background of the research and was able to probe deeply and challenge participants to fully explain their opinions and perspectives (Silverman, 1997). Each focus group was audio-recorded and transcribed verbatim for analyses. After transcription, I matched each transcript against the audio recording to ensure its accuracy.

One-on-One Interviews

Each interview took place over the telephone, at a time that was convenient for the parent. I conducted the interviews over a one-month period (January 2012). All parents participated from the privacy of their homes or workplaces. The interviewees signed and returned an informed consent form (see Appendix P) to me prior to the interview. The average length of the interviews was 24 minutes (range: 21 to 27 minutes). Each interview was audio-

recorded and transcribed verbatim for analyses. After transcription, I matched each transcript against the audio recording to ensure its accuracy.

Data Analyses

Data analysis is a critical part of research and, to efficiently analyze the data, the process must be systematic and verifiable (Krueger & Casey, 2000). I used NVivo 9® and Miles' and Huberman's (1994) three simultaneous activities—data reduction, data analysis, and conclusions/verifications—to inform the cyclical and iterative analytic process of the focus group and interview data for Phase 3. As mentioned in Chapter 3, the strategy used to analyze the qualitative data in this phase was very similar to the process used in Phase 2. Therefore, for the purposes of this section, I will highlight only the main features of this analysis and note the variations in methodology from Phase 2.

Overall, my goal in Phase 3 was to identify the major themes articulated by staff members and parents. Throughout the analysis, I identified concepts that were present in more than one focus group or interview (Morgan, 1997). Given the similarities between the focus group and interview data, I will present the findings from each together. Through NVivo, I tracked pieces of data, queried and reflected on emerging concepts, and graphically modeled trends and relationships among the various codes (see Appendix Q) and sources in visual displays (Bazeley, 2007). Immediately following each focus group and interview, I summarized key points and identified additional questions or probes for subsequent interviewees or focus groups using memos in NVivo.

Trustworthiness of Analyses

Once again, I used Lincoln's and Guba's (1985) four criteria—credibility, dependability, confirmability, and transferability—to establish the trustworthiness of my analyses for Phase 3. Given the similarities between this phase and Phase 2, I will provide only a brief summary of how I determined the trustworthiness of the present analysis.

Credibility

I established credibility of the findings in this phase in three ways. First, I used peer debriefing and met regularly with research colleagues to review various aspects of the analyses and to discuss areas where I was having difficulties. Second, I conducted member checks to ensure the accuracy of the focus group and interview transcripts as well as my findings and interpretations. With the exception of two participants who did not respond, all other participants responded and confirmed the accuracy of the transcripts and study findings. Finally, I triangulated the findings across the interviewees and focus group participants to establish the credibility of the themes that emerged.

Dependability

Similarly to Phase 2, I also had another independent researcher, with expertise in health program evaluation, code one randomly selected focus group transcript and one interview transcript in NVivo using my existing coding system for dependability. I then ran a coding comparison query to determine the kappa coefficient and percentage of agreement between her coding and mine. Despite having high inter-coder reliability at 86% (Miles & Huberman, 1994), we discussed the inconsistencies in our coding, and I slightly modified the final coding system and analyses.

Confirmability

Once again, I used audit trails as a strategy to ensure confirmability. I created memos, which were dated and time stamped, to note my coding decisions as well as other important study-related information.

Transferability

Lastly, although this phase was specific to participants from two focus groups and six interviews, there is some capacity for transferability. In this phase, I gathered perspectives from a diverse group of participants to establish the potential applicability of the findings across different disciplines and settings within pediatric rehabilitation. I also obtained thick descriptions of the contexts and experiences relevant to the topic area and included detailed accounts of the research processes so that others could judge the transferability of the below-mentioned findings to their contexts (Lincoln & Guba, 1985).

Findings

Characteristics of Focus Group and Interview Participants

As mentioned earlier, I conducted the focus groups at two different pediatric rehabilitation centres. Both of these freestanding centres were located in large cities (population greater than 100,000) in Ontario. At Centre A, 60 staff members involved in program evaluation received an invitation letter inviting them to participate in a focus group. Of these individuals, 10 were willing and able to participate. At Centre B, 90 staff members involved in program evaluation received an invitation letter and, of those, 12 were interested and able to participate. However, as was the case in the previous phases, the site representatives from both centres did not know who was involved with program evaluation activities, and thus, they distributed the information letters to all staff members whose departments were active in program development

and delivery and potentially engaged in program evaluation. Again, this wide distribution may have contributed to apparent low interest in Phase 3.

The participants in these focus groups were actively involved with program evaluation. At Centre A, four of the participants held management or supervisory positions within their centres (e.g., clinical coordinator roles, program managers) whereas the remaining six were full-time clinicians who provided therapy or programming to clients and their families. At Centre B, three participants held clinical coordinator roles or the equivalent and the remaining nine were full-time service providers. Once again, with the exception of one participant, all were female. This is consistent with the organizational context in this sector, as described in Chapter 3. Overall, the varied characteristics and comprehensive knowledge of these participants provided me with the opportunity to obtain broad insights into staff members' program evaluation activities and perceptions.

I also interviewed a diverse group of parents. I interviewed three parents from Centre A and three parents from Centre B. At the time of the interviews, all parents had been involved with their given centres, in some capacity, for more than five years. From Centre A, one parent interviewee is a volunteer at the centre (one day per week), one parent sits on the Board of Directors for the foundation at the centre, and another has an adolescent who is a long-term service user of the centre. At Centre B, all three interviewees are members of the family advisory committee. At the time, all parents were caring for a child aged 6 to 18 with various disabilities such as cerebral palsy, autistic spectrum disorders, or physical and learning disabilities. As such, these interviewees represented a diverse range of parental and family experiences. I will now provide answers to the major research questions that guided Phase 3.

3.1 How can the evaluation of family-centred programs be improved?

Focus group participants and interviewees highlighted seven major ways for improving the evaluation of family-centred programs. Based on their suggestions, it is evident that all participants focused primarily on the *family-centred* aspects of their programs and, as such, suggested improvements for better engaging families in program evaluation. To identify many of the below-mentioned improvement areas, participants reflected on their own programs, experiences, or beliefs related to FCS. One major suggestion supported by all participants involved the inclusion of a more diverse group of parent service users in the design of evaluations as well as their participation in them (e.g., completion of surveys, participation in interviews).

Include a diverse group of program recipients. Both staff members and parents suggested the need for involving a wider range of families in program evaluation activities. One staff member summarized clearly, "We need to be demonstrative in showing that we do want participation from all cultures and levels of families." Parents, who sat on the family advisory committee for their centre, reiterated the following idea:

> As a board, we have not done a good job at involving like First Nations, we have different cultures at the table but we have never had anyone from a truly, truly difficult socio-economic background, we are all middle to upper class. We really need to do better especially because we sometimes review evaluation surveys and give feedback that what might be easy for us but not work for others.

Moreover, in terms of the design of program evaluations, staff members and parents emphasized the need for involving parent representatives who are using or have used the evaluand. As a

parent stated, “At least having a representative group of families that are using the services would be good.” A staff member also explained,

> We had one hour’s worth of a family consultation with the team and it was not a family member that we were serving, it was a family member from another program…a parent advisory for [centre’s name], so it was not very helpful and not appropriate for the design of the evaluation.

The parent interviewees from the above-mentioned family advisory committee echoed this statement. They described how staff members frequently ask them to be family representatives on evaluation advisory committees for programs that neither they nor their children have used. As one parent acknowledged,

> I know on the family advisory and family leadership we always get asked what our perceptions are of how [to] evaluate something or how it can be improved, but I don’t always know because I don’t know anything about the service they ask me about.

Another parent also stated,

> It can be become an extremely guided type of discussion and it is interesting because they want to ask me about this and not that or we don’t really want your opinion on this, just that and I am sitting there thinking well that is where I have the most to give, that is what I know and you want me to comment on this instead.

While these parents recognized that they could offer the “perspective of a parent in general,” they thought that their involvement, combined with the exclusion of those served by the programs, might lead to distorted perspectives of the evaluand. The parent interviewees described how their views might differ from parents who have used or are using the programs. As one parent explicated, “In some ways, I am privileged because I get to be involved with the

family committee and I have longstanding relationships with staff and I because of that I see things a little different." Other parent interviewees also suggested that their active involvement with their centres may have professionalized their views of programs as well as their evaluation contributions. In fact, some thought that their roles in their centres enabled them to see evaluation issues more from the vantage points of clinicians rather than parents. One parent articulated,

> Myself, I think I think I have too many conflicts of interest. I struggle with some of the same questions as the staff. I think because I have become too close to the [centre's name], I start to think like a staff person not a parent. I have become too involved. I become too use[d] to reviewing budgets and reports like that and I am on the organization's side.

Both staff members and parents also thought that their centres were primarily capturing the perspectives of affluent families in the design of evaluations as well as the evaluation data collected. As such, one staff member thought that her centre could improve both the design of the evaluations and the quality of data collected by "better representing more of our demographic instead of the family that can drop off their kids at school and drive here and spend the day because they are not working." Other staff members also supported the following suggestion in regards to obtaining data for the evaluation:

> Involve large numbers of parents and large numbers of parents who do not speak English and have various differences from the staff here. Most of the parents who are involved are middle-class, highly educated and speak the same language as us. So, it does not speak to the volumes of people that we really do serve.

All participants thought that relying heavily on English-language satisfaction questionnaires and feedback on program delivery from family representatives formally associated with the centres limited evaluation findings. As one staff member summarized, “It is the same families over and over again and we’re not necessarily representative of the broad range of families that we serve; our data represents a very narrow group.” Another staff member also stated that “the ESL families, their voice may be very, very different from the other survivors that make up our caseload and they should be included in the evaluation.” In light of these comments, several participants advocated for broad parent selection as a means to gather multiple perspectives on the program and to guard against potential biases. Staff members agreed that they need to “really, invite in different groups each time” because they “are always getting the same—you know, it is going to be [children’s names] parents.” In addition, parent interviewees expressed the importance of involving parents with young children as well as grouping parents together with similar needs in the evaluation. One parent stated,

> I think for parents with young children it is important to be involved because they are really starting out in the system and between the ages of two and four staff want to hear from them because they are going to move through the ranks of the centre and they have a lot of good information to share.

Meanwhile, another parent said,

> It is good if the group has common children with maybe common needs. The diagnosis does not have to be the same, it could be a varied diagnosis, but you would get more of a sense of collaboration if everyone has children that have common needs. You can brainstorm more about what—you have more of a feeling of belonging around the table if there are people with groupings of children with common needs—not diagnoses.

Overall, the participants thought that by involving a more diverse group of parents in the evaluation design processes and evaluation itself, their centres could provide a more "balanced picture" of programs and program outcomes. However, in order to do this, all participants agreed that their centres needed better processes to accommodate families and facilitate their involvement in evaluation.

Use processes that facilitate family involvement. In order to improve the evaluation of family-centred programs and to include a more diverse group of program recipients in evaluation processes, participants suggested three major advances needed at the evaluation design, data collection, and dissemination levels. First, staff members and parents spoke about the importance of involving interpreters and translators in these processes. As one parent participant stated, "I think they would need to hire people who speak their language for sure." Staff members also described how language barriers encountered in program evaluations have adversely affected parent engagement in all aspects of the evaluation as well as the overall quality of the evaluation data collected. As such, they suggested that the use of interpreters and translators would facilitate parent input and feedback on evaluation designs, the programs themselves, and the dissemination of evaluation findings. As one staff member suggested, "To speak to the practicality of how to get it done too, we would need to do it with an interpreter."

In addition, staff members and parents alluded to the idea that their centres should be embracing the Internet and other digital technologies as innovative ways to engage parents in the evaluation of their children's programs. As one parent noted in reference to technology, "The interesting thing is that the most—where the greatest potential for evaluation lies—is meeting the children and us where we are." Both parents and staff members commented on how, for example, iPhones, iPads, Blackberries, and computers are now a part of life, and thus, it is

essential to devote more resources to figuring out how to use these tools to involve families in evaluation initiatives. As one staff participant articulated,

> I would like to see things go online because we are moving in a world that things are available when you want them. We should have this available online—the access when we want it—very future thinking and that is where especially the younger generation is going toward, but if we cannot even establish it for us here my own perception is if we want to get ahead and looking at that kind of system would be really helpful.

Some staff members and parents also suggested the ideas of online forums or message boards as another way of improving the evaluation of family-centred programs. They thought that these platforms would provide structured, topic-based discussions between various stakeholder groups. Moreover, they viewed the asynchronous nature of these tools, where parents and staff were not required to be in the "same place at the same time to interact," as beneficial. One parent said,

> Well again email is great to get things started, the real-time computer interaction is good too and I think it needs to be a supplement to the written emails…the phone is good or the computer is good. Some people are are concerned about privacy. I am not just because with [child's name] situation we have chosen to be really open and vocal but I regardless, I think there needs to be some real-time dialogue.

A staff member also suggested the idea of putting computers in community places where several of her clients and their families live. She said, "If you put a computer out in a community where the families live—the library. Yes, the library. Then they do not have to worry about driving so far." However, both the staff members and parents recognized the importance of having trained moderators seven days per week, perhaps with some evaluation expertise, to facilitate the discussions, keep postings on topic, and ensure that the forums were respectful to and inclusive

of everyone's ideas and suggestions. For example, one staff member noted, "If you cannot broaden it out to a seven-day-a-week opportunity or evenings or whatever to make it more possible to get more participation, then what's the point." Meanwhile, one parent said,

> For me, it's just having someone working with me, guiding me through options, and kinda of like this conversation, me just being able to shoot the breeze and give my observation and someone else do the synthesis and keeps me on topic.

Lastly, staff members suggested that Skype would be another great mechanism for encouraging more family engagement in evaluation. One individual made a convincing argument stating, "I was just going to say Skype. People are visiting Santa Claus on Skype now—why not use it for program evaluation?" With Skype, the participants thought that they, for instance, could obtain input and feedback from geographically dispersed families, families without transportation, or families unable to attend meetings in person because of caregiving responsibilities. In this sense, "Skype would provide them with the opportunity to voice their opinions and perspectives from their homes on the evaluation or the care received." The focus group participants also noted how Skype would be beneficial because it is "cheap," allows for synchronous participation, is "user-friendly," and has an instant-messaging function that they could use to share information during meetings with families. Overall, participants thought that these online mechanisms for communication would provide parents who are interested in program evaluation with flexible, convenient ways to become actively involved. After all, as staff member noted, "Using technology would be good because it is at your convenience and you do not have to physically be somewhere; it does not have to be a group necessarily."

Parent interviewees also reiterated the importance of this flexibility and convenience when engaging parents in evaluation processes. All parents wanted improvements that would

minimize travel time for them but increase their options, if they were interested, to participate in program evaluation advisory committees or in evaluations as participants. As one parent stated,

> I think you have to think of different families and how they would work because when I am home with the children it's hard, you need to come to me. For me its email, email, email, or the phone works too, that's what would work for me.

To complement and encourage the uptake of these alternative approaches for reaching and involving families in program evaluation, some staff members and parents also suggested the idea of "family champions."

Recruit family champions. Some parents and staff members suggested the creation of "family champions" or "parent ambassadors" for program evaluation. They thought that these individuals, if selected appropriately, could improve parent involvement in the evaluation of family-centred programs. As one staff participant articulated,

> We need a champion or someone dedicated to it. Someone with the ability to really know everything, keep it on track for the families within the centre, knowing how to communicate well with families. There really is not a central person that really particularly is looking at that right now.

Both staff members and parents envisioned that the primary job of these champions or ambassadors would be to enhance the visibility of and communicate the value of program evaluation to parents across their centres. One staff member's quote reflected this idea: "I think you have to have the champions to really move it forward because I think we do little snippets and I do it whenever there is time but there is a lot of updating to families needed." Parents also commented on how these individuals, through "parent-to-parent communication," could make program evaluation initiatives more transparent. As one parent stated, "We will know what was

going on—why we have to do the survey." These champions, as another parent also suggested, could "help communicate about upcoming evaluations or findings to us." In terms of family involvement, all participants also discussed the notion of involving families in program development.

Involve families in program development. In the focus groups and interviews, the participants discussed how family involvement in program development has important implications for subsequent program evaluation efforts. As a parent noted, "From my own work experience at [place of employment], the project development part is really the key to success of program evaluation." A few staff members also reflected on their own program evaluation experiences to illustrate how family participation in program development was a determinant of long-term family engagement in all programming aspects, including evaluation. For example, a staff member stated the following:

> What I have used for implementation in my program and it is very much participatory from the very beginning. From the onset, when you are planning a program, like some of these other program reviews, we tend to bring families in at the end, but if they are with you from the onset in planning for the program, then the goals and evaluation outcomes are planned from the beginning with the family, right.

Many also advocated for further involvement of families in the development and evaluation of their programs. Several staff participants echoed the following statement:

> I was going to say something similar. I think if they [parents] are involved in the creation of the program and really understand what we are looking to get out of the program, then I think their feedback at the end of the evaluation is going to be more meaningful, especially if we have them engaged throughout the process. We run into the same thing

> with families who really, really want service and we offer them program after program that they do not come to. So, having them involved from the beginning to ensure we understand what their goals are around that and evaluate whether or not we met those goals; again, just the process.

However, other staff members admitted how they lacked training on how to engage families in program development and evaluation, and as such, they often overlooked the input of the service users when developing programs. They suggested that they could potentially improve the evaluation of their family-centred programs by obtaining additional training in this area. For instance,

> I think everyone needs some training in that area and if families are involved at that stage, to give input. You need them to be engaged at the first step to be engaged at the last step, but we do not know how to do that.

Furthermore, parent interviewees emphasized the idea of building evaluation into the program from the beginning and promoting active participation by parents in both program development and evaluation. A couple of parents stated how important it is to design the evaluation during the planning of programs. The following parent account summarizes this:

> I think we need to be part of the program development. If it is a specific program, what are the goals of the program and engaging us from the start of what a program could look like, what could be the steps in achieving the goals for our child and what are some activities for smaller, more short-term programs potentially in rec and leisure. That could be in engaging us as well; how could it look for us? We might then be more engaged at the end.

Overall, parents viewed this evaluation component and their contributions in it as extremely important because it helps ensure that the programs for their children are providing meaningful and quality care. As one parent stated,

> We are not going to have meaningful programs I think if we don't really start to integrate families into even into program delivery, that it's something else, it does not just end and start at evaluation, it's weaving the families into program design, program delivery and then measurement of the success.

Overall, parents explained how their involvement in the design and evaluation of programs would provide them with opportunities to identify assessment and evaluation measures that are appropriate for their children and allow them to "have more appreciation for the evaluation and the forms they need to fill out for it." Similar to this idea, parents and staff members also stressed the importance of improving the evaluation of family-centred programs by making the evaluative activities more relevant for families.

Establish relevance for families. In the context of evidence-based practice, many staff members commented on how they rely heavily on quantitative approaches to evaluation. Although many described how these approaches provide "clear-cut" and "easy-to-interpret results," they acknowledged that several quantitative measures are irrelevant to parents because they provide limited parent-level information about individual children's progress in the program. The following is an example of this opinion:

> I mean, you can do all types of program evaluation, which may be meaningful to administrators and clinicians, but to parents, what is it that they really care about and what really makes a difference in their lives in terms of outcomes? A speech therapist might find that this is a really good outcome or in physio, he can walk but cannot do

> something else, but really engaging them into what type of outcome should be looked at in terms of doing an evaluation. What tools should be used really should depend on what is meaningful. Yes, there are things that may be are meaningful to the Ministry, but we should also look at what is meaningful to the families.

In one of the focus groups, some participants also discussed how qualitative methodologies provided families from their programs with more contextually relevant data, and as such, the families were more willing to participate in the evaluation. For example, the participants described how a parent volunteer helped coordinate the interviews with other parents. Likewise, other staff members commented on how their use of focus groups helped improve the data collection and quality of program evaluations within their centres. They thought that this method of data collection encouraged parents to "reflect in-depth" about what was working in the program, to "share their stories with others," and to "meet other parents" involved with the program. As one staff member explained, "We invited them in larger focus groups of particular languages and specific age groups. It worked well for networking and evaluation."

However, a couple of staff members at one site commented on how qualitative approaches and the use of focus groups, from their experience, did not necessarily enhance parent engagement in the evaluation. For example, one participant stated, and others agreed,

> It is still about the engagement of the parent. You can have a key worker and use whatever methods and the parents still has to be an engaged piece to participate in the program evaluation. It is making it relevant so that it is not seen as either a research project or a program evaluation. I think it has to be relevant to the outcome and indicative of their interests in doing it; it is about what do you do to get that engagement piece.

These participants also emphasized that regardless of the data-collection procedures used, clinicians/evaluators need to develop program evaluations from the viewpoints of the service users. As one participant stated,

> I think it is really important to engage them early on to find out what is really important to them and meaningful in terms of an outcome and evaluation. Empower them. It is good for nothing unless you make it more relevant to them. What is important to them, what do they want to see, what is not working now and what can be done in the future? It is their program.

On another note, the parent interviewees stated that family participation in program evaluation should be dependent on families' desires to be involved. One participant described how her husband was not interested in being involved, but how the sibling of her disabled child was interested. She recounted,

> I think it's pretty meaningful to have input from a nine year old, you know who loves her sister, and who has seen the OT in action and says why are they asking her these questions because don't they know she can't speak….geez they are always focusing on this but when I play with [child's name] this is what I really want her to do. Could we work on this in the program? She is really involved in defining those important program outcomes that we should be evaluating…[child's name] is going to be relying on a lot of people to take care of her as the years go by, primarily her sister. Why wouldn't I be engaging her now in the program or its evaluation?

In order to facilitate this type of family engagement, parents and staff members commented on the need for organizational statements on family involvement in program evaluation.

Develop centre-wide statements about family involvement in program evaluation. Staff members discussed how the level and opportunity for family involvement in program evaluation varies widely and means different things within their organizations. As one individual articulated,

> One difficulty is just the terms "family involvement" or "family engagement." I find that buzz words like these are too generic and when we have sat down at meetings, people say the evaluation seems to be family-centred, involving families, or engaging families. I ask what they mean. It just becomes meaningless because there is no specificity behind these terms especially in terms of evaluation. I almost feel that they are tacked on. We want this project to go through so we will write family-centred or family engagement underneath it.

Moreover, parents and staff members also commented on how some programs involve parents in the planning phases whereas others only ask them to complete questionnaires. In reference to these varied approaches one parent noted, "I think people have good purposes behind what they do, but it is never articulated." As such, the parent suggested the need to develop a centre-wide statement that details when and how to engage families in evaluation processes. They thought that this was important for both parents and staff because many families access more than one program and thus may be unclear and question staff about their roles within evaluation. Staff members also emphasized the importance of letting families know how they can become involved, if they so choose, in the evaluation of their children's programs. Overall, they thought that centre-wide policies or statements in regards to families' involvement in program evaluation may represent an initial stepping stone towards more family-centred approaches to evaluation. As one participant concluded,

> Certain things are hugely mandated. We have what is called key performance indicators, which were designed to ensure that what we are saying is evidence-based but we have no evidence or evidence-based policies for the best way to involve families to get these indicators. This is a problem.

With that, staff members thought that compensation for families may be one mechanism for better involving them in program evaluation.

Compensate families. Finally, focus group participants suggested that the evaluation of family-centred programs could be improved by compensating families for their involvement in evaluation initiatives. The majority of staff participants thought that parents should receive financial payment for their involvement, much the same as external consultants. The following quotations exemplify participants' thoughts:

> They bring in an external consultant who is obviously paid big bucks to do this but where parents are involved we don't pay them—we need to pay them if we pay the consultants.

> I can think of many of my families who would love to contribute to what is happening here, but have absolutely—there is no possible way because they are home with three kids and working two jobs and they can barely pay for bus fare to get here for appointments. If we could give them some money, I far rather have them than an external consultant. We are not going to be paying them the thousands of dollars consultants get anyways.

However, many participants recognized that full compensation might not be available because of resource limitations. Instead, to encourage families to participate, they thought that families should receive some other form of compensation. As one participant suggested, "If you have the

support in place like paid parking, food, child care, and maybe language interpretation they will be more likely to participate." Conversely, another stated,

> I personally feel really strongly about that and I do not think we can afford getting wider perspectives unless we actually have a mechanism for compensating somehow people for their exceptionally valuable input—most valuable input and what we really want. Who can afford to volunteer during the daytime when we want them to do all of these things.

Summary for Question 3.1

The staff members and parents who participated in Phase 3 identified seven interconnected ways for improving program evaluation activities to make them more congruent with FCS philosophy. They suggested that a more diverse group of parents should be included in the program evaluation activities, as the current activities cater to a specific group of affluent parents. They also noted that clinicians/evaluators should use interpreters and translators, digital technologies, as well as more flexible evaluation designs to develop evaluation approaches that better engage families and fit their needs and lifestyles. Moreover, participants mentioned the ideas of recruiting family champions to promote family involvement in program evaluation, compensating families for their involvement in evaluation, developing more centre-wide statements about family involvement in evaluation, and involving families in the initial program development stages in hopes that they will then be more engaged in future evaluation activities. Finally, they also explained how the evaluation processes need to be more relevant to the needs and priorities of families.

In terms of improvements, it is also important to think about what types of evaluation approaches might be more compatible with FCS philosophy and logic.

3.2(a) Are alternative evaluation approaches likely to be more compatible with FCS philosophy and logic?

Although the focus group and interview participants stated that they had minimal knowledge of alternative approaches (i.e, collaborative and participatory approaches) to program evaluation, all acknowledged that the idea of staff members and families working in partnership to evaluate family-centred programs within their rehabilitation centres was ideal and, in many ways, compatible with their perceptions of FCS philosophy and logic. Throughout the focus group discussions and interviews, the participants characterized families as the primary stakeholders of program evaluation. Given this view, they described how participatory approaches to evaluation, in congruence with FCS, would increase the relevance of program evaluations for families, help support program interventions, assist in the development of clinician-parent relationships, and facilitate the empowerment of families. I will now turn to a description of these four inter-related ideas to illustrate how the participants thought that participatory approaches to program evaluation were consistent with FCS philosophy and logic.

Increases relevance of program evaluation for families. Both staff members and parents noted that by involving family members in the identification of evaluation priorities, evaluation findings are more likely to be applicable to the questions that families have about their children's services and care. With regard to evaluation practices, one parent stated,

> If the waste-of-time instances are repeated over and over again with other families, why would they want to be involved? Unless you zero in from the end users' perspectives—why that didn't work and really have an evaluation system that can fair out that information, why would you keep spending money on methods and things that don't

> work or don't address the overall needs of the end-users? And the end user, for me, is the collective not just in our case [child's name], it's the family.

Conversely, reflecting on her own evaluation experience, a staff member stated,

> I was involved in an electronic scheduling evaluation project and we had a family member there for four days, and they were there through every step and process—what was important to them, what they want to see in the evaluation, what is not working now and what can be done in the future. It was interesting to have them there. It made the evaluation more relevant to them.

After hearing this participant's description of what a more participatory process looked like in action as well as my mini overview of participatory evaluation, another staff member reacted by stating, "I want to be evaluating things that are important to the family, so I think this approach would work. By involving families, I can see how I can make it more relevant to them. This is a start."

With that said, staff members described how they currently derive the identification of most evaluation areas from their own perspectives. In terms of current practice, one participant commented, "It is the good for us but unless you make it more relevant to them [families] is useless." However, with more participatory approaches, they thought that this top-down identification approach would become more family driven and hence, provide information that is more applicable to families. One focus group participant summarized,

> Being able to set evaluation goals in collaboration with the family would be excellent, we could really set the goal properly so that it will be not too far out of reach—within reach. That would be better for the family.

Moreover, others agreed with this comment and suggested that this approach would be more compatible with the family-centred element of providing families with "appropriate information" so that they can make informed decisions about "if the care their child is receiving meets their expectations." As one participant concluded nicely, "If you set realistic evaluation goals with families at the beginning, they are going to be more satisfied with the service and will understand their child's needs, make good decisions, and be more engaged in the whole thing."

Overall, all participants thought that alternative or participatory approaches would encourage better family engagement in evaluative activities relevant to their needs. They also thought that these approaches would assist in the development of strong clinician-parent relationships—a key component of FCS.

***Assists in the development of clinician-parent relationships*.** The majority of the participants mentioned that participatory approaches to program evaluation could improve the level of communication and trust between clinicians and parents—two important concepts under the umbrella of FCS. As one staff member pointed out, "There is something nice about the intimacy of getting to know the people on the team, the families, trusting them and working with them and feeling free to ask what you want to ask."

As part of a participatory evaluation process, staff members envisioned small staff-parent group discussions or clinician-parent brainstorming sessions around the design of evaluations, the collection of data, or programs themselves. They thought that these types of opportunities would bring families and staff closer together and provide all those involved with the opportunity to listen to one another's concerns and viewpoints.

A few parents, on the other handed, expressed that trust is an essential component of clinician-parent relationships. For them, this trust is bi-directional and based primarily on

previous experiences between themselves and the clinicians. As such, they thought that the participatory approach might help nurture trusting relationships because it would provide them with additional opportunities to get to know clinicians. Through working together, they believed that they could foster mutual respect and open communication with the clinicians, which would be useful in clinical situations involving the care of their children. As one parent highlighted,

> You know if you had worked with the physio you get to know them different, maybe develop a work-type relationship you, respect and trust them. We would trust the physio on lots of levels, not the external evaluation officer because we know the physio.

The nurturing of this trust between parents and clinicians through program evaluation may also contribute to the effectiveness of the program intervention itself.

Helps support program interventions. Some staff members and parents highlighted how parents' active involvement in evaluation via a participatory approach may complement the intervention process. They described how the information parents might obtain by, for example, assisting with the design of the evaluation for their children's program could foster feelings of control and self-efficacy, which, in turn, could help them better cope with stressful situations. As one parent explained,

> One of my social workers recommended that I go to evening groups for parents of children with ASD recently diagnosed. At that time, I just wanted to get as much information as possible. This type of group might work well for evaluation too. Parents, at that point in time, they really want to get information and get engaged. I do not know if that if you could get them involved in program evaluation but these types of group things help with stress for sure.

Similarly, staff members commented on how many of the programs, under the philosophy of FCS, encourage family-to-family networking and support; as such, they thought that the idea of families working together in program evaluation could facilitate additional family networking sessions that are incorporated into many rehabilitation programs. In this regard, one staff member noted, “With this [approach], they would feel more comfortable talking to another parent.” Another highlighted,

> You are providing them with resources as well at the same time because they are meeting parents who are in similar situations as them and that could be another draw to getting them there. They are talking about program evaluation and program creation, but they are also meeting families in the same situation as them. It is an opportunity for brainstorming and resource sharing, as well.

In this sense, allowing parents to get involved in the evaluation of their children’s programs might help to improve their quality of life and, as such, complement the goals of selected programs. It might provide families with valuable opportunities to reflect on their own circumstances, to develop the capacity to address some of their own needs or those of their families, and thus, to empower them.

Facilitates the empowerment of families. Overall, the focus group participants and interviewees thought that participatory approaches to program evaluation would empower families. Many staff members agreed that, “In this approach, families would know their voice is being heard and something is being done about it.” Furthermore, in terms of participatory evaluation, one staff member highlighted,

> We really want to connect with families on a regular basis about it. Because they have a much smaller voice than staff. Staff will have immediate feedback. Staff will have some

> power and the ability to network and navigate to see changes made. Patient and families do not have that advantage, that is why I advocate and say, have more voice.

Conversely, one parent said that, “It’s a process like this where I can make a difference in the outcome of my child’s health, absolutely I want it.” Another noted,

> I don’t know how you can run anything without an evaluation and the perspective of the the end user… [child’s name] can’t speak for herself so you need to are going to go to her family. We need to speak for her; that is important to us.

Furthermore, staff members described how the ideas of clinician-family partnerships, accessibility to additional information, and the idea of self-confidence interconnect within the concept of empowerment. Commenting on her experience in involving families in program evaluation, a staff member stated,

> We found by talking with those families, that they found participating beneficial—that it helped them to understand what was happening and what was going on sooner. They showed an increase in their confidence level as a result and, I guess, more to that is a decrease in their anxiety level. They were able to think of questions about going home sooner and start learning what they needed to ask rather than having those questions when they got home, which often times lessens the process for leaving if you do not feel ready to go.

All participants also described a number of other potentially empowering benefits of participatory approaches. For example, staff members noted how family members could have increased opportunities to recognize that they, as parents, have much to offer in terms of their children’s programming and its improvement. They commented on how participatory evaluation could provide parents greater insight into the “behind the scenes” of their children’s programs

and as such provide them with more confidence and knowledge on the treatments, services, and activities that their children receive. Parents, on the other hand, emphasized that "it becomes really the family member addressing the centre as the initiator of the service."

Summary for Question 3.2(a)

The focus group and interview participants unanimously thought that alternative or participatory approaches to program evaluation showed substantial promise for and compatibility with their family-centred environments. As mentioned earlier, they thought that this type of approach would increase the relevance of program evaluations for families, help support program interventions, assist in the development clinician-parent relationships, and facilitate the empowerment of families. Given their positive reactions to the theoretical ideas of such approaches, I also explored how feasible and practical it would be to implement them within their pediatric rehabilitation contexts.

3.2(b) How feasible and practical would it be to implement such approaches?

Although the participants saw active family involvement in program evaluation as important and congruent with many aspects of FCS, they questioned the ability to implement and use it regularly within their centres. As described below, the majority of their concerns revolved around limited time and funding to carry out more family-oriented or participatory-based evaluations.

Time. From an efficiency viewpoint, many staff members argued that involving families in the evaluation of programs would require additional time for evaluation—time that they currently do not have. More specifically, many commented on how the involvement of families would require additional time to identify families interested in evaluation, to arrange logistics for family participation, to review relevant program documents, to reflect on the processes, as well

as to offer feedback. For example, one staff member stated, "There is lots of really good information there if somebody wanted to go and get it, but—there is no time." Others pointed out,

> I think the coordination of the families and contacting them. Clinician time is so limited to do that whole administrative piece of finding the clients who could be eligible or interested for the evaluation, the parents who might want to participate and going over what the program evaluative component could be and their time around that and getting them to agree—like that whole pre-stuff, you know? Takes so much time!

> Once we finish a program we are focused on the next program because there is this push to get another one going and we do not necessarily have the time to evaluate the program effectively. It would take a lot of time in terms of engaging parents, like I said, with the phone call follow-ups to see if they are interested two and three times because they may not call back. Once we get them on the phone they are happy to be involved, but time would be a real challenge for us.

Staff members also emphasized that they need to juggle both their clinical and evaluation responsibilities; as such, they often have limited time for evaluation and tight timelines to collect evaluation data. Many agreed that "stuff gets started and then it—then it gets dropped. Dropped or whatever." Thus, they argued that it would be difficult to incorporate the additional time that they believed participatory evaluation requires. As one individual said, "Well, it would be added work for the clinician."

Furthermore, staff recognized that participatory evaluation approaches might put added demands on families who already have extremely busy and stressful lives or are in crises. As one participant articulated,

> I think it could be very confusing to families. I think we numb them over with jargon when they walk in the door. The program I am in, we have a lot of people that are in their face in the first twenty-four hours asking and expecting them to participate actively. We know where we are in this. Our kids are coming in usually fresh off injury and the families are still spinning. They do not have a clue what physio does or a speech therapist does, yet we are going to be talking about goals, evaluation and have to have it within seventy-two hours—that is an absurd amount of time. The family has not even figured out where the cafeteria is!

Likewise, parent interviewees suggested that they are sometimes in a state of crisis and may not have the time to participate in program evaluation. As one parent stated,

> To my memory, based on my memory, in the beginning we were really in a state of crisis. Someone could have offered me an evaluation; I am not sure I would have remembered it, let alone participated in it.

Another parent also said,

> I'd be interested, and of course it's subject to time, in everything, in in looking at the questionnaire, in providing the feedback, even so far as to getting involved in the design. I think I think the parents of these children, again where they have the time, and they are out of the crisis or they are temporarily out of the crisis because I guess we are never out of crisis. You could comment so much on what will work and what will not.

Furthermore, other parents commented on how they are limited in terms of the amount of time that they can dedicate to extra or volunteer activities. As one parent stated, "Time is always the enemy." Adding anything to the to-do list it is tricky." Others explicated,

> Well again this is just me, I got, depending on the day, two or three of them at home under eleven, so it is busy when I am not at work. Work is almost the quiet time, which is really sad. So, where I never use to do this before, now for me I would try to schedule these times of things during the day because when I am at home after six o'clock it is don't speak to me that has got to be my time with the children.

> It's a tough call because some families are so busy just kinda of keeping body and soul on their children together especially if they are severely disabled, that asking them to commit to like evaluating, they are just hoping they get some help let alone evaluating what help they got.

Thus, although parents and staff members liked the notion of alternative and participatory evaluation, many thought that it may be difficult to implement because of time constraints. Staff members also thought that funding for such initiatives may be limited.

Funding. Staff members believed that the additional time required for participatory evaluation approaches would translate to increased evaluation costs. One individual noted,

> When systems are set up they are very heavily resourced for the beginning sessions and setup, but then there are no resources or time allocated. We give all of those dates for starting projects, but there are no dates set up, like March 2012 this evaluation will be done and family leaders will be involved. Those specifics are not done and if you want to get that stuff done then we need to set it up and have more money.

Currently, many of them reflected on how they receive minimal funding for program evaluation and that this could be problematic in terms of implementing alternative or participatory evaluation approaches. As a participant summarized,

> Resources are at an absolute, you know, bottom. In fact, we are more in a cutting phase right now when it comes to evaluation. Evaluation can be quite costly, which is one of the reasons why we rely on the systems and approaches we already have.

They did, however, note that their senior managers do sometimes employ consultants for evaluation-type work, and perhaps, that some of the funds used to pay the consultants could be used to facilitate participatory processes or compensate families for their involvement. For example, many participants agreed with the following sentiment, “It would cost, but we spend a lot of money on all kinds of other extraneous pieces, like externals, that could be devoted to participation.”

In terms of payment, staff members emphasized that, in order to ensure the successful implementation of a participatory evaluation involving families, families need to be reimbursed for their time and expertise. As one staff member emphasized, “I have been in presentations about children participating in research and evaluation, or anybody participating and they should be paid because they are partners in it as well!” Another also pointed out, “I think, also, the funding is helpful if they are being asked to give up time with their children.”

However, they noted that if they pay participating families at similar rates to other consultants, evaluations would become too expensive and impossible to do. To minimize some of these costs, but still compensate families and effectively implement participatory approaches, other staff suggested that program staff only cover participating families’ travel costs and child-

care expenses while they are working on evaluation projects. The following quotation summarizes this idea:

> I mean, if there is a grant out there that would be a specific pocket of money that would be allocated to that and giving honorariums to families for participation, I think that would be really neat, but I do not know what kinds of grants exist like that. In order for families to take the time to come to a meeting, you know—well, if they are still working in the home, available during evenings, if they need to pay a caregiver, pay for transportation and parking—there has to be something just to take the time away from their home life, yes, it would be fair.

In terms of funding, staff members also thought that a pocket of money would be needed to train both staff members and parents on alternative and participatory evaluation approaches.

Training. As suggested by staff members, additional training would be essential for the successful implementation of alternative and participatory evaluation approaches. For example, one staff member noted how her centre would need to offer specific training to the parents involved. She said,

> That input can be a bit limited because to have families help analyze the data in order for it to be, you know, kind of summarized, they need to understand the context. That means bringing them in and going over that, training which I advocate for.

In terms of staff member training, all agreed that “It is something that people are really just kind of starting to wrap their heads around” and, as such, “we are going to need to be providing staff with training in how to do that because for some of them it will be new.” Many staff members further discussed how they have minimal knowledge of program evaluation and no or little

training in alternative or participatory evaluation approaches. For instance, one staff member noted,

> I think the staff just needs education on project evaluation and even project planning to lead to project evaluation because we are clinicians and if we have not taken a class in that, it is something that you do not necessarily think about when you are planning a program. That is a big gap of skills that could be facilitated by some education so when they are explaining the rationale around program evaluation to their clients, they have the language and background to show how important it is.

Evidently, they thought that this lack of knowledge and training would affect the implementation of program evaluations involving active family participation. In response to participatory evaluation, one individual stated, “It is so theoretically high up that it is not even interesting to read let alone participate in.”

Staff members also commented on how they need training to help “demystify the concept of family-centred in evaluation.” They also thought that joint training sessions between themselves and interested parents would provide a strong basis from which to begin participatory program evaluations. Essentially, through these joint sessions, they could better understand the priorities and interests of families—something that parents identified as essential for the future implementation of participatory approaches to program evaluation.

Priorities and interests of families. Lastly, parent interviewees commented on how the priorities of families often vary according to the age of their children with the disabilities, the nature of the disabilities, and the families’ demographic characteristics. As one parent highlighted,

> Somebody like me, I would be happy to participate and say, “Well I think this works or that works or the other works.” But I have, I just only have the one child so I had a bit more time… And my mom and dad had been hugely active with her, so I got a lot of support. So if someone said can you evaluate the program, I would have said “yes” but I do understand how some others might have difficulty.

Conversely, another parent made the following comment when asked about the idea of participating in program evaluation:

> There is a spectrum of ability and disability and [child’s name], is at the far end, the wrong end of the spectrum… It’s got to work for the end user and I guess that is hard as I am saying it because what works for one family might not work for another but you have got to know that… It’s the whole issue of stakeholder engagement. Different families will have different circumstances.

Similarly, one individual articulated,

> So, you will have cerebral palsy, etc. and their experiences can be very in-depth, lifelong—will be lifelong. You get a real intensity experience with that too and by that it means that there are certain families who will have very different experiences with rehab than others.

In light of these differences, they highlighted that the participation and interest of families in evaluation processes may also vary. One individual stated, “For some, that is not their priority; their priority is very different. I do not think the system is very flexed to that.” Whereas another said, “I guess the other thing is just because it is the most important thing for one parent right now does not mean it is the most important thing for all.” Several parents thought that the priorities and interest levels of families might make it is easier to use a participatory approach in

some programs rather than others. As pointed out by many parents, “Whether it is going to work every time or not—probably not—but they can really try hard to do that.”

They also noted that it might be challenging to find consensus among groups of families on evaluation priorities. In reference to this one parent stated, “Different priorities come along. I think to engage the parents is really a challenge.” Likewise, another said, “When you get families who have just had a really difficult experience—due to their diagnoses and own journeys—it will be hard to find agreement.” Therefore, parents thought that because of the uniqueness of their children’s needs as well as their own circumstances, they might identify different programming aspects needing evaluation. They thought that these competing interests and priorities might pose some challenges for participatory or alternative approaches to program evaluation.

Summary for Question 3.2(b)

Participants were somewhat skeptical of the ability to implement collaborative and participatory evaluation approaches within their pediatric rehabilitation centres. They thought that such approaches would require additional time and funding—two things that they have very little of. They also discussed how the priorities of families often vary, and as such, they were not sure if these types of approaches would be of interest to all, or possible to implement in all, family-centred programs. Lastly, they described how it might be challenging to find consensus on evaluation priorities if diverse groups of families are actively involved with the evaluation.

Summary for Phase 3

Overall, Phase 3 included two focus groups with staff members and six interviews with parents and aimed to explore how the evaluation of family-centred programs can be improved as well as the ability to use alternative evaluation approaches within the family-centred pediatric rehabilitation context. Participants noted several ways for improving program evaluation

activities in order to make them more congruent with FCS philosophy. While they thought that collaborative and participatory approaches would support many FCS elements, they questioned how their limited resources and diverse rehabilitation centres could realistically implement them.

The next chapter will integrate and discuss the above-mentioned findings for Phase 3 with those from Phases 1 and 2 and offer some implications for evaluation research and practice.

Chapter 7: Discussion, Contributions, and Future Directions for Research

Although the literature suggests that program evaluation activities have expanded in recent years within health services (Brazil, 1999), the results from this study suggested that expansion has not yet occurred within Canadian pediatric rehabilitation settings. Staff members and parents who participated in this three-phase study offered several perspectives and suggestions that might help us to better understand program evaluation and ways to stimulate it within this sector. Through integrating the findings of this three-phase study with views from the literature, I will explain the current state of program evaluation within Canadian rehabilitation centres, establish the need for those working in these centres to increase their evaluation activities, and suggest some areas for improvement. Prior to this integration, I will also provide an overview of the study, and discuss the limitations. In closing, I will then reflect on the contributions of this study to theory, methodology, and practice, discuss areas for future research, and present some concluding thoughts on the topic area.

Overview of the Study

Divided into three phases, this sequential mixed-methods study had an overall aim of describing and analyzing current program evaluation practices in family-centred pediatric rehabilitation settings. With a specific focus on Canadian pediatric rehabilitation centres, the primary goal of the study was to examine the strengths, limitations, and consequences of current practice along with its compatibility with FCS philosophy. As a secondary goal, the study aimed to understand the promise and prospects of alternative (i.e., collaborative and participatory) evaluation approaches that, in theory, are more compatible with FCS philosophy than traditional ones.

Over a one-year period, I used questionnaire surveys, one-on-one interviews, and focus groups to obtain answers to the following research questions:

Phase 1

1.1 To what extent are pediatric rehabilitation settings engaged in the evaluation of family-centred programs?

1.2 Why do pediatric rehabilitation settings engage in the evaluation of family-centred programs? To what extent are purposes oriented towards accountability versus learning?

1.3 To what extent are the evaluations of family-centred programs consistent with FCS philosophy and logic?

1.4 Does evaluation practice vary as a function of organization size, location, resources, participant characteristics, and beliefs?

Phase 2

2.1 What values, factors, and conditions support or inhibit the evaluation of family-centred programs? How do these values, factors, and conditions affect the evaluation?

2.2 What are the benefits and limitations of mainstream practices in the evaluation of family-centred programs?

Phase 3

3.1 How can the evaluation of family-centred programs be improved?

3.2 (a) Are alternative evaluation approaches likely to be more compatible with FCS philosophy and logic?

3.2 (b) How feasible and practical would it be to implement such approaches?

I collected, analyzed, and interpreted the data using the conceptual framework explained in Chapter 2. The sequential mixed-method design of the study included several mechanisms to

enhance the quality and ensure the validity of the findings. Through this design, I answered complex questions that I could not have addressed using solely qualitative or quantitative approaches. As mentioned in Chapter 3, I also used the results from one phase to inform the development of the data collection tools for the next phase. Furthermore, by using multiple phases, each with their own guiding research questions, I increased the scope of the inquiry and provided more information on the evaluation of family-centred programs in pediatric rehabilitation settings. Lastly, I provided participants with opportunities to comment on and assess my interpretation of the findings. While these features strengthened the study, it did have some limitations.

Limitations of the Study

Regardless of the study design or methods used, all research has specific strengths and limitations (Babbie, 2008). While I referenced many of the strengths and limitations of this study in the preceding chapters, I will reiterate and discuss the main limitations of this three-phase study in the sections below.

Main Limitations of Phase 1

While the Phase 1 survey was useful in describing the characteristics and perspectives of a large and geographically dispersed group of individuals involved with program evaluation at selected pediatric rehabilitation centres, it relied on self-reports of recalled evaluation activities (Babbie, 2008). When asked to recall the evaluation activities of their centres, some respondents, even though they were actively involved in program evaluation, indicated that they did not know the answers to certain questions and thus, the validity of some of the survey data is questionable. The survey also dealt with sensitive items regarding staff members' perceptions of family-centred behaviours and program evaluation. As such, respondents may have provided socially desirable responses and answered the questions more positively than is actually true. However,

my assurances to the participants that their survey responses were anonymous should have encouraged them to provide candid responses. Conversely, another limitation of Phase 1 was the survey anonymity. Since non-respondents were unidentifiable, I was unable to investigate the possibility of a non-response bias or determine the response rates from each of the participating centres.

On a related note, some may argue that the response rate and sample of Phase 1 were also limitations. However, as mentioned in Chapter 4, the survey literature suggests that there is no agreed-upon minimum response rate for surveys (Fowler, 2009). For instance, Babbie (2008) and Dillman (2000) suggest a minimum 50% response rate whereas Church and Waclawski (1998) report that response rates often vary between 30% and 85% for organizational surveys of employees. Furthermore, Hill, Fahrney, Wheeless, and Carson (2006) describe how surveys in health-care environments, such as the ones targeted in this study, often have low response rates due to respondents' characteristics and high workload demands. Hence, I consider the 29.9% response rate for the present study acceptable. I do, however, recognize that the data would have yielded more reliable results if the response rate was higher or if all site representatives knew who was involved in program evaluation at their centres. Moreover, since it was unknown if the distribution lists used by the site representatives were representative of the intended population, there is the potential of coverage errors (i.e., failure to include some portion of the targeted population) (Lee, 2012).

Furthermore, in light of privacy concerns from a research ethics board as well as the limited availability and accuracy of the data at the centres, I was unable to collect the size of the participants' centres or the number of programs operating in the centres. The absence of these data limited the generalizability of the study findings as well as my ability to examine if there

were variations in evaluation practice because of the size of the centre or the number of programs offered. However, I did collect information on the classification of the centres (i.e., freestanding or sub-centre) as well as the size of the cities in which the centres were located (i.e., small to medium city; large city).

Lastly, the survey consisted mostly of closed-ended questions. These questions facilitated the data-analysis process and made the data-collection tool more respondent-friendly. However, the format might have limited participants' abilities to provide additional data. As such, the survey was somewhat superficial in its coverage of the complex topic area (Babbie, 2008). Still, the survey results provided me with insight into where follow-up questions were needed in Phase 2.

Main Limitations of Phases 2 and 3

Some of the main limitations associated with Phases 2 and 3 are similar to the above-mentioned limitations of Phase 1. First, the information that I gained through interviews and focus groups in Phases 2 and 3 was based on self-reports and filtered through the views of the selected participants. My presence in the interviews and focus groups may have also led some participants to edit their comments in order to reflect themselves or their centres in more favourable views.

In addition, participation in Phases 2 and 3 was voluntary and it is unknown if there were any systematic differences between those who participated and those who did not. It is likely that staff members and parents who participated in these phases where more vocal, active within their rehabilitation centres, and interested in the topic area. Hence, they may have expressed different views than those who did not participate.

Moreover, while the level of FCS can vary among centres and individual programs and potentially affect the degree to which individuals incorporate it into evaluation activities, this

study did not assess the actual level of FCS occurring within the participants' centres and programs. As such, it is unknown how the degree of FCS in the participants' programs and centres influenced the level of family involvement in program evaluation or their responses in the interviews and focus groups.

Furthermore, it was particularly challenging to find participants for Phase 3. Due to staff availability, the non-existence of committees, or limited availability of committees, the CEOs at the two participating centres each decided that their centres could only commit to one heterogeneous focus group of staff members. Although these focus groups provided checks and balances for the participants (Patton, 1990) and were an efficient way to gather information from several staff members, the heterogeneous composition of the groups could have resulted in some participants being unduly influenced by other participants' managerial positions. However, to minimize this limitation, I prefaced each focus group discussion by highlighting the participants' similar interests in program evaluation and invited them to individually follow up with me if they were uncomfortable sharing specific information in the focus group setting. Organizational issues (e.g., lack of family advisory committees) and lack of interest at the participating centres also limited the amount of family participation in Phase 3. Given the family-centred focus of this study, more family input would have been ideal. However, the parents who participated provided a substantial amount of information that will help inform future research initiatives in this area. Thus, despite the foregoing limitations, the findings of this study are valuable and provide new insights into the evaluation activities of family-centred pediatric rehabilitation centres.

Integration of Findings

Since I used the results from one phase to inform the development of the subsequent phase, in this section, I will explicitly integrate the findings of the three phases in order to obtain

a better understanding of evaluation activities in family-centred pediatric rehabilitation centres. I will also situate and discuss the key findings within the context of the academic knowledge base.

Type and Extent of Evaluation in Canadian Family-Centred Pediatric Rehabilitation Centres

Many researchers have commented on the expansion of evaluation activities within the health sector. They have suggested that this growth is a response to (a) requests from governments and foundations who want information about the performance and effectiveness of the programs that they fund and (b) administrators and managers who recognize the importance of process and outcome evaluations in the assessment of organizational progress and program improvement (Botcheva et al., 2009; Brazil, 1999). However, the results of the present study demonstrate that there is minimal evaluation occurring as well as some vagueness and variability about the type and extent of evaluation activities occurring in one health area namely Canadian pediatric rehabilitation. Concerning vagueness, in Phase 1, there were 188 respondents who indicated that they were involved in or responsible for program evaluation. Of these respondents, one-third stated that they were involved in all listed aspects of evaluation, and almost half noted that they were able to make decisions about the type of program evaluation activities used at their centres. However, when asked specific question about their centres' program evaluation activities, many individuals did not know the extent to which their centres engaged in various program evaluation activities or used certain evaluation designs or data-collection tools. This uncertainty results in questions about the real extent to which some individuals are involved in program evaluation and how they are conducting it.

Moreover, in Phase 1, respondents indicated that their pediatric rehabilitation centres more commonly conduct need assessments and assessments of program process rather than assessments of program theory, impact, and efficiency, but in Phases 2 and 3 the participants primarily focused on their use of impact evaluations. While this difference might suggest that

those who participated in Phases 2 and 3 were the specific Phase 1 respondents who stated that their centres do impact assessments or that the participants in Phases 2 and 3 did not participate in Phase 1, it does generate some confusion in terms of the types of evaluation activities used in these centres. Lastly, in terms of variability, a few participants described how their centres had some additional resources for evaluation (e.g., research assistants, funding, time) whereas, most noted that their centres had none. As suggested by Love (1983, 1991), Brazil (1999), and Cousins et al. (2008), a lack of such resources can impact the evaluation capacity of organizations and thus, the lack of resources might suggest why some centres in this study are doing more evaluation than others.

Regardless, many of the study findings are similar to those found by Flynn, Glueckauf, Langill, and Schacter (1984) in their study of program evaluation practices and activities in Canadian rehabilitation facilities that served children and adults. In their study, they found that, as of 1982, no participating facility had completely implemented a program evaluation system. More specifically, they noted that the average facility "could be characterized as somewhat below the 'halfway point' in terms of implementation of a complete program evaluation system" (p. 19). Observing that program evaluation activities varied widely among participating facilities, they suggested that program evaluation in these centres would become routine only if there was one staff member at every site whose primary or secondary role was program evaluation. At the time, 30% of the surveyed centres had dedicated staff for the collection, analysis, and dissemination of evaluation data. Furthermore, they found that only 9% of Canadian rehabilitation centres reported documenting cost-outcome relationships formally. In light of this finding, they recommended the need for increased documentation and assessment of program costs.

Almost 30 years later, the results of the current study illustrated that not much has changed in Canadian rehabilitation centres in terms of program evaluation. The findings suggested that the participating pediatric centres are, at the very most, midway in terms of establishing program evaluation systems. In fact, given that only 18% of surveyed centres have an employee whose primary responsibility is program evaluation, there is the potential that evaluation activities have actually decreased over the decades. Furthermore, despite current discourse about cost containment and hierarchies of evidence, this study showed that there has been minimal use of efficiency assessments or RCTs. Merely 5% of those surveyed indicated that their centres frequently or always use experimental or quasi-experimental designs and no participants in Phases 2 and 3 specifically mentioned using RCTs for evaluation. Furthermore, participants in Phases 2 and 3 did not provide examples of efficiency assessments and, only 30% of those surveyed indicated that their centres frequently or always report assessments of program cost. In fact, several respondents were unsure if their centres evaluated the cost and cost-effectiveness of their programs or determined if the effects of their programs were attained at reasonable costs. Nonetheless, the results did hint that the rehabilitation sector might be moving in the direction of cost-related evaluations, as newer employees were more likely to report that their centres do efficiency assessments. This potential trend is important especially given the current provincial and federal governments' demands for accountability and use of evaluation data for the allocation of scarce resources (Labin, 2011).

On another note, the study showed that the family-centred context of programs is embraced to varying degrees in evaluation. Despite admitting that they understand fully the family-centred context of their programs, many clinicians/evaluators noted how they were unable to incorporate it into their evaluations. Many stated the above-mentioned resource limitations as

the primary reasons for not incorporating it. In this sense, many of the evaluations described throughout the study reflected some aspects of traditional evaluation. Cousins and Whitmore's (1998) three dimensions—control of decision making, stakeholder diversity, depth of participation—for collaborative-inquiry processes, which I described in Chapter 2, help to describe the evaluation approaches used in the participating centres and provide some insight into how the approaches used are not overly participatory or congruent with FCS philosophy.

With respect to *control of decision making* (i.e., who controls the technical decision making about evaluation processes and conduct: evaluator or community member?), the findings indicated that control resides primarily with clinicians/evaluators. While these individuals have the power to make decisions about how to use evaluation findings (Yarbrough, Shulha, Hopson, & Caruthers, 2011), their "top-down" approaches contradict the FCS philosophy, which indicates that families should have the right to be the ultimate decision makers in the care of their children and have their expectations and voices heard in decision-making processes (Law et al., 2003).

Similarly, in terms of *stakeholder diversity* or who among the program community is involved in carrying out the evaluation, the findings illustrated how diverse groups of clinicians/evaluators, who have varying levels of authority to utilize evaluation findings are most frequently involved in multiple aspects of the evaluation. While this type of involvement supports Cousins and Earl's (1995) conception of practical participatory evaluation as the involvement of these clinicians fosters program decision making, problem solving, and the use of evaluation findings, family members are not regularly asked to join the evaluation teams. As such, many of the described evaluations are incongruent with the family-centred expectation that service providers collaborate with parents in program evaluation (Law et al., 2003).

Lastly, concerning *depth of participation*, which describes the extent to which stakeholders are involved in the evaluation, the findings showed that clinicians/evaluators are involved closely in all aspects of the evaluation. However, in most of the participants' accounts family participation was minimal. In some cases, some participants described how they invited parents from FACs to be involved in a few technical inquiry tasks such as the development and review of questionnaires but in most cases, families were involved only as data sources (i.e., people from whom data was extracted), rendering the process decidedly non-participatory by definition. While it is unknown if families chose to limit their participation in these evaluations, under FCS philosophy, families should feel welcomed and supported in the level of participation they choose, and staff should provide an environment that encourages family participation (Law et al., 2003).

Overall, this brief analysis shows that involving families more actively could help to better align program evaluation with the philosophy of FCS and increase the level of FCS in the participating centres. However, given the current resource issues, it might be challenging to make program evaluation in these settings more participatory and congruent with FCS philosophy. There might not be a single participatory evaluation approach that is a perfect fit for family-centred pediatric rehabilitation settings. Instead, a combination of various collaborative and participatory approaches might work best, but it is still unknown what this combined approach might look like in practice. Nevertheless, in light of this incongruence between the FCS philosophy and evaluation practices as well as the vagueness and variability about the type and extent of evaluation activities occurring in Canadian pediatric rehabilitation settings, this study also explored ways for improving program evaluation in these settings.

Reflections on Current Evaluation Activities and Areas for Improvement

Throughout the study, participants identified the strengths, limitations, and consequences of current evaluation practice. Their thoughts on and discussion of these items provided insight into the factors that support and hinder program evaluation in general as well as the use of participatory or family-centred approaches for evaluation within the Canadian rehabilitation context. The key factors identified in this study relate to resources such as staff availability, time, funding, training, and technology. Interestingly, many of these factors are similar to the documented facilitators and barriers of FCS implementation. For instance, Wright, Hiebert-Murphy, and Trute (2010) found that caseload size, time, resources, training, and existing policies hindered the implementation of family-centred practice in two disability service organizations in Manitoba, Canada. Likewise, Conway and colleagues (2006) identified several educational (e.g., lack of understanding and skills about collaboration and family-centred care) and organizational barriers (e.g., scarce resources and competing priorities) to the development of sustained, meaningful partnerships between service providers and families in various health-care systems. As such, improvements and investments in these areas may help to improve both the implementation of FCS as well as program evaluation within pediatric rehabilitation settings. I will now turn to a description of these factors as they relate to the present study.

Staff, time, and funding. As noted, the study findings illustrated that the majority of Canadian pediatric rehabilitation centres have not invested substantial resources into program evaluation. Throughout the study, participants mentioned the availability of staff, time, and funding as major factors that inhibit their program evaluation activities. The notion that resources influence evaluations is supported by Love (1983, 1991), Brazil (1999), and Cousins et al. (2008) who all discuss how a lack of personnel, funding, and time can impact the evaluation capacity of organizations to do evaluations or to oversee external evaluation activities.

Many staff members also described that their juggling of clinical and evaluation responsibilities as well as their clinician/evaluator roles makes doing evaluation difficult. Love (1983) and Majchrzak (1982) concur that balancing evaluation activities with other full-time responsibilities is challenging and that this type of situation may lead to, as Brazil (1999) states, "superficial data or post-hoc designs, instead of evaluation plans that are an integral component of program development" (p.viii). While it is unclear how superficial the current evaluation projects in these centres are, many interviewees acknowledged that the clinician/evaluator approach diminished the credibility and objectivity of the overall evaluations. The interviewees who saw these roles as problematic suggested that additional staff members, who could devote time to evaluation, could enhance the type of evaluation conducted, the quality of data analyses, and the utilization of evaluation findings. However, many also noted that there was limited funding within their organizations to employ internal or hire external program evaluators.

This type of evaluation resembles what Mathison (1991) described as organizational self-evaluation. That is, the participating centres have staff members who are reflective and interested in self-improvement even though they may not always have expertise in program evaluation (Senge, 1990; Wildavsky, 1972). Given their self-evaluating characteristics, these rehabilitation centres, for the most part, do not have evaluation units or departments (Love, 1991). Instead, clinicians/evaluators prepare and collect systematic information about the functioning of their own programs, analyze and judge this information, and make recommendations. As mentioned, many of the participants interviewed in the study suggested that their clinician/evaluator approaches resulted in the viewing of programs through "rose-coloured glasses." Inevitably, this one-sided view is common in self-evaluation because individuals tend to focus on what they want to see (Alvik, 1996). Hence, it is important to analytically look at the evaluation findings

produced through self-evaluation from another position (Devos & Verhoeven, 2003). Alvik (1996) recommends the use of a critical friend who has not been involved in the evaluation. This individual can help to eliminate places of intentional or unintentional oversight.

Furthermore, many staff members thought that the involvement of families in program evaluation would require additional time—time that they currently do not have. Many commented on the additional time needed to identify families interested in evaluation, to arrange logistics for family participation, to review relevant program documents, to reflect on the processes, and to offer feedback. Critics of participatory methods support these claims and suggest that the inclusion of multiple stakeholder groups results in increased time and financial burdens (Stufflebeam & Shinkfield, 2007). However, proponents of participatory evaluation warn against rushing the evaluation process because hurrying participants through could negatively affect their evaluation experience and diminish the use of the findings (J. A King, 1998). Instead, with proper planning, early involvement of families in program development and evaluation processes, and recognition from administrators, managers, and funding agencies that participatory evaluation is valuable even though it requires additional time, the use of participatory approaches within the rehabilitation sector is feasible.

However, in certain situations where, for instance, there are non-negotiable timelines, a lack of family interest or limited staff or family availability, participatory evaluation might be unsuccessful. As study participants suggested, participatory evaluation approaches might put added demands on families who already have extremely busy and stressful lives or who are in crises; as such, some thought that participatory evaluation might be difficult, at times, to implement. Some did suggest that family participation might be feasible as long as families were compensated for their involvement in evaluation initiatives. In this regard, participants thought

that parents should receive financial payment for their involvement, much the same as external consultants. However, if funding is, as the survey findings suggested, almost non-existent, it might be challenging to pay interested families for their involvement. If participatory evaluation is to become routine within these centres, stakeholders would need to seek additional funding opportunities from external sources.

Despite some interviewees' desire to involve families more routinely in the design and implementation of program evaluations, others discussed how their centres no longer have FACs that could advise them on how to engage families in these processes. This lack of infrastructure often stopped clinicians/evaluators from seeking family input and developing partnerships with families in terms of evaluation activities. On the other hand, a number of staff members stated that they had trouble working with their FACs to identify family representatives who had experiences with their programs and were interested in becoming involved with evaluation activities.

Overall, this lack of resources within Canadian pediatric rehabilitation centres is negatively affecting and will continue to negatively affect their ability to develop evaluation capacity and thus to implement evaluation systems and processes within their own organizations (Connolly & York, 2002; Garcia-Iriarte & Suarez-Balcazar, 2011). In order for these centres to routinely and effectively document and assess the implementation and impact of their programs and services, they will need additional resources (Garcia-Iriarte & Suarez-Balcazar, 2011; Preskill & Boyle, 2008). These resources should ideally include ECB evaluators who can act as evaluation facilitators and educators and teach the clinicians/evaluators how to evaluate their own programs and processes effectively (J. A. King, 2002; Volkov & King, 2007). Through this ECB approach, the centres would be better able to address their current evaluation needs and

prepare themselves to engage in higher quality evaluation activities in the future with the ultimate goal of integrating evaluation into their everyday work. However, training and mentorship would be essential in developing this evaluation capacity.

Training and partnerships/mentorship. Lavelle and Donaldson (2010) suggested that "evaluators are made, not born, and an extended period of training is necessary to master the evaluation-specific skills and knowledge necessary to provide quality service" (p. 10). While many of the participants in this study described their hands-on experiences in program evaluation, the survey results highlighted that only 19% had formal training in program evaluation. As such, these findings suggest that many participants have some technical (e.g., handling missing data) and non-technical evaluation skills (e.g., communicating with various stakeholder groups), but might not have theoretical knowledge of, for example, various evaluation approaches and methods (Trevisan, 2004). Given the participants' experiences and practical knowledge, it is important to develop appropriate, responsive, and contextually relevant professional development activities for them to improve their critical understanding of evaluation (Christie & Vo, 2011). This training might also focus on participatory evaluation approaches that are more congruent with the FCS philosophy of their programs. Given that the focus group and interview participants had minimal knowledge of alternative or participatory approaches to program evaluation, they also suggested that they would like training on how to engage families in program development and evaluation. This training could also focus on important competencies for their professional development as evaluators.

According to Ghere, King, Stevahn, and Minnema (2006) evaluator competencies are "the essential knowledge, skills, and dispositions that evaluators need to conduct program evaluations effectively" (p. 109). As noted in Chapter 2, King, Stevahn, Ghere, and Minnema

(2001) described an initial taxonomy of essential evaluator competencies and Stevahn, King, Ghere, and Minnema (2005) further developed it to include the following six categories: (a) professional practice, (b) systematic inquiry, (c) situational analysis, (d) project management, (e) reflective practice, and (f) interpersonal competence. From 2008 to 2009, the Canadian Evaluation Society, in consultation with its members, also developed a similar list of competencies for Canadian evaluation practice. The list included reflective, technical, situational, management, and interpersonal practice competencies (The Canadian Evaluation Society, 2010). These competencies are valuable for the development of training programs. Clinicians/evaluators in the rehabilitation field can also use these competency lists as self-assessment tools to determine their current evaluation skill levels and to identify what type of additional training they require (Stevahn et al., 2005; The Canadian Evaluation Society, 2010).

In terms of formal training, there are also comprehensive university programs that offer certificates and degrees in evaluation (LaVelle & Donaldson, 2010). However, recognizing that most of the participants in this study characterized themselves as clinicians/evaluators, it is probable that they might prefer a more experiential teaching model that includes networking, mentorship and periodic classroom-based education over a classroom-driven or university-based model (Christie & Vo, 2011). In terms of academic institutions and mentorship, participants described how partnerships and mentorship between their centres and academic institutions (e.g., universities and hospital-based research institutes) facilitated evaluation efforts. They felt that these partnerships provided them with opportunities to seek advice from experts in evaluation theory, data-collection tools, and analyses. The participants also appreciated oversight and feedback on their evaluation activities from internal review or steering committees and thus would like to have more mentors and committees.

Technology. On a different note, the participants discussed how technology could facilitate program evaluation and family engagement. Given the prevalent use of, for instance, cellphones, iPads, blogs, social media, and instant messaging, it is easy to see that technology is a seamless, natural part of everyday life and that we are living in a digital age. Statistics Canada (2010) found that eight out of ten households in Canada had access to the Internet and that over one half of connected households used more than one type of electronic device to connect to the Internet. Study participants noted how technology fluency presents a unique opportunity to engage families in program evaluation and, as such, may become an instrumental aspect of a family-centred approach to program evaluation. Echoing the thoughts of Smith and Brandon (2011), they emphasized the need to capitalize on these new technological opportunities and use them to build more effective evaluation activities and opportunities. As Kistler (2011) explained, social-media technological tools such as Twitter and Facebook may "facilitate the discussion and exchange of ideas and resources and create virtual groups that can both supplement existing communities and create new connections where ones previously did not exist" (p. 568). Similarly, Scriven (2009) commented on how webinars or other such devices improves critical dialogue between individuals and facilitates data collection. The participants also suggested that their centres should invest in better data-management systems that would provide them with timely access to evaluation data. Some participants also commented on how electronic charting and other web-based software initiatives would make data easily available through program planning and evaluation processes—an idea that is supported by many in the evaluation field (Labin, 2011). For instance, both Love (1983) and Brazil (1999) note that organizational structure , such as access to information management systems that provide timely access to valid and reliable data, is key for the development and implementation of evaluation as well as the use

of findings. In addition, Scriven (2009) describes how electronic databases provide mechanisms for quickly searching through and analyzing evaluation data.

FCS and program evaluation. The involvement of families was also suggested as another way to improve program planning and evaluation. Although the majority of participants believed their pediatric rehabilitation centres valued and promoted FCS, many did not know the extent to which their centres engaged in the various family-centred behaviours in program evaluation. From the participants' responses and stories, it was also evident that the involvement of families in evaluation processes varied among centres and programs. More specifically, respondents from centres in small to medium cities reported their centres as showing more interpersonal sensitivity to families during evaluation activities than centres situated in larger cities. A possible explanation for this difference might be that clinicians in smaller cities typically have smaller caseloads (Wright et al., 2010) and thus have additional time to establish relationships with families during evaluations, discuss and explore each family's feelings about participating in evaluation activities, and select program evaluation designs and methods that fit each family's unique needs and lifestyle. While explanations for variances at the program level are endless, one plausible reason might be differences in families' desires and abilities to be involved in evaluation activities. As parents suggested in Phase 3, family interests and priorities in program evaluation activities may differ according to the age of their children with the disabilities, the nature of the disabilities, and the families' demographic characteristics.

Interestingly, there were several areas of disagreement between participants' responses in Phases 1, 2, and 3 regarding families' involvement in program evaluation. For instance, in Phase 1, the majority of respondents stated that their centres did not treat children and families as "data sources" during program evaluations. Yet, most participants in Phases 2 and 3 described

how they asked clients and families to complete various forms and provide data only for evaluations. Likewise, several of the participants in Phase 1 stated that their rehabilitation centres treat families as partners in the program evaluation process; but, in Phases 2 and 3 participants commented on how a lack of infrastructure often stopped them from seeking family input and developing partnerships with families in terms of evaluation activities. Finally, in Phase 1, almost 40% of participants noted that their centres view families as essential members of the program evaluation team; however, in Phase 2, numerous participants described how evaluation practices did not provide family members with opportunities to become a part of the evaluation team or to voice their concerns or ideas about evaluation processes. These findings suggest the need for additional inquiry to understand how clinicians/evaluators truly view and treat families in various evaluation activities.

Still, on a more positive note, participants in Phase 3 thought that by involving family members in the identification of evaluation priorities, evaluation findings would be more applicable to the questions that families have about their children's services and care, and thus, would be better utilized by families and service providers. This concept of evaluation utilization has been of particular importance within the program evaluation community for some time (Cousins et al., 2004). The type of use described by both the staff members and families relates primarily to instrumental and conceptual uses of evaluation findings, that is, findings that help stakeholders support decisions or better understand and learn about program areas that are of interest to them (Cousins et al., 2004; Shulha & Cousins, 1997).

On another encouraging point, participants in Phase 3 commented and suggested that participatory evaluation approaches would be more compatible with the key elements of FCS. For example, participants commented how the use of such approaches could provide families

with additional information about the care that their children are receiving so that they can make informed decisions about whether the care is meeting their expectations. Some participants also highlighted how parents' active involvement in evaluation could complement the intervention process itself. They described how the information from the participatory evaluation process could empower parents and provide them with a sense of control and self-efficacy.

In light of the positive sentiments about the compatibility between participatory approaches and FCS, participants commented on the feasibility of using such approaches within the Canadian pediatric rehabilitation context. As mentioned earlier, the majority of comments focused on limited time and funding to carry out more family-oriented or participatory-based evaluations. Notwithstanding, some participants implied the value of participatory program planning as a facilitator to future participatory program evaluations. Nichols (2002) echoed this idea by suggesting that evaluators could minimize some of the major challenges in conducting participatory evaluation if they addressed them in program planning. She advocated that by placing program clients at the centre of the program-planning process, they could assist in the design of programs that fit their needs, become valuable members of the decision-making team, gain a better understanding of the program structure, and participate actively in future evaluation initiatives (Nichols, 2002). In this sense, the concept of participatory program planning is highly congruent with the family-centred elements that families be the ultimate decision makers and that they define the priorities of interventions, have their opinions sought and listened to, and have their needs and concerns taken into account (Law et al., 2003).

Although both the evaluation and family-centred fields have advanced the need for respecting and understanding the role of culture and diversity in their respective activities, staff members and parents in this study also suggested the need for involving a wider range of

families in the evaluation of family-centred programs. Participants commented on how their centres are primarily catering to and capturing the perspectives of affluent families in evaluations. As such, they advocated for broader parent selection as a means of gathering multiple perspectives on their programs, and thus, guarding against potential biases. As the literature demonstrates, many researchers, evaluators, and clinicians working in family-centred areas or program evaluation concur with these ideas. Researchers view the embracement of diversity as essential for asking the right questions, gathering appropriate information, constructing valid conclusions and recommendations, and providing answers that are relevant and useful for all stakeholders in evaluation or clinical contexts (Pettoello-Mantovani, Campanozzi, Maiuri, & Giardino, 2009; Thomas, 2011). Pettoello-Mantovani and colleagues (2009) describe how cultural competence[16] and cultural diversity are essential within the family-centred approach. Given that the FCS philosophy values the cultures, traditions, and the expertise of families, they suggest that clinicians must be culturally competent in order to develop and cultivate partnerships with the diverse families that they serve. They also noted that non-traditional strategies, such as the inclusion of community cultural brokers, must also be adopted to support the care of diverse families (Pettoello-Mantovani et al., 2009).

Conversely, in regards to program evaluation, Cousins and Whitmore (1998) note that stakeholder diversity refers to individuals among the program community who are involved in carrying out the evaluation. In family-centred pediatric rehabilitation settings, there are many stakeholders with different cultures, health conditions, socio-economic statuses, levels of power, and other demographic characteristics who could actively participate in evaluation. For Mathie

[16] Pettoello-Mantovani (2009) define cultural competence as a set of values, behaviours, attitudes, and practices within a program or among individuals, which enables them to work effectively cross culturally. They also note that cultural competency refers to the capability of service providers to respect the beliefs, language, interpersonal styles and behaviours of the clients and families they serve.

and Greene (1997), a diverse group of stakeholders can take many forms. For example, it can be composed of individuals with a range of different program experiences, backgrounds, or different positions of power and authority within the program. Nevertheless, Mathie and Greene (1997) caution that too much diversity might undermine and delay participatory evaluation activities because it might be difficult to establish agreement amidst too many voices and perspectives. As such, it is important for staff members and families in pediatric rehabilitation centres to decide the level of family diversity needed to adhere to FCS philosophy in program evaluation. Overall, the aforementioned findings and areas for improvement contributed to the advancement of theory, methodology, and practice.

Contributions to Evaluation Theory

With this study, I contributed to theory and extended our knowledge of program evaluation in several ways. First, despite increased demands for program evaluation, the evaluation and rehabilitation sectors knew little about the evaluation activities of pediatric rehabilitation centres prior to this study. Aside from the survey of Canadian rehabilitation facilities conducted by Flynn and colleagues (1984), no other studies have examined program evaluation activities in the rehabilitation field. As such, in the present study I provided insight into the evaluation activities occurring in this sector.

Furthermore, while researchers have developed several different evaluation approaches and methods over the past couple of decades (Brazil, 1999; Shadish, et al., 1991; Stufflebeam, 2001), none attempted to develop an approach or method that considers the FCS context, a context that is now prevalent in many health, social services, and community sectors. They have also not examined the degree to which participatory evaluation approaches are congruent with the FCS philosophy. Therefore, by identifying and understanding the promise and prospect of

participatory evaluation approaches that are more congruent with FCS philosophy than traditional evaluation approaches, I completed the initial steps in the development of a family-centred approach to program evaluation. With the development of such an approach, evaluators working in these areas might better recognize and understand the implications that FCS has for program evaluation.

Next, my conceptual framework, which provided a considerable degree of structure to the study and steered the development of the data-collection tools and analyses, illustrated the theoretical relationships between various evaluation concepts (i.e., context, purposes, nature of practice, consequences). The fluid characteristics of the framework as well as its inclusion of general evaluation concepts also allowed for unanticipated relationships between concepts or emergent ideas, not captured in the existing literature, to emerge over the course of the study. Below I discuss these emergent concepts and ideas and describe their significance to evaluation theory. As shown in Figure 3, I also illustrate these new concepts and ideas in a slightly revised conceptual framework.

Context ↔ Purposes ↔ Nature of Practice ↔ Consequences

Context

Family-Centred Service

Organizational Factors

Physical location & classification of organization

Evaluators' Characteristics

Type of evaluator; Evaluators' attitudes, desires , priorities, & interests

Polictical Factors

Purposes

Accountability

Learning

Unknown

Nature of Practice

Actions and Recommendations

Family-Centred Evaluation

Participatory & Traditional evaluation

Consequences

Use of Findings

Other

Process Use

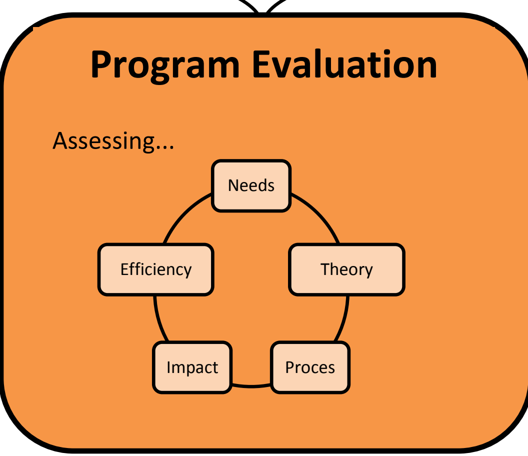

Figure 3. Visual diagram of new conceptual framework.

Context

In Phase 1, I found it somewhat difficult to operationalize the context component of the conceptual framework because there were numerous variables that related to its aligning sub-components (i.e., family-centred service, organizational factors, evaluators' characteristics, political factors). To ensure that I alluded to all of the major contextual items that might influence program evaluation, I needed to expand organizational factors to include the physical location and classification of the respondents' centres. In doing so, I highlighted the important influence that the geographical characteristics of an organization might have on its capacity to do evaluation; an item sometimes overlooked in evaluation research.

On another note, I noticed that the participants' comments and discussions about evaluators' characteristics and their influence on evaluation focused primarily on evaluators' attitudes towards evaluation, their desire to involve families in evaluation as well as their priorities and interests. For the most part, the participants did not acknowledge or discuss the common evaluator characteristics (e.g., responsiveness, listening skills, abilities to invoke trust and develop relationships) that others such as, Greene (1988) found to be important for evaluation processes. Although this lack of acknowledgement and discussion might be a reflection of the participants' lack of training in evaluation, it might also suggest the need for or value of different characteristics or traits depending on the type of evaluator (i.e., self-, external, or internal evaluator). For instance, in comparison to external evaluators, self-evaluators (i.e., those evaluating their own programs) might focus less on their responsiveness, listening skills, or abilities to invoke trust and develop relationships because they are already familiar with the programs they are evaluating and have pre-established relationships with the relevant stakeholders. Instead, they might focus more on their own reflective abilities, attitudes towards

evaluation, or their priorities and interests in evaluation. In this sense, this study might encourage other researchers to investigate what characteristics evaluators need and value in different forms of evaluation (e.g., self-, internal, external evaluation).

Purposes

Next, while this study confirmed that the purposes of program evaluation within rehabilitation fall into two main categories namely, accountability and learning, it also emphasized the need for an "unknown purpose" category, as many of the participants did not know the purpose(s) of their evaluation activities. Therefore, this study reminds evaluators and researchers to consider the purposes of evaluation in their work and consider what the implications are for evaluation activities if there is a lack of clarity in this area.

Nature of Practice

Throughout this study, I also found that instead of emphasizing the distinctions between traditional and participatory evaluation, it was more relevant and practical for the participants to focus on how to make program evaluation more family-centred. While alternative and participatory approaches appear to be more congruent with FCS philosophy, the participants and subsequent findings tended to focus on the need for family-centred evaluation activities that include a diverse group of stakeholders, are relevant for families, and adhere to policies or statements that support these efforts. For most participants, the day-to-day actions and recommendations were more important than the participatory or traditional labels assigned to their evaluation approaches or activities. As such, evaluation researchers might want to consider the terminology that they use when discussing evaluation approaches with those who are unfamiliar with evaluation theory. More specifically, they may want to decide whether the use of

specific terminology is important for the study, if it might detract from the topic, or if it might confuse or overwhelm study participants.

Consequences

Lastly, in terms of emerging concepts and ideas, the data for Phases 2 and 3, led me to expand the evaluation consequences component beyond knowledge production, use of findings and process use, to include several other factors. For instance, specific to the rehabilitation context, the participants described how evaluation activities should lead to more consistency between centres, family involvement, family empowerment, and better clinician-parent relationships. Therefore, this study highlights the importance for theorists to think of evaluation consequences more broadly and recognize that they can be the results or effects of any evaluation actions.

Contributions to Methodology

Through this study, I also provided some contributions to research methodology. For example, I showed how a complex topic that involved multiple factors and perspectives benefitted from the use of a mixed-methods approach. By using mixed-methods, I was able to use a wide variety of tools and methods to answer various research questions. I was also able to demonstrate that a mixed-methods approach can provide broader and more comprehensive understandings of research problems than either quantitative or qualitative approaches alone (Creswell & Plano Clark, 2007; Johnson & Onwuegbuzie, 2004). In this study, I used a quantitative phase followed by two qualitative phases. The follow-up qualitative phases added considerable value in terms of understanding and clarifying the quantitative results. On their own, the quantitative results of Phase 1 portrayed a somewhat superficial and relatively positive picture of evaluation practice within the rehabilitation context. However, the subsequent

qualitative results of Phases 2 and 3 helped to clarify and illustrate a more accurate description and understanding of evaluation activities within this environment.

Moreover, although rehabilitation centres tend to rely heavily on quantitative research, I exemplified that it is feasible to conduct mixed-methods research within these settings. As such, this study might encourage other researchers within rehabilitation to explore new possibilities for collaboration with researchers from all backgrounds (i.e., qualitative, quantitative, mixed-methods) to answer more complex research questions that might otherwise have gone unanswered. Lastly, by keeping the focus on the research questions and enabling the gathering and integration of multiple types of data, I highlighted the key advantages of pragmatism and was able to reach interesting and insightful conclusions.

Contributions to Practice

The findings from my research also have implications for evaluation practice within family-centred pediatric rehabilitation settings. In response to requests from study participants to help them improve program evaluation within their centres, I reviewed the findings from Phases 1, 2, and 3 and created an initial table of realistic recommendations (see Table 26) that directors, clinicians/evaluators, and families might consider. It is important to note that I based this table on some of the key findings from this study. However, it is not exhaustive, and directors, clinicians/evaluators, and families have not validated it. As such, readers should view the table as a work in progress. For ease of interpretation and utilization, I present the specific recommendations for directors (i.e., senior managers who oversee finances and operations at the centres), clinicians/evaluators (i.e., those who currently perform the evaluation activities), and families (i.e., those who receive the services and care).

Table 26

Draft Recommendations for Improving Program Evaluation in Pediatric Rehabilitation Centres

Recommendations for…		
Directors	**Clinicians/Evaluators**	**Families**
Offer training in program evaluation.	Obtain training in program evaluation.	Acquire knowledge to understand program evaluation activities.
Hire one part-time evaluation capacity building (ECB) evaluator who can act as an evaluation facilitator and educator for your centre.	Work with the EBC evaluator to learn how to better evaluate your own programs.	Work with the ECB evaluator to learn how to evaluate your children's programs.
Offer training in participatory program evaluation.	Obtain training in participatory program evaluation.	Acquire knowledge to understand participatory program evaluation and your role in it.
Develop policies and procedures for involving families in program evaluation.	Follow policies and procedures for involving families in program evaluation and promote family involvement in program evaluation.	Recognize that you have a right to be involved in the evaluation of your children's programs and that you can choose your level of involvement.
Allow for flexible evaluation activities.	Include numerous ways for families to become involved in evaluation activities.	Communicate how you would like to be involved in the evaluation of your children's programs.

By following these action-oriented recommendations, the evaluation capacity of pediatric rehabilitation centres will begin to develop. Through investing in evaluation resources and training, developing evaluation policies and procedures, and being open to the use of alternative evaluation activities, directors, clinicians/evaluators, and families will strengthen and sustain program evaluation activities in their settings. Moreover, these recommendations could become a teaching tool for stakeholders to understand what family-centred evaluation activities look like in

practice. It may also become a basis on which to measure the evaluation capacity and family-centred evaluation activities of pediatric rehabilitation centres.

Future Research

The findings of this study highlighted a number of other areas for future research. First, given the excellent information that parents provided in Phase 3, it would be advantageous to investigate how a larger group of parents perceive the evaluation of their children's programs and their current and ideal role(s) in it. For example, how are parents involved in the evaluation of their children's programs? What do parents think are the strengths and limitations of the evaluation activities used to evaluate their children's programs? What roles do parents want to play in the evaluation of their children's programs? What strategies would support parents' involvement in the evaluation of their children's programs?

Second, with continued interest in developing and exploring the implications of a family-centred approach to program evaluation, it would be beneficial to conduct a case study where families and staff members from a selected program work collaboratively to develop and implement an evaluation. Possible research questions driving this case study might include the following: What does participatory evaluation look like in pediatric rehabilitation settings? How do parents and staff members incorporate the philosophy of FCS into participatory evaluation? How to parents and staff members perceive their involvement in the participatory evaluation? Through studying and reflecting on this evaluation experience, we could obtain insight into the development and implementation of the collaborative process as well as the benefits and consequences associated with it.

Third, it would also be interesting to explore the role of new technologies such as Facebook, YouTube, and Skype in collaborative or participatory program evaluation. That is,

how can technology facilitate participatory evaluation? What are the strengths and limitations of using various types of technology in participatory evaluation? Although several researchers have mentioned the importance of using technology in evaluation, none have examined its specific applicability within participatory evaluation processes. This would make for an interesting study, as each type of technology has its own strengths and limitations and might help to facilitate stakeholder engagement and collaboration in ways that evaluators had not thought of previously.

In the long term, it would also be important to assess the effect of increased family involvement on the evaluation capacity of the pediatric rehabilitation centres as well as the utilization of evaluation results. For instance, does family involvement increase the effectiveness of the evaluations conducted? Does family involvement improve the quality of the program evaluations conducted? Does family involvement increase evaluation use?

Lastly, it would be worthwhile to examine if and how families' active involvement in program evaluation actually leads to increased adherence to interventions or treatment. As mentioned in Chapter 1, the FCS literature suggests that by empowering families to meet the needs of their children, they will often adhere better to interventions and treatments (Dunst et al., 1988). Yet, it is it is unclear if families' involvement in evaluation activities would produce the same effects and thus, result in improvements in children and youth's health and developmental outcomes as well as families' well-beings (Reva et al., 1998).

Conclusions

There is heightened interest within pediatric rehabilitation centres to provide comprehensive programs that adhere to FCS philosophy. To assess the improvements in and outcomes of these family-centred programs, service providers need to engage in program evaluation. This mixed-methods study examined the strengths, limitations, and consequences of

the current evaluation activities used in Canadian family-centred pediatric rehabilitation centres. It also illustrated the promise and prospects of alternative evaluation approaches that, in theory, are compatible with FCS philosophy.

In terms of current practice, the findings showed that program evaluation within Canadian pediatric rehabilitation centres is in need of sizeable improvements. To increase the evaluation capacity of these centres and uphold the FCS philosophy in evaluation, these centres need additional resources for program evaluation. Leaders and clinicians/evaluators within these settings must also place high priority on evaluation activities to ensure continued program funding and quality service delivery. Furthermore, those involved in program evaluation must understand: (a) the various forms of evaluation, (b) how context influences evaluation, (c) why they are doing evaluation, (d) the various approaches for evaluation, and (e) and the consequences of evaluation. Evidently, this level of understanding will develop over time and the use of alternative evaluation approaches, which are more congruent with the FCS philosophy, might facilitate this understanding among clinicians/evaluators and families.

Through participating actively in program evaluation, clinicians/evaluators and families may seek to increase their competencies in evaluation, understand program issues more completely, and increase their ability to think differently about problems or issues (Preskill & Torres, 1999). Furthermore, since many clinicians/evaluators in rehabilitation settings have extensive training in FCS—an approach that involves the development of a shared agenda for care, including an understanding of the wider context of each family—, the collaborative and dialogue-oriented environment of these centres provides a good foundation for participatory evaluation approaches.

In light of these circumstances, there is a strong rationale to further explore the applicability and use of participatory evaluation approaches within pediatric rehabilitation settings. While selected participatory approaches are more congruent with FCS, there might be some additional strengths and shortcomings that we can uncover through real-life applications. To fully understand what these might be, it is important for directors, clinicians/evaluators, and families who are part of these settings to engage in more collaborative and participatory evaluation and reflect on and publish their evaluation experiences. Similar to this study, such actions will extend the knowledge of evaluation issues within family-centred pediatric rehabilitation settings and contribute to the growing body of research on program evaluation.

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Appendix A

Principles, Premises, and Elements of Family-Centred Service

1st Premise (basic assumption)		**2nd Premise (basic assumption)**		**3rd Premise (basic assumption)**	
• Parents know their children best and want the best for their children.		• Families are different and unique.		• Optimal child functioning occurs within a supportive family and community context: The child is affected by the stress and coping of other family members.	
Guiding Principles ("should" statements)					
• Each family should have the opportunity to decide the level of involvement they wish in decision making for their child. • Parents should have ultimate responsibility for the care of their children.		• Each family and family member should be treated with respect (as individuals).		• The needs of all family members should be considered. • The involvement of all family members should be supported and encouraged.	
Key Elements (rights and responsibilities)					
Expectations and Rights of Families	**Service Provider Behaviours**	**Expectations and Rights of Families**	**Service Provider Behaviours**	**Expectations and Rights of Families**	**Service Provider Behaviours**
• Be the ultimate decision makers. • Utilize their own resources. • Receive information which will enable them to make decisions about the care that will most effectively meet their needs. • Define the priorities of intervention. • Choose their level and type of involvement and the level of support they require. • Receive services with a minimum of hassle and in a timely manner. • Have access to information regarding their child and family.	• Encourage parent decision-making in partnership with other team members (to utilize family empowerment strategies.) • Assist families to identify their strengths and build their own resources. • Inform, answer, and advise parents (to encourage informed choices). • Work in partnership with parents and children and help them identify and prioritize their needs from their own perspective. • Collaborate with parents at all levels (care of the individual child; program development, implementation and evaluation; policy formation). • Provide accessible services that will not overwhelm families with paperwork and bureaucratic red tape. • Share complete information about the child's care on an ongoing basis.	• Maintain their dignity and integrity throughout the care-giving process • Be supported in the decisions that they make. • Have their opinions sought and to be listened to. • Receive individualized services.	• Respect the values, wishes and priorities of families. • Accept and support decisions made by families. • Listen. • Provide flexible and individualized services (and to respond to the changing needs of the family). • Be knowledgeable about and accept diversity among families (racial, ethnic, cultural and socio-economic). • Believe and trust parents. • Communicate in a language understandable by parents.	• Have their needs and concerns taken into account. • Feel welcome and supported in the level of participation they choose.	• Consider and be sensitive to the psychosocial needs of all family members. • Provide an environment that encourages the participation of all family members. • Respect the family's own style of coping without judging what is right and what is wrong. • Encourage family-to-family support and the use of natural community supports and resources. • Recognize and build on family and child strengths.

Note. From *FCS Sheet #01 - What is family-centred service?*, by M. Law et al., 2003,. Copyright 2003 by McMaster University: CanChild.

Appendix B

Questionnaire Phase 1

We would like to understand and measure your experiences with program evaluation at your **pediatric rehabilitation centre** (i.e., freestanding centre or sub-centre/department of an organization/hospital) **over the past five years**. We would like to know about the motivating factors for doing evaluation, and the approaches and methods used. We would also like to know about your perceptions of the program evaluation activities conducted at your centre and the degree to which these evaluation activities are consistent with the philosophy of family-centred service (FCS).

For the purposes of this survey the term **programs** refers to any programs or services that recognize the philosophy of family-centred service or care.

Program evaluation or **program evaluation activities** refers to **any informal or formal** needs assessments, assessments of program theory, assessments of program process (e.g., assessments of client/patient satisfaction, process evaluations), impact assessments (e.g., outcome evaluations), or efficiency assessments (e.g., cost-benefit analyses) that are conducted on or for family-centred programs at your pediatric rehabilitation centre.

Please ✓ or X your answers.

1. At your pediatric rehabilitation centre have you been or are you involved in or responsible for the...	Yes	No
...design of program evaluation activities?	O	O
...development or selection of data collection instruments for program evaluation activities?	O	O
...collection of data/information for program evaluation activities?	O	O
...analyses of data from program evaluation activities?	O	O
...interpretation of results from program evaluation activities?	O	O
...preparation of reports for program evaluation activities?	O	O
...formulation of recommendations generated from program evaluation activities?	O	O
...dissemination of results and recommendations from program evaluation activities?	O	O

- If you answered **yes** to any of the above-mentioned questions please proceed to **question #2 (page 2)** and complete the remaining survey questions.

- If you **did not** answer **yes** to any of the above-mentioned questions, please return your survey in the enclosed envelope. Thank you for your participation!

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2. Who is involved in the delivery of programs in your pediatric rehabilitation centre?

Check all that apply.

O Parents/guardians
O Siblings
O Children/youth
O Other family members
O Clinicians
O Administrators
O Don't know
O Professional consultants
O Personnel from community service agencies
O Community volunteers
O Personnel from government departments/agencies
O Family Advisory Committee or equivalent
O Other (Please Specify): ______________________________

3. Who is involved in the planning of programs in your pediatric rehabilitation centre?

Check all that apply.

O Parents/guardians
O Siblings
O Children/youth
O Other family members
O Clinicians
O Administrators
O Don't know
O Professional consultants
O Personnel from community service agencies
O Community volunteers
O Personnel from government departments/agencies
O Family Advisory Committee or equivalent
O Other (Please Specify): ______________________________

4. Does your pediatric rehabilitation centre have an employee whose primary responsibility is program evaluation?

O Yes O No O Don't know

5. Does your Pediatric rehabilitation centre receive funding for program evaluation?

O Yes O No O Don't know

Appendix B

N (Never); R (Rarely); S (Sometimes); F (Frequently); A (Always); DK (Don't Know) *Select ONE response for each question.*						
6. To what extent does your pediatric rehabilitation centre...	**N**	**R**	**S**	**F**	**A**	**DK**
...assess the need for its programs?	O	O	O	O	O	O
...assess if its programs address its clients/patients' needs?	O	O	O	O	O	O
...assess what services are needed?	O	O	O	O	O	O
...create/obtain written plans on how its programs are supposed to work?	O	O	O	O	O	O
...examine how well its programs are designed?	O	O	O	O	O	O
...examine how its programs should be organized?	O	O	O	O	O	O
...investigate how well its programs are operating?	O	O	O	O	O	O
...examine if its programs are delivered according to design?	O	O	O	O	O	O
...investigate if its clients/patients are satisfied with its program processes?	O	O	O	O	O	O
...evaluate the outcomes and impact of its programs?	O	O	O	O	O	O
...determine if its programs have beneficial effects on its clients/patients?	O	O	O	O	O	O
...determine if its programs have adverse effects on its clients/patients?	O	O	O	O	O	O
...evaluate the cost and cost-effectiveness of its programs?	O	O	O	O	O	O
...determine if the effects of its programs are attained at reasonable costs?	O	O	O	O	O	O
...investigate if resources are used efficiently?	O	O	O	O	O	O
...use pre-test post-tests designs to evaluate its programs?	O	O	O	O	O	O
...use experimental or quasi-experimental designs (e.g., control trials, randomized control trials) to evaluate its programs?	O	O	O	O	O	O
...use standardized instruments or tests to evaluate its programs?	O	O	O	O	O	O
...use focus groups or interviews to evaluate its programs?	O	O	O	O	O	O

N (Never); R (Rarely); S (Sometimes); F (Frequently); A (Always); DK (Don't Know) *Select ONE response for each question.*						
7. To what extent does your pediatric rehabilitation centre…	**N**	**R**	**S**	**F**	**A**	**DK**
...work in partnership with families to identify program evaluation priorities?	O	O	O	O	O	O
...work in partnership with families to select program evaluation designs and data collection tools?	O	O	O	O	O	O

Appendix B

N (Never); R (Rarely); S (Sometimes); F (Frequently); A (Always); DK (Don't Know) *Select ONE response for each question.*						
7. To what extent does your pediatric rehabilitation centre…	**N**	**R**	**S**	**F**	**A**	**DK**
...allow families to choose their level and type of involvement in program evaluation activities?	O	O	O	O	O	O
...view families as essential members of the program evaluation team?	O	O	O	O	O	O
…take the time to establish relationships with families during program evaluation activities?	O	O	O	O	O	O
…discuss and explore each family's feelings about participating in program evaluation activities?	O	O	O	O	O	O
…select program evaluation designs and methods that fit with each family's needs and lifestyle?	O	O	O	O	O	O
…help each family to secure a stable relationship with at least one individual who works with them throughout the program evaluation process?	O	O	O	O	O	O
… treat families as the true experts on their children during program evaluation activities?	O	O	O	O	O	O
…make sure families have a chance to say what is important to them during program evaluation activities?	O	O	O	O	O	O
…treat children and their families as people rather than as "data sources" during program evaluations?	O	O	O	O	O	O
...treat families as partners in the program evaluation process?	O	O	O	O	O	O
...establish strategies to encourage communication among families, service providers, and evaluators during program evaluation activities?	O	O	O	O	O	O
...use language that families can understand when communicating about program evaluation activities?	O	O	O	O	O	O
...offer information about program evaluation activities to families in a variety of ways?	O	O	O	O	O	O
...provide individualized information to each family about program evaluation results?	O	O	O	O	O	O

N (Never); R (Rarely); S (Sometimes); F (Frequently); A (Always); DK (Don't Know) *Select ONE response for each question.*						
8. To what extent does your pediatric rehabilitation centre engage in program evaluation to...	**N**	**R**	**S**	**F**	**A**	**DK**
...satisfy accountability demands?	O	O	O	O	O	O

Appendix B

N (Never); R (Rarely); S (Sometimes); F (Frequently); A (Always); DK (Don't Know) *Select ONE response for each question.*						
8. To what extent does your pediatric rehabilitation centre engage in program evaluation to...	**N**	**R**	**S**	**F**	**A**	**DK**
…produce evidence of program effectiveness?	O	O	O	O	O	O
...make decisions about programs?	O	O	O	O	O	O
...develop evaluation and inquiry skills?	O	O	O	O	O	O
…understand programming issues more fully?	O	O	O	O	O	O
...stimulate changes in clinical practice?	O	O	O	O	O	O
…learn about other people's perspectives of programs?	O	O	O	O	O	O
…improve its overall practices and services?	O	O	O	O	O	O

SD (Strongly Disagree); D (Disagree); A (Agree); SA (Strongly Agree); DK (Don't Know) *Select ONE response for each statement.*					
9. Please indicate the extent to which you agree or disagree with each of the following statements.	**SD**	**D**	**A**	**SA**	**DK**
My pediatric rehabilitation centre uses evaluation to better understand its programs and practices.	O	O	O	O	O
My pediatric rehabilitation centre uses evaluation to learn from its experiences.	O	O	O	O	O
My pediatric rehabilitation centre bases decisions about programs on evaluation results.	O	O	O	O	O
My pediatric rehabilitation centre uses evaluation results to influence changes in program policies and procedures.	O	O	O	O	O
My pediatric rehabilitation centre uses evaluation to comply with reporting demands.	O	O	O	O	O
My pediatric rehabilitation centre uses evaluation to justify decisions previously made about programs.	O	O	O	O	O
My pediatric rehabilitation centre uses evaluation to develop its research and inquiry skills.	O	O	O	O	O
My pediatric rehabilitation centre's behaviour and thinking changes as a result of engaging in evaluation.	O	O	O	O	O

Appendix B

Select ONE response for each statement.					
10. To what extent do <u>you</u> believe your pediatric rehabilitation centre...	**Not at all**	**To a small extent**	**To a moderat e extent**	**To a great extent**	**Don't know**
...values family-centred service?	O	O	O	O	O
...promotes family-centred service?	O	O	O	O	O
...is interested in a family-centred approach to program evaluation?	O	O	O	O	O

11. Do you have formal training in program evaluation?

O Yes O No

If yes, please describe: ____

12. Do you have formal training in research methods?

O Yes O No

If yes, please describe: ____

13. Are you able to make decisions about the type of program evaluation activities used at your pediatric rehabilitation centre?

O Yes O No

14. How long have you worked at this pediatric rehabilitation centre?

O Less than 1 year O 1 to 5 years

O 6 to 10 years O 11 or more years

15. What is your primary discipline?

O Medicine O Education

O Nursing O Psychology

O Business Administration/Management O Recreational Therapy

O Occupational Therapy O Speech-Language Pathology

O Social Work O Physiotherapy

O Audiology O Other (Please Specify):

____

Appendix B

16. What is your primary role at this pediatric rehabilitation centre?

O Clinician/Service provider
O Researcher
O Director/Manager
O Program Evaluator
O Research Assistant/Research Coordinator
O Other (Please Specify): ______________________________

17. Please indicate your gender.

O Male
O Female

18. In what geographical context is your pediatric rehabilitation centre located?

O Large city (100,000+)
O Small to medium size city (10,000-100,000)

19. How would you classify your pediatric rehabilitation centre?

O As a freestanding centre
O As a sub-centre/department in a organization or hospital

Additional Comments:

Please return the completed survey in the enclosed envelope to:

Katherine Moreau

Thank you for your participation!

Appendix C

Debriefing Questionnaire Phase 1

How was your experience taking this survey?

Here is your chance to tell me what you thought about this survey. Please be honest! Your feedback will help me improve the survey-taking experience for our future participants. Please consider the following statements and give each a 'thumbs up' if you agree or a 'thumbs down' if you disagree. Thank you for your help!

Statement		
1. This survey provided answer choices that reflected my true thoughts, opinions, or experiences.		
2. I found this survey interesting.		
3. I felt the survey was an acceptable length.		
4. The survey questions were clear.		
5. I would recommend this survey to my colleagues.		

Additional Comments:

Appendix D

Information Letter Phase 1

Embracing the Context of Pediatric Rehabilitation Programs: Investigating the Role of Family-Centred Service in Program Evaluation

Research Team: Katherine Moreau, PhD (candidate)
Faculty of Education
University of Ottawa

Brad Cousins, PhD (advisor)
Faculty of Education
University of Ottawa

Dear [insert name of Pediatric rehabilitation centre] employee,

You are invited to take part in the above-mentioned three-phase research study conducted by Katherine Moreau, PhD candidate from the University of Ottawa under the supervision of Professor Brad Cousins. You have been identified as a potential participant in this study because of your involvement in program evaluation activities at [insert name of insert name of Pediatric rehabilitation centre]. This study has been approved by [insert name of Pediatric rehabilitation centre]. *If applicable, write: [insert name of Pediatric rehabilitation centre] Research and Review Committee or Research Ethics Board has reviewed and approved the study.*

The main purpose of the study is to examine the strengths, limitations, and consequences of current program evaluation practice in Pediatric rehabilitation settings including its consistency with the philosophy of family-centred service (FCS). It also examines ways for improving program evaluation practices in these settings.

For Phase 1 of the study, you are invited to complete the attached survey. The survey asks a range of questions about your experiences with program evaluation at your Pediatric rehabilitation centre. It asks about the motivating factors for doing evaluation and the approaches and methods used. In particular, it asks about **your** perceptions of the program evaluation activities conducted at your centre and the degree to which these evaluation activities are consistent with the philosophy of FCS. It also asks you some demographic questions. The survey will take approximately **30 minutes** to complete. We ask that you return the survey in the enclosed pre-stamped envelope to Katherine Moreau at the University of Ottawa by **[insert date of return]. By completing and returning this survey you are consenting to participate in Phase 1 of this study.**

There is little risk associated with your involvement in Phase 1 of the study. Some of the items and questions on the survey may make you feel uncomfortable because they ask about your experiences and perceptions of program evaluation practices at your Pediatric rehabilitation centre. You do not have to respond to any items or answer questions that make you feel uncomfortable. Your employment at [insert name of Pediatric rehabilitation centre] will not be affected by your agreement or refusal to complete the survey. Your manager(s) and colleagues at [insert name of Pediatric rehabilitation centre] will not have access to your specific survey responses.

Appendix D

You may or may not benefit directly from Phase 1 of the study. The study will generate awareness for family involvement in the evaluation of family-centred programs. The study will also potentially improve the evaluation of family-centred programs and increase the level of FCS within Pediatric rehabilitation centres. To thank you for your participation in the study, you will receive a summary of the findings in [insert timeframe for delivering results].
The questionnaire survey is designed so that your identity will remain strictly confidential and anonymous. Your responses to the survey will only be used for identifying the strengths and limitations of program evaluation practices in Pediatric rehabilitation settings and exploring ways for improving program evaluation practices in these settings.

You will not be asked to state your name or the name of your centre on the questionnaire survey. Your survey responses will be combined with other responses so that you cannot be identified in published reports or presentations. Also, any written responses that could potentially reveal your identity (e.g., name, town, or region) will be blacked out from the survey and not included in the database.

Completed surveys will be stored in a locked research office and locked filing cabinet at the University of Ottawa. All electronic data will be stored on a password-protected computer in the same research office. Only the members of the above-mentioned research team will have access to the questionnaire surveys. Data will be conserved for five years after the publication of research findings. After this time, data will be shredded and appropriately discarded.

The completion of this survey is **voluntary**. You can withdraw from the study at anytime and/or refuse to answer any questions without suffering any negative consequences. If you choose to withdraw, all data gathered until the time of withdrawal will be deleted, destroyed, and not included in any presentations or publications.

In future, you will receive invitation letters inviting you to participate in Phase 2 and/or Phase 3 of this study. Your participation in these other phases is **optional.** Phase 2 involves one-on-one interviews with staff members from Pediatric rehabilitation centres who are responsible for or involved with program evaluation. The interview focuses on the values, factors, and conditions that support and hinder the evaluation of family-centred programs. Each interview will last approximately 1-hour and will be scheduled at a time that is convenient for the staff member. Phase 3 will involve focus groups at three selected Pediatric rehabilitation centres and will focus on how the evaluation of family-centred programs can be improved as well as the use of alternative evaluation approaches in Pediatric rehabilitation settings that may be more compatible with the philosophy of FCS. Service directors, program administrators, professional practice leaders, clinical coordinators, program coordinators, other staff responsible for or involved with program evaluation and members from your centre's family, youth, or community advisory committees **may be invited** to participate in one of these focus groups. Each focus group will last approximately 1-hour and will be scheduled at a time and location that is convenient for the majority of the participants. Additional information will be sent to you by mail over [insert timeframe], inviting you to participate in Phases 2 and/or 3. **By completing the attached survey for Phase 1, you are <u>not</u> consenting to participating in Phases 2 and/or 3 of the study.**

Appendix D

If you have any questions about the study please contact Katherine Moreau or Brad Cousins, at the coordinates below. If you have any questions regarding the ethical conduct of this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa at:

Sincerely

_____________________________	_____________________________
Katherine Moreau, PhD (candidate)	Brad Cousins, PhD (advisor)
Faculty of Education	Faculty of Education
University of Ottawa	University of Ottawa

Appendix E

Reminder Letters Phase 1

2 Week Reminder Letter

Embracing the Context of Pediatric Rehabilitation Programs: Investigating the Role of Family-Centred Service in Program Evaluation

Research Team:	Katherine Moreau, PhD (candidate)	Brad Cousins, PhD (advisor)
	Faculty of Education	Faculty of Education
	University of Ottawa	University of Ottawa

Dear [insert name of Pediatric rehabilitation centre] employee,

Recently, you were invited to take part in the above-mentioned three-phase research study conducted by Katherine Moreau, PhD candidate from the University of Ottawa under the supervision of Professor Brad Cousins. The main purpose of the study is to examine the strengths, limitations, and consequences of current program evaluation practice in Pediatric rehabilitation settings including its consistency with the philosophy of family-centred service (FCS). It also examines ways for improving program evaluation practices in these settings.

For the study, you were invited to complete a survey. The survey asks a range of questions about your experiences with program evaluation at your Pediatric rehabilitation centre. It asks about the motivating factors for doing evaluation and the approaches and methods used. In particular, it asks about **your** perceptions of the program evaluation activities conducted at your centre and the degree to which these evaluation activities are consistent with the philosophy of FCS. It also asks you some demographic questions. **If you have completed and returned the survey to us – THANK YOU!**

The completion of this survey is **voluntary** but each response is valuable to us. If you have not yet completed and returned the survey, we would appreciate if you would consider taking approximately 30 minutes to do so. Please remember that your identity and responses will be kept confidential.

Appendix E

4 Week Reminder Letter

Embracing the Context of Pediatric Rehabilitation Programs: Investigating the Role of Family-Centred Service in Program Evaluation

Research Team:	Katherine Moreau, PhD (candidate)	Brad Cousins, PhD (advisor)
	Faculty of Education	Faculty of Education
	University of Ottawa	University of Ottawa

Dear [insert name of Pediatric rehabilitation centre] employee,

Approximately four weeks ago, you were invited to take part in the above-mentioned three-phase research study conducted by Katherine Moreau, PhD candidate from the University of Ottawa under the supervision of Professor Brad Cousins. The main purpose of the study is to examine the strengths, limitations, and consequences of current program evaluation practice in Pediatric rehabilitation settings including its consistency with the philosophy of family-centred service (FCS). It also examines ways for improving program evaluation practices in these settings.

For the study, you were invited to complete a survey. The survey asks a range of questions about your experiences with program evaluation at your Pediatric rehabilitation centre. It asks about the motivating factors for doing evaluation and the approaches and methods used. In particular, it asks about **your** perceptions of the program evaluation activities conducted at your centre and the degree to which these evaluation activities are consistent with the philosophy of FCS. It also asks you some demographic questions. **If you have completed and returned the survey to us – THANK YOU!**

The completion of this survey is **voluntary** but each response is valuable to us. If you have not yet completed and returned the survey, we would appreciate if you would consider taking approximately 30 minutes to do so. Please remember that your identity and responses will be kept confidential.

In the event that the survey has been misplaced, a replacement survey, a copy of the original information letter, and a stamped, pre-addressed return envelope is enclosed.

Appendix F

Dummy Variables Phase 1

Independent Variable	**Categories**
Classification of Organization	0= Freestanding centre; 1= Sub-centre
Location of Organization	0= Large city; 1= Small to medium city
Formal Training in Evaluation	0= No training; 1=Yes training
Formal Training in Research Methods	0= No training; 1=Yes training
Ability to Make Decisions about Evaluation	0= No decision-making ability; 1=Yes decision- making ability
Primary Discipline	0= Other Professional; 1= Rehabilitation Science Professional (i.e., S-LP, OT, PT, Audio.)
Primary Role	0= Clinician/Service Provider; 1= Manager/Director
Length of Employment	0= 0-10 years; 1= 11 or more years

Appendix G

Interview Guide Phase 2

Thank you for taking the time to talk to me about the values, factors, and conditions that support program evaluation at your centre as well as the benefits and limitations of the current evaluation approaches and methods used. Today's interview will last approximately 1 hour and with your consent it will be audio-recorded.

This interview is a part of a studying that examines the strengths, limitations, and consequences of program evaluation activities in Pediatric rehabilitation settings. The study explores how program evaluation activities fit with the philosophy of family-centred service (FCS). It also examines ways for improving program evaluation in these settings.

The information that you share in the interview will be kept confidential. Because the interview will be conducted with me, your anonymity cannot be protected. Only I will know your identity and you will not be asked to state your name or the name of your centre in the interview. Any information that may reveal your identity (e.g., name, town, or region) will be erased from the audio-recording and transcript so that you cannot be identified. I will email you a copy of your interview transcript to review and revise prior to analyses. I will password-protect the transcript and will call you directly to provide you with the password. Your manager(s) and colleagues will not have access to your specific interview responses, recordings, or transcripts.

Before we begin, I would like to remind you that there are no correct answers. Your participation is **voluntary**. You do not have to answer any questions that make you feel uncomfortable.

1. Briefly describe your work setting(s).
2. In what capacity have you been involved in program evaluation activities at your centre/department? *Probe:* *What activities/duties do you perform in relation to program evaluation?*
3. Describe any training that you have in program evaluation.
4. Why does your centre/department do program evaluation?
5. What types of program evaluations does your centre/department conduct?
6. How are these program evaluations designed? *Probes:* *What types of designs are used?* *Who determines which types of designs are used?* *Who is involved in the design process?*

Appendix G

7. How is data collected? *Probes:* *What types of tools/instruments are used to collect data?* *Who determines which tools/instruments are used?* *Who is involved in the development of these tools/instruments?* *How is technology used in the collection and maintenance of data?*
8. How is data analyzed? *Probes:* *Who determines how the data is analyzed?* *Who is involved in the data analysis?*
9. How are evaluation findings disseminated/reported? *Probes:* *What types of dissemination methods are used?* *Who determines how the information will be disseminated?* *Who is involved in the dissemination process?*
10. What are the benefits of your centres/departments current evaluation practices? *Probes:* *If applicable, what does program evaluation contribute to your clinical practices?* *What does program evaluation contribute to your centre/department?*
11. How does the availability of resources in your organization affect program evaluation?
12. What role, if any, does the philosophy of family-centred care or service play in program evaluation? *Probes:* *How are families and clients involved in your centre's program evaluation activities?* *How should families and client be involved in program evaluation?*
13. What other factors, values, or conditions influence how you or your centre/department conducts program evaluation? *Probe:* *How do these values, factors, and conditions affect the evaluation?*
14. How does your organization encourage program evaluation? *Probe:* *Is it mandated?*

Appendix G

15. What, if any, governing bodies (e.g., OACRS, provincial governments) encourage program evaluation? *Probe:* *Do these bodies determine how and which data are collected?*
16. What are the limitations of your centres/departments current evaluation practices?
17. If you were to make any changes in your centre/departments evaluation process, what would your recommendations be?

At this time, I would like to thank you for your participation. Your contribution to this study has been beneficial and insightful. If you have any further comments or questions please contact me. My contact information is included on your copy of the consent form.

Appendix H

Information Letter Phase 2

Embracing the Context of Pediatric Rehabilitation Programs: Investigating the Role of Family-Centred Service in Program Evaluation (Phase 2)

Research Team:	Katherine Moreau, PhD (candidate) Faculty of Education University of Ottawa	Brad Cousins, PhD (advisor) Faculty of Education University of Ottawa

Dear [insert name of Pediatric rehabilitation centre] employee,

You are invited to participate in a one-on-one interview for the above-mentioned study. Recently, you may or may not have completed a survey for the above-mentioned three-phase research study conducted by Katherine Moreau, PhD candidate from the University of Ottawa under the supervision of Professor Brad Cousins. It has been approved by [insert name of Pediatric rehabilitation centre]. *If applicable, write: [insert name of Pediatric rehabilitation centre's] Research and Review Committee or Research Ethics Board has reviewed and approved the study.*

The main purpose of the study is to examine the strengths, limitations, and consequences of current program evaluation practice in Pediatric rehabilitation settings including its consistency with the philosophy of family-centred service (FCS). It also examines ways for improving program evaluation practices in these settings.

If you agree to participate in Phase 2 of the study, you may take part in one, one-on-one interview. We are aiming to interview one to two individuals from each of the participating Pediatric rehabilitation centres. If more than two individuals from your centre are interested in participating in an interview, two individuals will be randomly selected for interviews. The interview may take place by phone or in person at a time that is convenient for you. If you are located in the Ottawa area, you may choose to conduct the interview in person with Katherine Moreau in a private office at the Ottawa Children's Treatment Centre. If you are outside the Ottawa area or prefer a telephone interview, we will ask that you select a location for the telephone interview that is private and convenient for you. Katherine Moreau will then conduct the interview with you by telephone from a private office at the University of Ottawa. The interview will be structured as a question and discussion session. In the interview, you will be asked a range of open-ended questions focusing on the values, factors, and conditions that support and hinder the evaluation of family-centred programs at [insert name of Pediatric rehabilitation centre]. You will also be asked about the benefits and limitations of the approaches and methods currently used to evaluate family-centred programs at your centre. The interview will take approximately **1 hour** to complete. With your consent, the interview will be audio-recorded and transcribed by Katherine Moreau for analysis.

There is little risk associated with your involvement in Phase 2 of the study. Some of the questions in the interview may make you feel uncomfortable because they ask about your experiences and perceptions of program evaluation practices at your Pediatric rehabilitation

centre. You do not have to respond to any questions that make you feel uncomfortable. Your employment at [insert name of Pediatric rehabilitation centre] will not be affected by your interview responses or your agreement or refusal to participate in the study. Your manager(s) and colleagues at [insert name of Pediatric rehabilitation centre] will not have access to your specific interview responses, recordings, or transcripts.

You may or may not benefit directly from Phase 2 of the study. The study will generate awareness for family involvement in the evaluation of family-centred programs. The study will also potentially improve the evaluation of family-centred programs and increase the level of FCS within Pediatric rehabilitation centres. To thank you for your participation in the study, you will receive a summary of the findings in [insert timeframe for delivering results].

The information that you share in the interview will remain strictly confidential. The information you provide in the interview will only be used for identifying the strengths and limitations of program evaluation practices in Pediatric rehabilitation settings and exploring ways for improving program evaluation practices in these settings. Because the interview will be conducted in person or by telephone with Katherine Moreau, your anonymity cannot be protected. Only Katherine Moreau will know your identity and you will not be asked to state your name or the name of your Pediatric rehabilitation centre in the interview. Any information that could potentially reveal your identity (e.g., name, town, or region) will be eliminated from the audio-recording and transcript so that you cannot be identified in published reports or presentations. We will email you a copy of your interview transcript to review and revise prior to analyses. We will password-protect the transcript and will call you directly to provide you with the password.

The digital audio-recording of the interview will be downloaded and erased from the audio-recorder immediately after the interview. All data will be stored in a locked research office at the University of Ottawa. All audio- recordings will be stored on a password-protected computer in the same research office at the University of Ottawa. Only the members of the above-mentioned research team will have access to the data. Data will be conserved for five years after the publication of research findings. After this time, data will be shredded and appropriately discarded.

Your participation in the study and interview is **voluntary**. You can withdraw from the study at anytime and/or refuse to answer any questions without suffering any negative consequences. If you choose to withdraw, all data gathered until the time of withdrawal will be deleted, destroyed, and not included in any publications or presentations.

If you are interested in participating in a one-on-one interview for this study please contact Katherine Moreau at [insert email] by [insert date] to obtain additional information about the interview. As mentioned, the interview will be schedule at a time that is convenient for you. Your written consent will be obtained prior to the interview. We will email you a copy of the consent form to review, sign, and return to Katherine Moreau prior to the interview. We will password-protect the consent form and call you directly to provide you with the password. If you choose to conduct the interview by phone, you can print and sign the consent form and then send

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a password-protected electronic copy of the completed consent form to Katherine Moreau by email or you can mail her a signed copy of it.

If you have any questions about the study please contact Katherine Moreau or Brad Cousin, at the coordinates below. If you have any questions regarding the ethical conduct of this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa at:

Sincerely,

____
Katherine Moreau, PhD (candidate)
Faculty of Education
University of Ottawa

____
Brad Cousins, PhD (advisor)
Faculty of Education
University of Ottawa

Appendix I

Consent Form Phase 2

Embracing the Context of Pediatric Rehabilitation Programs: Investigating the Role of Family-Centred Service in Program Evaluation (Phase 2)

Research Team: Katherine Moreau, PhD (candidate), Faculty of Education, University of Ottawa
Brad Cousins, PhD (advisor), Faculty of Education, University of Ottawa

Invitation to Participate: I am invited to participate in a one-on-one interview for Phase 2 of the above-mentioned research study conducted by Katherine Moreau, PhD candidate from the University of Ottawa under the supervision of Professor Brad Cousins.

Purpose of the Study: The main purpose of the study is to examine the strengths, limitations, and consequences of current program evaluation practice in Pediatric rehabilitation settings including its consistency with the philosophy of family-centred service (FCS). It also examines ways for improving program evaluation practices in these settings.

Participation: My participation will consist of taking part in one, one-on-one interview. The interview may take place by phone or in person at a time that is convenient for me. The interview will be structured as a question and discussion section. In the interview, I will be asked a range of open-ended questions focusing on the values, factors, and conditions that support and hinder the evaluation of family-centred programs at my Pediatric rehabilitation centre/department. I will also be asked about the benefits and limitations of the approaches and methods currently used to evaluate family-centred programs at my Pediatric rehabilitation centre. The interview will take approximately **1 hour** to complete. With my consent, the interview will be audio-recorded and transcribed by Katherine Moreau for analysis.

Risks: There is little risk associated with my involvement in Phase 2 of the study. Some of the questions in the interview may make me feel uncomfortable because they ask about my experiences and perceptions of program evaluation practices at my Pediatric rehabilitation centre/department. I have received assurance from the researchers that every effort will be made to minimize these risks. I do not have to respond to any questions that make me feel uncomfortable. My employment at my Pediatric rehabilitation centre/department will not be affected by my interview responses or my agreement or refusal to participate the study. My manager(s) and colleagues will not have access to my specific interview responses, recordings, or transcripts.

Benefits: I may or may not benefit directly from Phase 2 of the study. The study will generate awareness for family involvement in the evaluation of family-centred programs. The study will also potentially improve the evaluation of family-centred programs and increase the level of FCS within Pediatric rehabilitation centres. To thank me for my participation in the study, I will receive a summary of the findings.

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Confidentiality and anonymity: I have received assurance from the researchers that the information I will share will remain strictly confidential. I understand that the information I provide in the interview will only be used for identifying the strengths and limitations of program evaluation practices in Pediatric rehabilitation settings and exploring ways for improving program evaluation practices in these settings. Because the interview will be conducted in person or by telephone with Katherine Moreau, PhD candidate from the University of Ottawa, my anonymity cannot be protected. Only Katherine Moreau will know my identity and I will not be asked to state my name or the name of my Pediatric rehabilitation centre in the interview. Any information that could potentially reveal my identity (e.g., name, town, or region) will be eliminated from the audio-recording and transcript so that I cannot be identified in published reports or presentations. Katherine Moreau will email me a copy of my interview transcript to review and revise prior to analyses. Katherine Moreau will password-protect the transcript and call me directly to provide me with the password.

Conservation of data: The digital audio-recording of the interview will be downloaded and erased from the audio-recorder immediately after the interview. All data will be stored in a locked research office at the University of Ottawa. All audio- recordings will be stored on a password-protected computer in the same research office at the University of Ottawa. Only the members of the above-mentioned research team will have access to the data. Data will be conserved for five years after the publication of research findings. After this time, data will be shredded and appropriately discarded.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at anytime and/or refuse to answer any questions without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will be deleted, destroyed, and not included in any publications or presentations.

Acceptance: I ________________________________, agree to participate in Phase 2 of the above-mentioned research study conducted by Katherine Moreau, PhD candidate from the Faculty of Education, University of Ottawa under the supervision of Professor Brad Cousins.

If I have any questions about the study, I may contact Katherine Moreau or Brad Cousin at:

Katherine Moreau, PhD (candidate)
Faculty of Education
University of Ottawa

Brad Cousins, PhD (advisor)
Faculty of Education
University of Ottawa

Appendix I

If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa at:

There are two copies of the consent form, one of which is mine to keep.

Participant's signature: Date:

Researcher's signature: Date:

Appendix J

Final NVivo Codes Phase 2

- **Context**
  - Clinician/Evaluator characteristics
    - Attitudes towards program evaluation
    - A desire to involve families in evaluation
    - Training
    - General demographic characteristics of interviewees
  - Organizational factors
    - Affiliations with academic centres
    - Establishment of committees to assist with program evaluation
    - Existence of family advisory committees
    - Funding for evaluation
    - Data-management systems to for evaluation
    - Policies and procedures for evaluation
    - Staff and time for program evaluation
- **General purpose(s) for program evaluation**
- **Consequences**
  - Limited family involvement in evaluation
  - Lack of transparency
  - Minimal collaboration between other departments, centres, and organizations
  - Inability to balance evaluation and clinical work
  - Bias in evaluation processes
  - Evaluation use
    - Conceptual use
    - Instrumental use
    - Symbolic use
    - Process use

Appendix K

Focus Group Guide Phase 3

Thank you for taking the time to talk to me about how program evaluation activities at your centre. This focus group is a part of a studying that examines the strengths, limitations, and consequences of program evaluation activities in Pediatric rehabilitation settings. The study explores how program evaluation activities fit with the philosophy of family-centred service (FCS). It also examines ways for improving program evaluation in these settings.

The information that you share in the focus group will be kept confidential. Because the focus group will be conducted in person with other individuals, your anonymity cannot be protected. However, only I and the other focus group participants will know your identity and responses. Everyone will be asked to keep one another's identity and responses confidential. Any information that may reveal your identity (e.g., name, town, or region) will be erased from the audio-recording and transcript so that you cannot be identified. I will email you a copy of the transcript from your focus group to review for accuracy prior to analyses. If you think that any statements in the transcript are inaccurately transcribed, you may contact me by phone or email. I will compare the transcript with the audio recording and if necessary revise the transcript. You will then receive a revised copy of the transcript for review. I will password-protect all transcripts and will call you directly to provide you with the password.

Before we begin, I would like to remind you that there are no correct answers. Your participation is **voluntary**. You do not have to answer any questions that make you feel uncomfortable.

Describe your role at the centre.
1. How are family-centred programs evaluated at your centre? *Probe:* *What types of evaluation approaches and methods are used?*
2. How are families and clients involved in the evaluation process?
3. In your opinions, what roles should families and clients play in the evaluation process?
4. In your opinions, how can we make the evaluation process more family-centred? *Probes:* *How can we actively involve families in, for example, the design of program evaluations, data collection, data analysis, and reporting and dissemination phases?*

Appendix K

There are participatory approaches to evaluation, where individuals with some evaluation knowledge, such as you, work in partnership with other stakeholders, such as families and clients, who may or may not have evaluation training to, for example, design and conduct evaluations. In working as a team, each member of this partnership brings different knowledge and skills to the evaluation process. Program staff or evaluators may bring expertise in evaluation logic and methods. Whereas, families and clients may bring a deep, implicit, or possibly explicit, understanding of the program, what it is expected to do, and how it is to do it. They also are intimately familiar with the program context because this is where they receive services. In these participatory approaches, all stakeholders come together, in various ways, to for example, select evaluation questions to explore, design evaluations, collect data, analyze data, or dissemination findings.

5. What are your thoughts on these participatory approaches?

6. In your opinions, how are these participatory approaches more relevant or consist with the philosophy of family-centred service?

7. How interested would you be in using these types of approaches at your organization?

Probes:
How interested would you be in working as part of a team with families to design and conduct evaluations? To design data collection forms? To disseminate findings?

8. What do you think a participatory evaluation approach would look like, in action, in your centre?

Probes:
Who would control the evaluation process? Families? Staff? A mix?
How would families be involved in the evaluation? Sit on steering committees? Lead the evaluation? Play a consultant type of role?
What aspects of the evaluation would you involve families in?
Who would you involve? Family Advisory groups? Program participants?

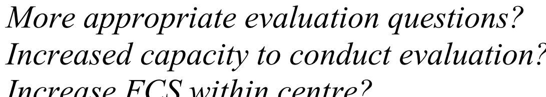
9. How feasible would it be to use these types of approaches at your organization? In your opinions, how interested would your clients/families be in using these participatory evaluation approaches?

Probe:
What types of resources would you need to be able to use these approaches?

10. What do you think would be some of the benefits to using these participatory approaches to evaluate programs at your centre?

Probes:
Use of findings?

Appendix K



More appropriate evaluation questions?
Increased capacity to conduct evaluation?
Increase FCS within centre?

11. What do you think would be some of barriers or limitations to using these participatory approaches to evaluate programs at your centre?

Probes:
Time?
Costs?
Families/Clients' interests?

Conclusion:

12. All things considered, what do you think is the most important thing to considering when trying to improve the evaluation of family-centred programs at your centre?

13. Is there anything else you would like to discuss in relation to the topic that we did not discuss already?

At this time, I would like to thank you for your participation. Your contribution to this study has been beneficial and insightful. If you have any further comments or questions please contact me. My contact information is included on your copy of the consent form.

Appendix L

Interview Guide Phase 3

Thank you for taking the time to talk to me about how program evaluation activities at your rehabilitation centre. This interview is a part of a studying that examines the strengths, limitations, and consequences of program evaluation activities in Pediatric rehabilitation settings. The study explores how program evaluation activities fit with the philosophy of family-centred service (FCS). It also examines ways for improving program evaluation in these settings.

The information that you share in the interview will be kept confidential. Any information that may reveal your identity (e.g., name, town, or region) will be erased from the audio-recording and transcript so that you cannot be identified. I will email you a copy of the transcript from your interview to review for accuracy prior to analyses. If you think that any statements in the transcript are inaccurately transcribed, you may contact me by phone or email. I will compare the transcript with the audio recording and if necessary revise the transcript. You will then receive a revised copy of the transcript for review. I will password-protect all transcripts and will call you directly to provide you with the password.

Before we begin, I would like to remind you that there are no correct answers. Your participation is **voluntary**. You do not have to answer any questions that make you feel uncomfortable.

1. Have you been asked to fill out questionnaires to help evaluate the services and programs that you receive/at your centre?
2. How else have you been involved in the evaluation of your child's/your centre's services or programs?
3. In your opinions, what roles would you like to play in the evaluation of your child's/your centres programs and services?
4. In your opinions, how can we make the evaluation process more family-centred? *Probe:* *How can we actively involve families in, for example, the design of program evaluations, data collection, data analysis, and reporting and dissemination phases?*
There are participatory approaches to evaluation, where individuals with some evaluation knowledge, such as you, work in partnership with other stakeholders, such as staff members, who may or may not have evaluation training to, for example, design and conduct evaluations. In working as a team, each member of this partnership brings different knowledge and skills to the evaluation process. Program staff or evaluators may bring expertise in evaluation logic and methods. Whereas, families and clients may bring a deep, implicit, or possibly explicit, understanding of the program, what it is expected to do, and how it is to do it. They also are intimately familiar with the program context because this is where they receive services. In these participatory approaches, all stakeholders come together, in various ways, to for example, select evaluation questions to explore, design

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evaluations, collect data, analyze data, or dissemination findings. 5. What are your thoughts on these participatory approaches?
6. In your opinion, how are these participatory approaches more relevant or consist with the philosophy of family-centred service?
7. How interested would you be in using these types of approaches at your organization? *Probes:* *How interested would you be in working as part of a team with staff members to design and conduct evaluations? To design data collection forms? To disseminate findings?*
8. What do you think a participatory evaluation approach would look like, in action, in your centre? *Probes:* *Who would control the evaluation process? Families? Staff? A mix? How would families be involved in the evaluation? Sit on steering committees? Lead the evaluation? Play a consultant type of role? What aspects of the evaluation would you involve families in? Who would you involve? Family Advisory groups? Program participants?*
9. How feasible would it be to use these types of approaches at your organization? *Probes:* *In your opinions, how interested would you be in using these participatory evaluation approaches? What types of resources would you need to be able to use these approaches?*
10. What do you think would be some of the benefits to using these participatory approaches to evaluate programs at your centre? *Probes:* *Use of findings?* *More appropriate evaluation questions?* *Increased capacity to conduct evaluation?* *Increase FCS within centre?*

Appendix L

11. What do you think would be some of barriers or limitations to using these participatory approaches to evaluate programs at your centre? *Probes:* *Time?* *Costs?* *Families/Clients' interests?*
Conclusion:
12. Is there anything else you would like to discuss in relation to the topic that we did not discuss already?

At this time, I would like to thank you for your participation. Your contribution to this study has been beneficial and insightful. If you have any further comments or questions please contact me. My contact information is included on your copy of the consent form.

Appendix M

Focus Group Information Letter Phase 3

Embracing the Context of Pediatric Rehabilitation Programs: Investigating the Role of Family-Centred Service in Program Evaluation (Phase 3)

Research Team: Katherine Moreau, PhD (candidate), Faculty of Education, University of Ottawa
Brad Cousins, PhD (advisor), Faculty of Education, University of Ottawa

Dear [insert name of Pediatric rehabilitation centre] employee,

You are invited to take part in Phase 3 of the above-mentioned three-phase research study conducted by Katherine Moreau, PhD candidate from the University of Ottawa under the supervision of Professor Brad Cousins. It has been approved by [insert name of Pediatric rehabilitation centre]. *If applicable, write: [insert name of Pediatric rehabilitation centre's] Research and Review Committee or Research Ethics Board has reviewed and approved the study.*

The main purpose of the study is to examine the strengths, limitations, and consequences of current program evaluation practice in Pediatric rehabilitation settings including its consistency with the philosophy of family-centred service (FCS). It also examines ways for improving program evaluation practices in these settings.

Phase 1 involved the completion of a survey by staff members. The survey asked a range of questions about staff members' experiences with program evaluation at Pediatric rehabilitation centres. It asked about the motivating factors for doing evaluation and the approaches and methods used. In particular, it asked about their perceptions of the program evaluation activities conducted at their centres and the degree to which these evaluation activities are consistent with the philosophy of FCS. Phase 2 involved one-one-one interviews with staff members from Pediatric rehabilitation centres. It focused on the values, factors, and conditions that support and hinder the evaluation of family-centred programs. Using the findings from Phases 1 and 2, Phase 3 of the study has been developed to explore how the evaluation of family-centred programs can be improved as well as the potential use of alternative evaluation approaches in Pediatric rehabilitation settings that may be more compatible with FCS.

If you agree to participate in Phase 3 of the study, you may take part in one focus group discussion with 5 to 12 other individuals who are associated with or employees from [insert name of Pediatric rehabilitation centre]. If more than 12 individuals from your centre are interested in participating in one specific focus group, 12 individuals will be randomly selected for the focus group. The focus group will take place at [insert name of Pediatric rehabilitation centre] in a private meeting room at a time that is convenient for the majority of the participants. The focus group will be moderated by Katherine Moreau and structured as a question and discussion section. In the focus group, you will be asked a range of open-ended questions focusing on the ways that evaluation of family-centred programs can be improved. You will also be asked about the benefits and limitations of using various alternative evaluation approaches in

Pediatric rehabilitation centre centres. The focus group will last approximately **1 hour**. The focus group will also be audio-recorded and transcribed by Katherine Moreau for analysis.

There is little risk associated with your involvement in Phase 3 of the study. Some of the questions in the focus group may make you feel uncomfortable because they ask about your experiences and perceptions of program evaluation practices at your Pediatric rehabilitation centre. You do not have to answer any questions that make you feel uncomfortable. Your employment at or involvement with [insert name of Pediatric rehabilitation centre] will not be affected by your responses or your agreement or refusal to participate the study. Your manager(s) at [insert name of Pediatric rehabilitation centre] will not have access to your specific focus group responses, recordings, or transcripts.

You may or may not benefit directly from Phase 3 of the study. The study will generate awareness for family involvement in the evaluation of family-centred programs. The study will also potentially improve the evaluation of family-centred programs and increase the level of FCS within Pediatric rehabilitation centres. To thank you for your participation in the study, you will receive a summary of the findings in [insert timeframe for delivering results].

The information that you share in the interview will remain strictly confidential. The information you provide in the focus group will only be used for identifying the strengths and limitations of program evaluation practices in Pediatric rehabilitation settings and exploring ways for improving program evaluation practices in these settings. Because the focus group will be conducted in person with other individuals, your anonymity cannot be protected. However, only the moderator and the other focus group participants will know your identity and responses. Everyone will be asked to keep one another's identity and responses confidential. Any information that could potentially reveal your identity (e.g., name, town, or region) will be eliminated from the audio-recording and transcript so that you cannot be identified in published reports or presentations. We will email you a copy of the transcript from your focus group to review and revise prior to analyses. We will password-protect the transcript and will call you directly to provide you with the password.

The digital audio-recording of the focus group will be downloaded and erased from the audio-recorder immediately after the focus group. All data will be stored in a locked research office at the University of Ottawa. All audio- recordings will be stored on a password-protected computer in the same research office at the University of Ottawa. Only the members of the above-mentioned research team will have access to the data. Data will be conserved for five years after the publication of research findings. After this time, data will be shredded and appropriately discarded.

Your participation in the study and focus group is **voluntary**. You can withdraw from the study at anytime and/or refuse to answer any questions without suffering any negative consequences. If you choose to withdraw, all data gathered until the time of withdrawal will be deleted, destroyed, and not included in any publications or presentations.

If you are interested in participating in a focus group for Phase 3 of this study please contact Katherine Moreau at [insert email] by [insert date]. As mentioned, the focus group

will be schedule at a time that is convenient for the majority of the participants. Your written consent will be obtained prior to the focus group.

If you have any questions about the study please contact Katherine Moreau or Brad Cousin, at the coordinates below. If you have any questions regarding the ethical conduct of this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa at:

Sincerely,

_______________________________ _________________________
Katherine Moreau, PhD (candidate)
Faculty of Education
University of Ottawa

Brad Cousins, PhD (advisor)
Faculty of Education
University of Ottawa

Appendix N

Interview Information Letter Phase 3

Embracing the Context of Pediatric Rehabilitation Programs: Investigating the Role of Family-Centred Service in Program Evaluation (Phase 3)

Research Team:	Katherine Moreau, PhD (candidate)	Brad Cousins, PhD (advisor)
	Faculty of Education	Faculty of Education
	University of Ottawa	University of Ottawa

Dear [insert name of Pediatric rehabilitation centre] parent,

You are invited to take part in Phase 3 of the above-mentioned three-phase research study conducted by Katherine Moreau, PhD candidate from the University of Ottawa under the supervision of Professor Brad Cousins. It has been approved by [insert name of Pediatric rehabilitation centre]. *If applicable, write: [insert name of Pediatric rehabilitation centre's] Research and Review Committee or Research Ethics Board has reviewed and approved the study.*

The main purpose of the study is to examine the strengths, limitations, and consequences of current program evaluation practice in Pediatric rehabilitation settings including its consistency with the philosophy of family-centred service (FCS). It also examines ways for improving program evaluation practices in these settings.

Phase 1 involved the completion of a survey by staff members. The survey asked a range of questions about staff members' experiences with program evaluation at Pediatric rehabilitation centres. It asked about the motivating factors for doing evaluation and the approaches and methods used. In particular, it asked about their perceptions of the program evaluation activities conducted at their centres and the degree to which these evaluation activities are consistent with the philosophy of FCS. Phase 2 involved one-one-one interviews with staff members from Pediatric rehabilitation centres. It focused on the values, factors, and conditions that support and hinder the evaluation of family-centred programs. Using the findings from Phases 1 and 2, Phase 3 of the study has been developed to explore how the evaluation of family-centred programs can be improved as well as the potential use of alternative evaluation approaches in Pediatric rehabilitation settings that may be more compatible with FCS.

If you agree to participate in Phase 3 of the study, you may take part in one, one-on-one interview. We are aiming to interview one to two individuals from each of the participating Pediatric rehabilitation centres. If more than two individuals from your centre are interested in participating in an interview, two individuals will be randomly selected for interviews. The interview may take place by phone or in person at a time that is convenient for you. If you are located in the Ottawa area, you may choose to conduct the interview in person with Katherine Moreau in a private office at the Ottawa Children's Treatment Centre. If you are outside the Ottawa area or prefer a telephone interview, we will ask that you select a location for the telephone interview that is private and convenient for you. Katherine Moreau will then conduct the interview with you by telephone from a private office at the University of Ottawa. The

interview will be structured as a question and discussion session. In the interview, you will be asked a range of open-ended questions focusing on the ways that evaluation of family-centred programs can be improved. You will also be asked about the benefits and limitations of using various alternative evaluation approaches in Pediatric rehabilitation centre centres. The interview will take approximately **1 hour** to complete. With your consent, the interview will be audio-recorded and transcribed by Katherine Moreau for analysis.

There is little risk associated with your involvement in Phase 3 of the study. Some of the questions in the interview may make you feel uncomfortable because they ask about your experiences and perceptions of program evaluation practices at your Pediatric rehabilitation centre. You do not have to respond to any questions that make you feel uncomfortable. Your employment at [insert name of Pediatric rehabilitation centre] will not be affected by your interview responses or your agreement or refusal to participate in the study. Your service providers at [insert name of Pediatric rehabilitation centre] will not have access to your specific interview responses, recordings, or transcripts.

You may or may not benefit directly from Phase 3 of the study. The study will generate awareness for family involvement in the evaluation of family-centred programs. The study will also potentially improve the evaluation of family-centred programs and increase the level of FCS within Pediatric rehabilitation centres. To thank you for your participation in the study, you will receive a summary of the findings in [insert timeframe for delivering results].

The information that you share in the interview will remain strictly confidential. The information you provide in the interview will only be used for identifying the strengths and limitations of program evaluation practices in Pediatric rehabilitation settings and exploring ways for improving program evaluation practices in these settings. Because the interview will be conducted in person or by telephone with Katherine Moreau, your anonymity cannot be protected. Only Katherine Moreau will know your identity and you will not be asked to state your name or the name of your Pediatric rehabilitation centre in the interview. Any information that could potentially reveal your identity (e.g., name, town, or region) will be eliminated from the audio-recording and transcript so that you cannot be identified in published reports or presentations. We will email you a copy of your interview transcript to review and revise prior to analyses. We will password-protect the transcript and will call you directly to provide you with the password.

The digital audio-recording of the interview will be downloaded and erased from the audio-recorder immediately after the interview. All data will be stored in a locked research office at the University of Ottawa. All audio- recordings will be stored on a password-protected computer in the same research office at the University of Ottawa. Only the members of the above-mentioned research team will have access to the data. Data will be conserved for five years after the publication of research findings. After this time, data will be shredded and appropriately discarded.

Your participation in the study and interview is **voluntary**. You can withdraw from the study at anytime and/or refuse to answer any questions without suffering any negative consequences. If

you choose to withdraw, all data gathered until the time of withdrawal will be deleted, destroyed, and not included in any publications or presentations.

If you are interested in participating in a one-on-one interview for this study please contact Katherine Moreau at [insert email] by [insert date] to obtain additional information about the interview. As mentioned, the interview will be schedule at a time that is convenient for you. Your written consent will be obtained prior to the interview. We will email you a copy of the consent form to review, sign, and return to Katherine Moreau prior to the interview. We will password-protect the consent form and call you directly to provide you with the password. If you choose to conduct the interview by phone, you can print and sign the consent form and then send a password-protected electronic copy of the completed consent form to Katherine Moreau by email or you can mail her a signed copy of it.

If you have any questions about the study please contact Katherine Moreau or Brad Cousin, at the coordinates below. If you have any questions regarding the ethical conduct of this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa at:

Sincerely,

____
Katherine Moreau, PhD (candidate)
Faculty of Education
University of Ottawa

____
Brad Cousins, PhD (advisor)
Faculty of Education
University of Ottawa

Appendix O

Focus Group Consent Form Phase 3

Embracing the Context of Pediatric Rehabilitation Programs: Investigating the Role of Family-Centred Service in Program Evaluation (Phase 3)

Research Team: Katherine Moreau, PhD (candidate), Faculty of Education, University of Ottawa
Brad Cousins, PhD (advisor), Faculty of Education, University of Ottawa

Invitation to Participate: I am invited to participate in a focus group for Phase 3 of the above-mentioned research study conducted by Katherine Moreau, PhD candidate from the University of Ottawa under the supervision of Professor Brad Cousins. It has been approved by [insert name of Pediatric rehabilitation centre].

Purpose of the Study: The main purpose of the study is to examine the strengths, limitations, and consequences of current program evaluation practice in Pediatric rehabilitation settings including its consistency with the philosophy of family-centred service (FCS). It also examines ways for improving program evaluation practices in these settings.

Participation: My participation will consist of taking part in one focus group discussion with 5-12 other individuals who are associated with or employees from [insert name of Pediatric rehabilitation centre]. The focus group will take place at [insert name of Pediatric rehabilitation centre] in a private meeting room at a time that is convenient for the majority of the participants. The focus group will be moderated by Katherine Moreau and structured as a question and discussion section. In the focus group, I will be asked a range of open-ended questions focusing on the ways that evaluation of family-centred programs can be improved as well as benefits and limitations of using various evaluation approaches in Pediatric rehabilitation centres. The focus group will last approximately **1 hour**. The focus group will be audio-recorded and transcribed by Katherine Moreau for analysis.

Risks: There is little risk associated with my involvement in Phase 3 of the study. Some of the questions in the focus group may make me feel uncomfortable because they ask about my experiences and perceptions of program evaluation practices at my Pediatric rehabilitation centre. I have received assurance from the researcher that every effort will be made to minimize these risks. I do not have to respond to any questions that make me feel uncomfortable. My employment at or involvement with [insert name of Pediatric rehabilitation centre] will not be affected by my responses or my agreement or refusal to participate the study. My manager(s) at [insert name of Pediatric rehabilitation centre] will not have access to my specific focus group responses, recordings, or transcripts.

Benefits: I may or may not benefit directly from Phase 3 of the study. The study will generate awareness for family involvement in the evaluation of family-centred programs. The study will also potentially improve the evaluation of family-centred programs and increase the level of FCS within Pediatric rehabilitation centres. To thank me for my participation in the study, I will receive a summary of the findings in [insert timeframe for delivering results].

Appendix O

Confidentiality and anonymity: I have received assurance from the researchers that the information I will share will remain will remain strictly confidential. I understand that the information I provide in the focus group will only be used for identifying the strengths and limitations of program evaluation practices in Pediatric rehabilitation settings and exploring ways for improving program evaluation practices in these settings. Because the focus group will be conducted in person with other individuals, my anonymity cannot be protected. However, only the moderator and the other focus group participants will know my identity and responses. Everyone will be asked to keep one another's identity and responses confidential. Any information that could potentially reveal my identity (e.g., name, town, or region) will be eliminated from the audio-recordings and transcripts so that I cannot be identified in published reports or presentations. Katherine Moreau will email me a copy of the transcript from my focus group to review and revise prior to analyses. Katherine Moreau will password-protect the transcript and call me directly to provide me with the password.

Conservation of data: The digital audio-recording of the focus group will be downloaded and erased from the audio-recorder immediately after the focus group. All data will be stored in a locked research office at the University of Ottawa. All audio- recordings will be stored on a password-protected computer in the same research office at the University of Ottawa. Only the members of the above-mentioned research team will have access to the data. Data will be conserved for five years after the publication of research findings. After this time, data will be shredded and appropriately discarded.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at anytime and/or refuse to answer any questions without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will be deleted, destroyed, and not included in any publications or presentations.

Acceptance: I _________________________________, agree to participate in Phase 3 of the above-mentioned research study conducted by Katherine Moreau, PhD candidate from the Faculty of Education, University of Ottawa under the supervision of Professor Brad Cousins. If I have any questions about the study, I may contact Katherine Moreau or Brad Cousin at:

Katherine Moreau, PhD (candidate)
Faculty of Education
University of Ottawa

Brad Cousins, PhD (advisor)
Faculty of Education
University of Ottawa

If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa at:

Appendix O

There are two copies of the consent form, one of which is mine to keep.

Participant's signature: Date:

Researcher's signature: Date

Appendix P

Interview Consent Form Phase 3

Embracing the Context of Pediatric Rehabilitation Programs: Investigating the Role of Family-Centred Service in Program Evaluation (Phase 3)

Research Team: Katherine Moreau, PhD (candidate) Faculty of Education University of Ottawa

Brad Cousins, PhD (advisor) Faculty of Education University of Ottawa

Invitation to Participate: I am invited to participate in a one-on-one interview for Phase 3 of the above-mentioned research study conducted by Katherine Moreau, PhD candidate from the University of Ottawa under the supervision of Professor Brad Cousins.

Purpose of the Study: The main purpose of the study is to examine the strengths, limitations, and consequences of current program evaluation practice in Pediatric rehabilitation settings including its consistency with the philosophy of family-centred service (FCS). It also examines ways for improving program evaluation practices in these settings.

Participation: My participation will consist of taking part in one, one-on-one interview. The interview may take place by phone or in person at a time that is convenient for me. The interview will be structured as a question and discussion section. In the interview, I will be asked a range of open-ended questions focusing on the ways that evaluation of family-centred programs can be improved. I will also be asked about the benefits and limitations of using various alternative evaluation approaches in Pediatric rehabilitation centre centres. The interview will take approximately **1 hour** to complete. With my consent, the interview will be audio-recorded and transcribed by Katherine Moreau for analysis.

Risks: There is little risk associated with my involvement in Phase 3 of the study. Some of the questions in the interview may make me feel uncomfortable because they ask about my experiences and perceptions of program evaluation practices at my Pediatric rehabilitation centre/department. I have received assurance from the researchers that every effort will be made to minimize these risks. I do not have to respond to any questions that make me feel uncomfortable. My service at my Pediatric rehabilitation centre/department will not be affected by my interview responses or my agreement or refusal to participate the study. My service providers will not have access to my specific interview responses, recordings, or transcripts.

Benefits: I may or may not benefit directly from Phase 3 of the study. The study will generate awareness for family involvement in the evaluation of family-centred programs. The study will also potentially improve the evaluation of family-centred programs and increase the level of FCS within Pediatric rehabilitation centres. To thank me for my participation in the study, I will receive a summary of the findings.

Confidentiality and anonymity: I have received assurance from the researchers that the information I will share will remain strictly confidential. I understand that the information I provide in the interview will only be used for identifying the strengths and limitations of

program evaluation practices in Pediatric rehabilitation settings and exploring ways for improving program evaluation practices in these settings. Because the interview will be conducted in person or by telephone with Katherine Moreau, PhD candidate from the University of Ottawa, my anonymity cannot be protected. Only Katherine Moreau will know my identity and I will not be asked to state my name or the name of my Pediatric rehabilitation centre in the interview. Any information that could potentially reveal my identity (e.g., name, town, or region) will be eliminated from the audio-recording and transcript so that I cannot be identified in published reports or presentations. Katherine Moreau will email me a copy of my interview transcript to review and revise prior to analyses. Katherine Moreau will password-protect the transcript and call me directly to provide me with the password.

Conservation of data: The digital audio-recording of the interview will be downloaded and erased from the audio-recorder immediately after the interview. All data will be stored in a locked research office at the University of Ottawa. All audio- recordings will be stored on a password-protected computer in the same research office at the University of Ottawa. Only the members of the above-mentioned research team will have access to the data. Data will be conserved for five years after the publication of research findings. After this time, data will be shredded and appropriately discarded.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at anytime and/or refuse to answer any questions without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will be deleted, destroyed, and not included in any publications or presentations.

Acceptance: I ________________________________, agree to participate in Phase 3 of the above-mentioned research study conducted by Katherine Moreau, PhD candidate from the Faculty of Education, University of Ottawa under the supervision of Professor Brad Cousins.

If I have any questions about the study, I may contact Katherine Moreau or Brad Cousin at:

Katherine Moreau, PhD (candidate)
Faculty of Education
University of Ottawa

Brad Cousins, PhD (advisor)
Faculty of Education
University of Ottawa

If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa at:

Appendix P

There are two copies of the consent form, one of which is mine to keep.

Participant's signature: Date:

Researcher's signature: Date:

Appendix Q

Final NVivo Codes Phase 3

- **Context** (Description: Use for - Feasibility and practicality of implementing alternative approaches within context)
    - Time
    - Funding
    - Training
    - Priorities & Interests
    - General demographic characteristics of participants
- **Nature of Practice** (Description: Use for -Ways for improving evaluation of family-centred programs)
    - Diversity
    - Processes for Family Involvement
    - Family Relevance
    - Policies or Statements
    - Compensation
- **Consequences** (Description: Use for -Compatibility of issues or consequences of using alternative evaluation approaches within family-centred programs)
    - Increases Relevance
    - Assists with Clinician-Parent Relationships
    - Supports Program Interventions
    - Facilitates Empowerment of Families