The Promise of Participatory Evaluation in Family-Centered Rehabilitation Settings: A Qualitative Study

Katherine Ann Moreau
University of Ottawa and Children's Hospital of Eastern Ontario Research Institute

Kaylee Eady
University of Ottawa and Children's Hospital of Eastern Ontario Research Institute

Beth Peddle
Children's Hospital of Eastern Ontario Research Institute

Background: Family-centered service philosophy (FCS) is an important contextual aspect of many pediatric rehabilitation programs. It recognizes the importance of supporting family relationships and the benefits of active family participation in all aspects of programming. Unfortunately, many professionals often overlook FCS philosophy when designing and implementing evaluations. Given the emphasis that participatory evaluation places on collaboration and the engagement of stakeholders, it appears to hold substantial promise for evaluating rehabilitation programs that adhere to FCS philosophy.

Purpose: To explore staff members' and parents' perceptions of participatory program evaluation, including its potential benefits for evaluating rehabilitation programs that adhere to FCS philosophy, as well as the feasibility and practicality of using it within pediatric rehabilitation centers.

Setting: The study was conducted at two urban pediatric rehabilitation centers in Ontario, Canada.

Intervention: NA

Research Design: Qualitative exploration.

Data Collection and Analysis: The study included qualitative interviews, focus groups and a thematic analysis.

Findings: Participants described how participatory evaluation would beneficially increase the relevance of program evaluations for families, work as an intervention in and of itself, assist in the development of clinician-parent relationships, and facilitate the empowerment of families. They also described how a lack of time, funding, and training, as well as variations in the priorities and interests of families presented challenges for using participatory evaluation within their centers.

Keywords: participatory evaluation; family-centered; rehabilitation; pediatrics; qualitative.

The contexts of pediatric rehabilitation programs are multilayered and composed of organizational, social, and political dimensions that can facilitate or hinder evaluation efforts. It is important for evaluators to understand these contexts and adapt and validate their evaluation approaches, data collection tools, and procedures to them (Holden & Zimmerman, 2009). Family-centered service philosophy is one important contextual aspect of many pediatric rehabilitation programs. This philosophy was first introduced in the 1950s by Carl Rogers, an influential American psychologist, and delineated in the mid-1960s by the Association for the Care of Children in Hospital (Lewandowski & Tesler, 2003). It is comprised of values, attitudes, and approaches to service delivery that acknowledge that each family is unique, that parents know their children best, and that optimal child development occurs within supportive family contexts (Rosenbaum, King, Law, King, & Evans, 1998). Programs that adhere to FCS recognize the importance of supporting family relationships and families' rights as well as the benefits of active family participation in all aspects of pediatric care and programming including, the planning, delivery, and *evaluation* of services (Institute for Patient- and Family-Centered Care, 2012). As such, individuals responsible for, or involved in, program evaluation should view families as collaborators in the evaluation process rather than just sources of data (Humphries, 2003). Unfortunately, many professionals often overlook FCS philosophy when designing and implementing program evaluations (Moreau, 2012; Moreau & Cousins, 2011).

Not only do decision-makers, service providers, and evaluators need to generate evidence to demonstrate program effectiveness, but they also need to select evaluation approaches and methods that respect and support the FCS contexts of pediatric rehabilitation programs. In light of these circumstances, there is a strong rationale to explore the promise of using participatory evaluation within these programs. Participatory evaluation is conducted as a partnership between trained evaluators and program stakeholders (Cousins & Earl, 1995). 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. Complementing the evaluators' expertise, program stakeholders have a deep implicit or explicit understanding of the program, its objectives and its activities (i.e., program logic). They are also intimately familiar with the program context because this is where they live, work, or receive services. Given the emphasis that participatory evaluation places on collaboration and the engagement of program stakeholders, it appears to be theoretically compatible with FCS philosophy. Through the active involvement of stakeholders in the evaluation process, participatory evaluation can aid in the development of programs that are more effective and better suited to the needs of the beneficiaries (Cullen, Coryn, & Rugh, 2011; Patton, 1997). It can also provide an innovative way to generate evidence of program effectiveness (Humphries, 2003). However, since it is unknown if employees and clients/patients of pediatric rehabilitation programs agree with, or are able to implement participatory evaluation, the present study was initiated.

This study is one component of a larger program of research that aims to describe and analyze current program evaluation practice in a specific set of Canadian pediatric rehabilitation centers. It explores parents' and staff members' perceptions of participatory evaluation within their associated rehabilitation centers, including its congruence with FCS philosophy, as well as the feasibility and practicality of using it within their programs. The following research questions guide the present study:

1. Are participatory evaluation approaches compatible with FCS philosophy?
2. How feasible and practical would it be to implement participatory evaluation with FCS programs?

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. No other studies have examined the congruence between FCS philosophy and participatory evaluation or the potential of using participatory evaluation in these unique contexts. In fact, 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. As such, the present study fills a void, generates knowledge for improving evaluation practice, potentially enhances the level of FCS philosophy in these Canadian pediatric rehabilitation centers, and may increase various stakeholders' understanding of participatory evaluation.

Methods

Setting

This study was conducted at two urban pediatric rehabilitation centers in Ontario, Canada. These centers were purposively selected because of their continuing program development activities, their organizational emphasis on FCS, and their interest in participatory evaluation. Both centers provide various rehabilitation services to children and youth under 19 years of age who have developmental-behavioral conditions, neuromotor/neurological conditions, physical disabilities, musculoskeletal diagnoses, or sensory impairments (Canadian Network for Child and Youth Rehabilitation, 2012). Common programs[1] offered at these centers include: (a) augmentative communication, (b) blind and low vision, (c) seating and mobility, (c) respite, (d) recreation, (e) child development, (f) acquired brain injury, (g) autism, and (h) early childhood education.

Design

One focus group was conducted at each center with staff members involved in program evaluation activities. To be eligible for the focus group, individuals had to self-identify as being involved in at least one of the following activities: (a) the conceptualization and design of program evaluations, (b) the development of data collection instruments, (c) data collection, (d) data analyses, (e) the interpretation of data, (f) the preparation of evaluation reports, (g) the formulation of recommendations generated from program evaluation activities, or (h) the dissemination of evaluation results and recommendations. Three one-on-one telephone interviews were also conducted with parents from each center who were involved in program development, delivery, or evaluation through volunteer or board member positions at the centers.

Instrument Development

The above-mentioned research questions and literature on participatory program evaluation informed the development of the staff focus group and parent interview guides, both of which included the same participant-level questions with slightly different preambles. The focus group guide

was piloted through a mock focus group with five staff members involved with program evaluation at a non-participating pediatric rehabilitation center. Feedback was also sought on the interview guide from three parents who are members of the family-advisory committee at the same non-participating center. The guides each consisted of seven major questions and six probing questions. To ensure that all participants had a similar understanding of participatory evaluation, the following conception of participatory evaluation, influenced by the work of Cousins and Whitmore (1998), was briefly reviewed at the beginning of the focus groups and interviews:

> 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 select evaluation questions to explore, design evaluations, collect data, analyze data, or dissemination findings.

Following this description, participants were able to ask clarifying questions about participatory evaluation. The remainder of the sessions then focused on the participants' perceptions of participatory evaluation within their rehabilitation centers. Table 1 provides examples of the major questions asked in both the focus groups and interviews.

---

[1] For the purposes of this study, a program was defined as a set of planned systematic activities that recognize the philosophy of FCS and are designed to achieve specific outcomes or results.

Table 1. *Example Focus Group and Interview Questions*

Focus Group & Interview Questions
What are your thoughts on participatory evaluation?
In your opinion, how is participatory evaluation more relevant or consist with the philosophy of family-centered service?
How interested would you be in using participatory evaluation at [center's name]?
What do you think participatory evaluation would look like, in action, at [center's name]?
How feasible would it be to use participatory evaluation at [center's name]?
What do you think would be some of barriers or limitations to using participatory evaluation at [center's name]?
What do you think would be some of the benefits to using participatory evaluation at [center's name]?

Procedure

Once ethics approval was obtained from each rehabilitation center, research assistants (RA) distributed information letters to all potential participants. These letters instructed those who were eligible and willing to participate to contact the RA for additional details. All focus groups took place at the centers at a time that was convenient for the participants and lasted 1 hour. All parent interviews took place over the telephone and lasted approximately 30 minutes. The lead author moderated each focus group session, while an RA took note of any non-verbal responses from the participants, as well as emerging themes. The lead author also conducted the parent interviews. Since the interviews were conducted by telephone, it was possible for one individual to note any emerging themes and conduct the interviews concurrently. The staff members and parents signed informed consent forms prior to participating and all sessions were audio-recorded and transcribed verbatim by a professional transcriptionist.

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, the data was analyzed using

QSR International NVivo 9 and Miles' and Huberman's (1994) three concurrent activities—data reduction, data analysis, and conclusions/verifications. The overall aim was to present the major themes articulated by both staff members and parents and thus, to identify concepts that were present in more than one focus group or interview.

Immediately following each session, the lead author used the audio-recordings and notes to summarize emerging themes using the memos function in NVivo 9. These memos documented the research process, tracked the development of insights and ideas, and contributed to the trustworthiness of the analysis (Bazeley, 2007). Once the transcription of the audio-recordings was complete, the lead author compared the transcripts to the audio-recordings, verified their accuracy, and then embarked on data reduction by developing a starter coding system. The codes for this system were based on the above-mentioned memos and the research questions for the study. The lead author then read each transcript, annotated phrases within the text, and coded the transcripts using the starter coding system. At this point, nodes that were not identified *a priori* emerged from the data and the starter coding system was revised. To ensure the appropriateness and accuracy of the revised coding structure, the lead author engaged in a peer debriefing session with four research colleagues who had knowledge of qualitative research and participatory program evaluation. These individuals reviewed portions of the transcripts and analysis, deliberated on the credibility of the revised coding structure, and

helped the lead author refine the wording of the various codes. Using this revised coding structure, the lead author then re-read the transcripts several times and reworked the analysis. The RA, who attended the focus group sessions, then independently coded a randomly selected focus group and interview transcript in NVivo 9 using the revised coding structure. A coding comparison query was performed to determine the kappa coefficient and percentage of agreement between the lead author's and RA's coding. Regardless of the high inter-coder reliability of 86% (Miles & Huberman, 1994), inconsistencies in the coding were discussed and minor coding modifications were made.

Findings

This section presents a description of the participants in the focus groups and interviews from each center, followed by a summary of the results. The summary is divided by research question and further sub-divided into four themes.

Characteristics of Focus Group and Interview Participants

Table 2 describes the roles of the 22 focus group participants (Center A -N=10; Center B -N=12) and the 6 interviewees (Center A -N=3; Center B - N=3).

Table 2. *Characteristics of Focus Group and Interview Participants*

Characteristic	Center A	Center B
	n (%)	n (%)
Staff Focus Groups		
Manager/Supervisor	4 (40)	3 (25)
Full-time Clinicians	6 (60)	9 (75)
Parent Interviews		
Program Volunteer	2 (67)	0
Member of Board of Directors	1 (33)	0
Member of Family Advisory Committee	0	3 (100)

Question 1: Are participatory evaluation approaches compatible with FCS philosophy?

Although the focus group and interview participants stated that they had minimal knowledge of participatory evaluation, all acknowledged that the idea of staff members and families working in partnership to evaluate family-centered programs within their rehabilitation centers was ideal and, in many ways, compatible with their perceptions of FCS philosophy. In the focus groups and interviews, participants characterized families as the primary stakeholders of program evaluation and described how participatory evaluation, in congruence with FCS, would benefit patient care and family engagement. Four themes emerged from the discussions. Participants said that participatory evaluation would increase capacity by (1) increasing the relevance of program evaluations for families, and (2) helping support program interventions. They added that such evaluations would improve the quality of care by (3) assisting in the development

of clinician-parent relationships, and (4) facilitating the empowerment of families. We now turn to a description of these four inter-related findings.

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 concerns that families have about their children's services and care. Participants emphasized that involving parents in evaluation is frustrating and wasteful unless it is meaningful and relevant to the parents and used in decision-making processes. With regard to evaluation practices, one parent stressed that evaluation should focus on improving the family's experience, stating,

> 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.

Similarly, reflecting on her own participatory evaluation experience, where she actively involved parents/guardians in evaluation activities, a staff member spoke of the usefulness of involving family members in relevant evaluation processes, saying,

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.

With that said, staff members described how they derive the identification of most evaluation priorities from their own perspectives. In terms of current evaluation practice, one staff participant commented, "It is good for us but unless you make it more relevant to them [families] it's useless." However, they thought that increased use of participatory approaches would encourage more family-driven priority identification and hence, provide information that is more applicable to families. One focus group participant summarized,
Being able to set program 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.
Others agreed with this comment and suggested that collaborative goal setting would be more compatible with the family-centered principle of providing families with "appropriate information" so that they can make informed decisions about whether "the care their child is receiving meets their expectations." As one participant concluded, "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 participatory evaluation would encourage more meaningful family engagement in more relevant evaluative activities.

Assists in the development of clinician-parent relationships. The majority of the participants mentioned that participatory evaluation could improve the level of communication and trust between clinicians and parents—two important concepts under the FCS umbrella. 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, staff members envisioned small staff-parent group discussions or clinician-parent brainstorming sessions around the design of evaluations and the collection of data. 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 also expressed that these interactions would increase their trust towards clinicians. For them, this trust is bi-directional and primarily based on previous experiences between themselves and the clinicians, and thus, they thought that participatory evaluation might help nurture trusting relationships because it would provide them with additional opportunities to get to know the clinicians. They expressed a belief that, by working together, they could foster mutual respect and open communication with the clinicians, which would be useful in clinical situations involving their children. One parent highlighted the importance of relationship-building, saying, "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".

Helps support program interventions. Some staff members and parents highlighted how parents' active involvement in evaluation may contribute to the effectiveness of the intervention process. They described how the information parents might obtain through evaluation participation could foster feelings of control and self-efficacy; for example, by assisting with the design of the evaluation for their children's program, parents gain self-efficacy which 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 [Autism Spectrum Disorder] 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 you could get them involved in program evaluation but these types of group things help with stress.

Similarly, staff members commented on how many of the FCS-based programs encourage family-to-family networking and support; as such, they thought that the collaboration of families in program evaluation could facilitate additional family networking sessions. In this regard, one staff member noted, "With this [approach], they would feel more comfortable talking to another parent." Another highlighted the multiple opportunities that stem from such collaboration,

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.

Facilitates the empowerment of families. Overall, the participants thought that participatory evaluation would empower families by giving them a new medium through which to voice their concerns and feedback. 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[s] and families do not have that advantage, that is why I advocate and say, have more voice.

Consistent with the staff member's statement, one parent said that:

I don't know how you can run anything without an evaluation and the perspective of 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.

Staff members also described how clinician-family partnerships, accessibility to additional information, and self-confidence interconnect within the concept of empowerment. Commenting on her experience with 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 evaluation. 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 give parents greater insight into "behind the scenes" of their children's programs, building their confidence and knowledge on the treatments and services that their children receive. Parents—emphasized that "it becomes really the family member addressing the center as the initiator of the service."

Given these positive endorsements for participatory evaluation as well as its compatibility with FCS philosophy, it was important to explore the feasibility and practicality of implementing and using participatory program evaluation within these centers.

Question 2: How feasible and practical would it be to implement participatory program evaluation within FCS rehabilitation programs?

Although the participants saw participatory program evaluation as important and congruent with many aspects of FCS, they questioned the ability to implement and use it regularly within their centers. As described below, the majority of their concerns revolved around the discrepancy between time and funding restrictions and the resources needed to carry out more family-oriented or participatory evaluations. Both groups discussed the need for time and resources for additional training, and parent participants discussed the challenges of working with families' diverse priorities and interests. The findings for Question 2 are summarized according to these four concerns.

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 did not have. Many commented on how the involvement of families would require additional steps, including extra time to identify families interested in evaluation, arrange logistics for family participation, review relevant program documents, reflect on the processes, and 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." Another staff member elaborated on the potential time demands, pointing 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. Such timelines sometimes result in incomplete evaluations; 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 might increase demands on families who already have extremely busy and stressful lives, or are in crises due to their children's health condition(s) and healthcare needs. 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…. 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—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 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."

Thus, although parents and staff members liked the notion of participatory evaluation, many thought that it might be difficult to implement because of time constraints and the challenges of engaging families who are coping with their children's health conditions and in a state of crisis.

Funding. Staff members believed that the additional time required for participatory evaluation would translate to increased evaluation costs. One individual noted that the nature of existing funding is an additional barrier,

> 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.

Many of them reflected on how they receive minimal funding for program evaluation and that this could be problematic in terms of implementing participatory evaluation, or any innovation in evaluation. As a staff 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 suggested 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 possibility of allocating the funds spent on external consultants towards participatory approaches, echoing 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."

Regarding compensation, staff members emphasized that, in order to ensure the successful implementation of a participatory evaluation involving families, those families need to be reimbursed for their time and expertise. One staff member underlined that remuneration is part of recognizing patients' and families' status as a partner in the evaluation, saying, "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 that parents deserve payment for sacrificing their time, commenting, "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 honorarium-based remuneration:

> 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…. 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 sum, funding limitations and additional needs were a concern for the potential implementation of participatory evaluation in this context.

Training. As suggested by staff members, additional training would be essential for the

successful implementation of participatory evaluation. For example, one staff member noted how her center would need to offer specific training to the parents involved. She mentioned the challenges of data analysis in particular, saying,

> 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 [participatory evaluation] 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 evaluation and little or no training in participatory evaluation, nor in other areas of evaluation or project planning. 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.

The staff reported 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-centered in evaluation" and enact it in their practice. They also thought that joint training sessions between themselves and interested parents would provide a strong basis from which to begin participatory evaluation.

Priorities and interests of families. Lastly, while staff members did not report this as a concern, parent interviewees commented on how the priorities of families often vary according to the age of their children, the nature of their children's 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.
Similarly, 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.

In light of these differences, they highlighted that the participation and interest of families in evaluation processes may also vary. One parent described parents' diverse priorities, stating, "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 evaluation in some programs rather than others (e.g., outpatient versus inpatient rehabilitation programs). 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 both their children's needs and their own circumstances, they might disagree about which programming aspects need evaluation. They expressed that these competing interests and priorities might pose some challenges for participatory evaluation.

Discussion

These two focus groups and six interviews enabled the exploration of parents' and staff members' perceptions of participatory evaluation, including its congruence with FCS philosophy and viability for use within family-centered rehabilitation contexts. Most participants thought that participatory evaluation showed substantial promise and compatibility. They noted that this approach would increase the relevance of evaluation for families by identifying concerns that directly affected, or were of interest to, them. In this sense, a participatory evaluation would arguably increase the validity of the evidence generated through evaluation and be consistent with both the evidence-based practices and FCS contexts of these centers.

The findings also demonstrated that participatory evaluation can enhance evaluation use within these centers; program evaluation and rehabilitation communities have been particularly concerned with utilization for some time (Cousins, Goh, Clark, & Lee, 2004; Schnelker & Rumrill, 2001)**.** The participants alluded to both the use of evaluation findings and process use—an effect that Patton (2007) describes as use that leads to changes in stakeholders' attitudes, thought processes, and behaviors as a result of their involvement in program evaluation. First, participants discussed that by making program evaluation more relevant for families, the latter would be more inclined to use the evaluation findings to support their decisions. They also described how participatory evaluation would allow families to learn about and better understand specific programming areas. Moreover, the participants referenced examples of process use and suggested that participatory evaluation within their centers would enhance the program intervention itself, while increasing families' sense of engagement and empowerment. Thus, as Shulha and Cousins (1997) confirmed, this process use would not require changes in specific programs or direct actions because of the evaluation findings but would lead to changes in the families' attitudes,

thought processes, and behaviors (Patton, 1997, 2007), in addition to potentially enhancing program outcomes and the level of FCS in the programs and centers. Through their active involvement in the evaluation, families would also develop their critical thinking, facilitation, networking, and advocacy skills. Such skills would not only contribute to the program evaluation capacity of the centers, but also help families become even more aware, effective, and confident in navigating the healthcare system with their children.

Both groups of participants were somewhat skeptical of the ability to use participatory evaluation within their pediatric rehabilitation centers. The parents discussed how the priorities of families often vary, and as such, they were not sure if participatory evaluation would be appropriate for all families or programs. Furthermore, they described how it might be challenging to build consensus on evaluation priorities if diverse groups of families were actively involved with the evaluation. Many critics of participatory evaluation would support these claims, as it is rarely feasible for all relevant stakeholders to participate in a program evaluation (Stufflebeam & Coryn, 2014). Thus, participatory evaluators, or those who commissioned the evaluation, need to identify and select representatives from various stakeholder groups who would be interested in actively participating. This selection of stakeholders is hindered by a lack of both definitive procedures for choosing stakeholders and research on stakeholder selection (Daigneault & Jacob, 2009).

Similar to the participants' views, Weaver and Cousins (2004) also describe how it can be difficult to manage multiple stakeholders in participatory program evaluation and that conflict among stakeholders can sometimes arise from power differentials and differences in viewpoints or values. These conflicts, combined with the inclusion of multiple stakeholder groups, can result in a need for increased time and resources to mediate differences, solve logistical problems, and complete the evaluation (Stufflebeam & Coryn, 2014). Nevertheless, while this group diversity can add complexity to participatory evaluation, it is manageable if the evaluators have group facilitation skills (Burke, 1998) and are able to both balance power differentials and encourage trust among the various participating stakeholders (King, 1998).

Interconnected with the challenges of stakeholder group diversity, the participants also thought that participatory evaluation approaches

would require additional time, funding and training—three resources of which they have very little. The work of Moreau (2012) in Canadian pediatric rehabilitation settings demonstrates that these centers have not invested substantial resources into program evaluation and thus, it comes as no surprise that the parents and staff members mentioned time, funding, and training as major factors that would inhibit their use of participatory evaluation. This connection between resources and evaluations is supported by Love (1983, 1991), Brazil (1999), and Cousins et al. (2008) who each discuss how a lack of personnel, funding, training, and time can impact the capacity of organizations to do any form of evaluation. However, if some families are truly interested in becoming more actively involved in program evaluation, there is the potential that these rehabilitation centers could delegate some of the evaluation responsibilities to them. Such efforts would allow these centers to utilize the expertise of families and relieve some of the evaluation responsibilities that are currently placed solely on staff members.

Limitations

Regardless of the study design or methods used, all research has specific strengths and limitations (Babbie, 2008). First, the information gained in this study was based on self-reports and presented through the views of the selected participants. Participation in the study was voluntary and thus, it is unknown if there were any differences between those who participated and those who did not. Lastly, due to staff availability, the absence of specific program evaluation committees, or family-lead advisory groups, it was challenging to find participants. As a result of these issues, the two participating centers each decided that their centers could only commit to one heterogeneous focus group of staff members and a handful of parent interviews. Although these focus groups provided checks and balances for the participants (Patton, 1990) and were an efficient way to gather information from staff members who often work together on program evaluation initiatives, the heterogeneous composition of the groups may have resulted in some participants being influenced by other participants' managerial positions. Moreover, although the parent participants provided valuable information, more family input would have increased the validity of the findings. Nevertheless, the study made some contributions to the fields of rehabilitation and program evaluation.

Conclusion

This study was initiated as a result of heightened interest within pediatric rehabilitation centers to do program evaluation and adhere to FCS philosophy throughout the evaluative process. Given that researchers have not examined how participatory evaluation fits with FCS —a philosophy that is now prevalent in many sectors, the present study fills a gap in the rehabilitation and program evaluation literature and marks an initial step in the possible development of more family-centered program evaluations. Furthering the understanding whether participatory evaluation is feasible will require conducting pilot participatory evaluations in pediatric rehabilitation centers, and studying patient and staff experiences with the processes and results. In future, it would be advantageous to have selected groups of families and staff members conduct participatory evaluations in pediatric rehabilitation centers, and then study their experiences. These types of studies would provide an opportunity to see if participatory evaluation is truly compatible with FCS philosophy and if its implementation is possible within resource-limited rehabilitation centers. Such studies would also provide insight into the type(s) of evaluation approaches and methods that can be used to support FCS contexts. Ultimately, such understanding would help to ensure that program evaluation activities are more consistent with the multi-layered contexts of pediatric rehabilitation centers and that families are actually at the center of all programs.

References

Babbie, E. (2008). *The basics of social research* (4th ed.). Belmot, CA: Thomson.

Bazeley, P. (2007). *Qualitative data analysis with NVivo*. Thousand Oaks, CA: Sage.

Brazil, K. (1999). A framework for developing evaluation capacity in health care settings. *International Journal of Health Care Quality Assurance, 12*(1), vi-xi.

Burke, B. (1998). Evaluating for a change: Reflections on participatory methodology. In E. Whitmore (Ed.), *New Directions for Evaluation: Understanding and practicing participatory evaluation* (pp. 43–56). San Francisco, CA: Jossey-Bass.

Canadian Network for Child and Youth Rehabilitation. (2012). About CN-CYR Retrieved June 10, 2012, from http://cn-cyr.caphc.org/cn-cyr-dashboard/about-cn-cyr

Cousins, J. B., & Earl, L. M. (1995). *Participatory evaluation in education: Studies of evaluation use and organizational learning.* London, UK: Falmer.

Cousins, J. B., Elliott, C., Amo, C., Bourgeois, I., Chouinard, J., Goh, S., & Lahey, R. (2008). Organizational capacity to do and use evaluation: Results of a pan-Canadian survey of evaluators. *Canadian Journal of Program Evaluation, 23*(3), 1-35.

Cousins, J. B., Goh, S., Clark, S., & Lee, L. (2004). Integrating evaluative inquiry into the organizational culture: A review and synthesis of the knowledge. *Canadian Journal of Program Evaluation, 19*(2), 99-141.

Cullen, A., Coryn, C. L. S., & Rugh, J. (2011). The politics and consequences of including stakeholders in international development evaluation. *American Journal of Evaluation, 32*(3), 345-361.

Daigneault, P. M., & Jacob, S. (2009). Toward accurate measurement of participation: Rethinking the conceptualization and operationalization of participatory evaluation. *American Journal of Evaluation, 30*(3), 330-348.

Flynn, R., Glueckauf, R., Langill, G., & Schacter, G. (1984). Program evaluation in Canadian rehabilitation facilities for physically disabled persons: A national survey. *Rehabilitation Psychology, 29*(1), 11-20.

Holden, D., & Zimmerman, M. (2009). Evaluation planning here and how. In D. Holden & M. Zimmerman (Eds.), *A practical guide to program evaluation planning* (pp. 7-31). Thousand Oaks: Sage.

Humphries, B. (2003). What else counts as evidence in evidence-based social work? *Social work education 22*(1), 81-91.

Institute for Patient- and Family-Centered Care. (2012). *Advancing the practice of patient- and family-centered care in primary care and other ambulatory settings.* Bethesda, MD: Institute for Patient- and Family-Centered Care.

King, J. A. (1998). Making sense of participatory evaluation practice. *New Directions for Evaluation, 80*, 57-67.

Lewandowski, L., & Tesler, M. (2003). *Family-centered care: Putting it into action.* Washington, DC: Society of Pediatric Nurses.

Love, A. (1983). The organizational context and the development of internal evaluation In A. Love (Ed.), *Developing Effective Internal Evaluation* (pp. 5-21). San Francisco, CA: Jossey-Bass.

Love, A. (1991). *Internal evaluation: Building organizations from within.* Newbury Park, CA: Sage.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage.

Moreau, K. (2012). Embracing the context of pediatric rehabilitation programs: Investigating the role of family-centred service philosophy in program evaluation. Unpublished Doctoral Dissertation. Ottawa: University of Ottawa.

Moreau, K., & Cousins, J. B. (2011). Program evaluation in family-centred pediatric rehabilitation settings: A review of evaluation studies and the potential use of participatory and collaborative evaluation approaches. *Evaluation Journal of Australasia, 11*(2), 3-13.

Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage.

Patton, M. Q. (1997). *Utilization-focused evaluation: The new century text.* Thousand Oaks, CA: Sage.

Patton, M. Q. (2007). Process use as a usefulism. *New Directions for Evaluation, 2007*(116), 99-112.

Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centred service: A conceptual framework and research review. *Physical and Occupational Therapy in Pediatrics 18*(1), 1-20.

Schnelker, D., & Rumrill, D. (2001). Program evaluation in rehabilitation. *Work, 16*, 171-175.

Shulha, L. M., & Cousins, J. B. (1997). Evaluation use: Theory, research, and practice since 1986. *American Journal of Evaluation, 18*(1), 195-208.

Stufflebeam, D. L., & Coryn, C. L. S. (2014). *Evaluation theory, models, and applications* (2nd ed.). San Francisco, CA: Jossey-Bass.

Weaver, L., & Cousins, J. B. (2004). Unpacking the participatory process. *Journal of Multidisciplinary Evaluation, 1*(19-40).