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How do parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy?

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A thesis submitted in partial fulfillment of the requirements for the degree in Master of Science

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How do parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy?

(Spine title: How do parents use health information?)
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By: Stephanie E. Lagosky

Graduate Program in Health and Rehabilitation Science

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science

The School of Graduate and Post Doctoral Studies
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entitled:

How do parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy?

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Abstract and Keywords

This research aims to understand how parents use health information (such as those developed from the Move & PLAY study) with the aid of a knowledge broker when living with and caring for young children with cerebral palsy. This research was conducted under a qualitative case study methodology and used questionnaires and in-depth interviews to collect data. Findings include the complexity of both parental use of health information and the desire to use a knowledge broker. A provisional model has been created to help describe information use of parents with young children with cerebral palsy. This provisional model is an important addition to the field of knowledge translation and childhood rehabilitation, as it has implications for the facilitation of knowledge use in the everyday lives of families with children with chronic health conditions.

Keywords: Cerebral palsy, health information, dissemination, parents, children, case study, research, knowledge translation, knowledge broker.

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Table of Contents

List of Tables

List of Figures

List of Appendices

List of Abbreviations

GMFM – Gross Motor Function Measure

GMFCS – Gross Motor Function Classification System

MGCs – Motor Growth Curves

Chapter One - Introduction

Background and Significance

The incorporation of research findings into clinical practice and daily life has traditionally been a slow, haphazard process. Yet the information that such research provides has the potential to optimize people's health outcomes, inform treatment decisions and improve the delivery of health care (Tetroe et al., 2008). Ironically, up until quite recently, this process of moving research into practice has been ignored, despite the positive outcomes that such research could have. Traditionally, the assumption that existed in health research was that if important questions were addressed, the study was well done, and the paper was published in a good journal, the researcher had discharged his or her responsibility (Rosenbaum, 2005). Then it was left up to the users of the information to find and understand the paper, as well as to apply the results to their treatment decisions. However, with the changing Canadian health care system and the emergence of such service delivery philosophies as evidence-based practice (Sackett & Rosenberg, 1995) and client-centered care (Sumsion & Law, 2006), this notion of research dissemination is changing. There is greater pressure to understand the processes of moving research knowledge and health information into the daily lives and practice of individuals and families. This section begins by highlighting families of children with chronic health conditions and how family-centered care, evidence-based practice and client-centered care affect this group. Additionally, this section serves to outline the process of moving knowledge from research into practice, a process called knowledge translation that can be depicted using the knowledge-to-action framework.

Many decisions in health care involve the entire family. Specifically, young children with chronic health conditions must rely on their caregivers to make decisions regarding their management. Advances in medicine and the provision of health care, decreases in infant mortality, and the emergence of public health programs have yielded growing populations of children experiencing disabilities or chronic health conditions (Judson, 2004). These trends have resulted in families of these children becoming a large "end-user" group in regards to health information. These parents have different and greater demands placed on them as a result of their children's condition (Newton, 2000).

How well parents understand the diagnosis, treatment options and support systems available to them will greatly affect their abilities to participate in their children's health care (Johnson & Marder, 1994). Involving parents in their children's care can be accomplished using what King and colleagues (1999) refer to as the *family-centred approach* [see Appendix A for a glossary of common terms used in this thesis]. This approach encompasses three key elements: parents are treated respectfully and supportively, parents are provided with all the relevant information needed to make decisions and parents have final control and responsibility over decision making. This family-centred approach must be considered when transitioning knowledge from research to practice, such as in evidence-based practice.

Evidence-based practice [Appendix A] is a method of care delivery that integrates the best evidence from well-designed studies, the clinician's expertise, as well as the patient's preferences and values (Sackett & Rosenberg, 1995). According to Melnyk and Fineout-Overholt (2006), treatment that is based in evidence, as opposed to that which is based in 'tradition', supports the highest quality of health care and patient outcomes. The outcomes from evidence-based practice are encouraging leaders in healthcare across North America to re-examine how care is currently being provided and how it can be modified to promote the health of citizens. The process of providing evidenced-based care involves more than just health care providers. Factoring in and respecting patients' values and preferences is key in delivering evidence-based practice and subsequently the highest standard of care. Melnyk and Fineout-Overholt indicate that the great majority of health care practitioners do not provide evidence-based care to their patients (2006). In addition to health care providers not using evidence in their daily practice, problems also exist in actively engaging patients to become more involved in their health care decisions.

This issue can be addressed and mitigated when using a *client-centered care* [Appendix A] approach in providing evidenced-based care. In client-centered care, clients are encouraged to participate fully in the decisions regarding their care (Sumsion, 2005). Research by Sumsion (2005) shows that most clients prefer to be actively involved in decisions about treatment, as opposed to passively receiving treatment they have no role in deciding. This active decision to be involved in decision making is heavily engrained in patients themselves, but also relies on the provision of appropriate health-related information. Knowledge of the underlying principals of an intervention or service is a very common foundation in theories of individual change (Grol, Bosh, Hulscher, Eccles & Wensing, 2007). One source of knowledge is research findings disseminated in easily understood summaries (*dissemination* materials) [Appendix A]. Essentially, providing health information to patients will enable them to not only have choice over the treatments they receive and management strategies they engage in, but increase the likelihood of treatment adherence and uptake. This choice is important because it will empower patients to become more engaged in the decision making process. As well, the provision of knowledge will bridge the gap between the research that exists and these patients' health outcomes, which is the primary goal of knowledge translation (Graham et al., 2006).

Knowledge translation [Appendix A] is defined by the Canadian Institutes of Health Research to be:

> "the exchange, synthesis and ethically-sound application of knowledge- within a complex system of interactions between researchers and users- to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system" (Canadian Institutes of Health Research, 2009).

Knowledge translation is a broad concept; there are many different definitions for the process of moving research into practice. The common element among these different terms is a move beyond the simple dissemination of knowledge into the actual use of knowledge (Straus, Tetroe & Graham, 2009).

There are many steps between the initial creation of knowledge and its final application and uptake in practice. Each of these steps is not enough on its own to ensure the use of knowledge in decision making. Graham and colleagues (2006) have developed a *knowledge-to-action* [Appendix A] framework from commonalities in planned action theories to demonstrate the different steps in the movement of knowledge from research to practice (Figure 1-1) (Straus, Tetroe & Graham, 2009) This knowledge-to-action framework has been used as a framework for this research.

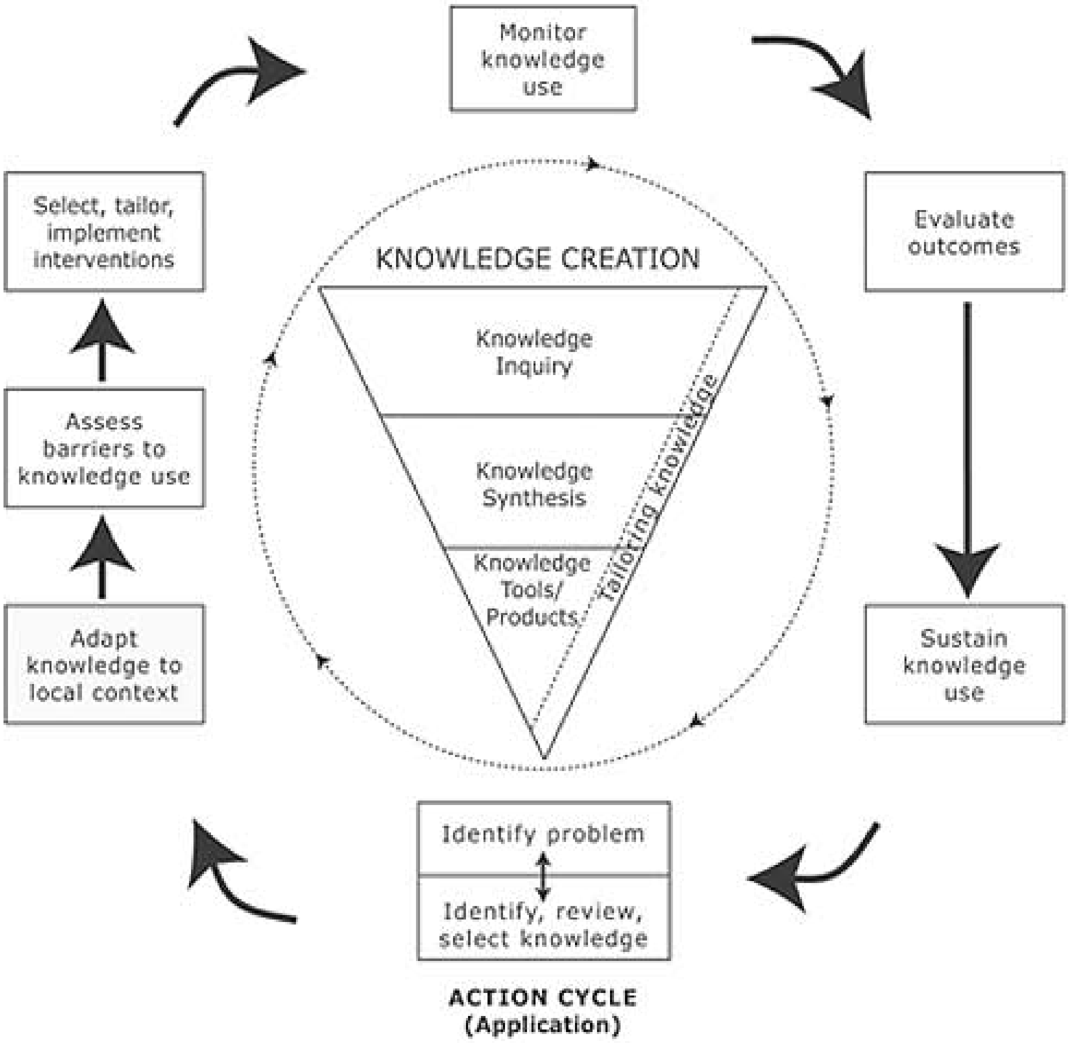

Figure 1-1. The knowledge-to-action framework, used with permission [See Appendix B for permission for use of figure]

To begin, the inverted triangle in the centre of the model represents the knowledge creation process. This is cyclic in nature, as various research questions are constantly being asked and answered. This process begins with individual knowledge inquiry, representing separate research projects. Individual research results are then synthesized across various research projects, eventually producing “end-result” knowledge tools or products. These often take the form of short summaries, instead of entire research articles. However, to ensure this knowledge is properly disseminated, it must pass through the action process of this model.

This action process consists of adapting the knowledge to a local context, assessing the barriers and supports to knowledge use, and selecting, tailoring, and implementing knowledge into the lives and practice of individuals. Recent research has demonstrated that knowledge brokers are effective in guiding clinicians through these initial steps in the knowledge-to-action framework (Rivard et al. 2010; Russell et al. 2010). A *knowledge broker* [Appendix A] is defined as someone who is capable of "bringing researchers and decision makers together, facilitating their interaction so that they are able to better understand each others' goals and professional culture, influence each other's work, forge new partnerships, and use research-based evidence" (Canadian Health Services Research Foundation, 2003). Four core competencies have been identified as being central to the knowledge broker role: developing mutual understanding of goals and cultures, collaborating with knowledge users and producers to identify issues and problems for which solutions are required, facilitating the identification, access, assessment, interpretation, and translation of evidence into practice, and facilitating the management of information and knowledge (Harris & Lusk, 2010). The knowledge broker in the study presented in this thesis focused on the everyday lives of parents and involved information classified other than "research-based evidence", such as the *tacit knowledge* [Appendix A] that parents possess. This leads to the next step in the knowledge-to-action framework and the main focus of this research: monitoring how such knowledge is used.

Study Purpose

Monitoring the actual use of knowledge is essential to determine how and the extent to which the knowledge has resonated with end users. According to Graham and colleagues (2006), there are three types of knowledge use to monitor: the conceptual use of knowledge (changes in understanding, knowledge, or attitudes), the instrumental use of knowledge (changes in behaviour or practice) and the strategic use of knowledge (to attain power or profit goals). All three are important to understand when examining how parents use knowledge with the assistance of a knowledge broker when living with and caring for their young children with cerebral palsy. Furthermore, when trying to uncover the deeply rooted understandings (such as how knowledge is used), qualitative methods tend to be more suitable than quantitative methods as they enable a deeper appreciation of processes and enactment of knowledge use in specific contexts. Specifically, when answering research questions regarding complex social phenomena, applying a case study approach is appropriate (Yin, 2003). By conducting this research using a qualitative case study design, the aim is to yield information that can lead to understanding how and in what ways knowledge is used by parents of children who have chronic health conditions. This same information will allow expansion of the knowledge-to-action framework and subsequently add a missing piece to current literature about knowledge translation to parents of children who have chronic health conditions, such as cerebral palsy.

Thesis Outline

Subsequent to this introductory chapter, in Chapter 2 I present an appraisal and review of research literature on what is currently known about the relationship between parents and health information, a description of exemplar research materials and how this entire process is mediated by a knowledge broker. The research methods used to conduct this study are presented in Chapter 3. Here, the methodology, paradigm, description of the researcher, ethics, methods used, analysis and quality criteria are discussed. In Chapter 4, I present a review of the findings and interpretations of the data collected. Lastly, in Chapter 5 I present a discussion of the findings, the implications of this research and conclusion to this thesis.

Chapter Two – Literature Review

Parents and Dissemination Materials: What Is Known

Introduction. Many different parenting situations exist, such as parenting of children developing typically, parenting of children with acute health problems and parenting of children with chronic health conditions. Among these categories, some differences exist in the way parents interact with dissemination materials, but there are similarities as well. For example, parents of children with chronic conditions were more likely than parents of children with non-chronic health issues to use a higher number of information sources (Khoo, Bolt, Babl, Jury & Goldman, 2008). There were differences between parents as well, such that mothers were more likely than fathers to seek health information (Allen & Rainie, 2002). Aside from the child's health situation, parents differ in many aspects such as education level, socio-economic status, levels of support, age and ethnic background. According to the *Social Cognitive Theory* [Appendix A] developed by Bandura (1986), individuals perceive, interpret and store information from their environments uniquely, depending on the aspects above. This impacts the specific health-related needs they want addressed in such materials. The Social Cognitive Theory is commonly used in health promotion initiatives, and has the potential to aid in the understanding and prediction of individual and group behaviour, and identify ways in which this behaviour could be changed (Bandura, 1986). This theory may help explain the relationship between parents and dissemination materials. The following section serves to divide what we know about parents and dissemination materials into distinct categories, and to explain the current and relevant literature that exists on each category.

Parents' understanding of health information. The importance of providing parents with appropriate health information to enable them to participate effectively in decision making and providing care is recognized (Rahi, Manaras, & Barr, 2003). However, this information is unused unless parents can understand it. Unfortunately, health care providers may avoid giving parents health information altogether if they believe the parents are unable to understand and make appropriate use of it. As defined by Bennett, Robbins & Haecker (2003) and Weiss, Hart, McGee & D'Estelle (1992), *health literacy* [Appendix A] is the parents' ability to read, understand, and use health information to make appropriate health care decisions that affect their children's health care outcomes. Mulligan et al. suggested that to ensure that parents understand the health information they are presented with, their health literacy could be assessed, or the health information could be conveyed in a less technical and blunt language (Mulligan, Steel, Macculloch & Nicholas, 2010). These studies that explore health literacy usually focused on the ability of parents to understand health information, instead of focusing on the actual management of health information and its eventual use (or lack of use).

Research exists on other aspects of how parents understand health information other than health literacy. Research by Cohen (1993, as cited in Fisher 2001) showed that parents 'managed' information they received by discounting, transforming or modifying it. The term *health information management* [Appendix A] is defined in a study about children with a genetic condition as "a complex process that involves the interplay of beliefs and behaviours related to accessing and interpreting [genetic] information as well as making decisions and taking action based on information" (Gallo, Knafl, & Angst, 2009, pg. 194). In the above study, the authors admitted that it was unclear if parental confusion regarding their children's genetic condition was grounded in parents not perceiving a need for information and therefore not asking for more information or if confusion resulted from the sources not being understandable to parents. Also, this study did not address the link between information and the decisions and actions taken by parents. Despite parents' varying abilities to understand and manage health information and how this may contribute to information use, they do have specific health information needs that they would like to be met.

Parents' health information needs. Parents have specific health information needs they want addressed in dissemination materials. Menghini (2005) studied the needs that parents of non-chronically ill children and found that they wished to receive culturally sensitive information that uses common language that is written in a warm and friendly tone. As well, parents liked information provided in a variety of formats to allow them to choose which format best suited their personal needs (Lehna & McNeil, 2008).

As outlined below, parents of children who are chronically ill also sought out more elaborate and extensive information specific to their individual children.

Parents of children who have chronic conditions sought information related to their child's specific condition and symptoms, management, accessing services and guidelines for their child's care (Jackson et al., 2008). These parents also expressed a need for this information to match their child's age and current trajectory in their condition (Huber, Dietrich, Cugini & Burke, 2005). As well, parents were interested in information that is based on evidence and developed with individuals who handle the disability on a daily basis (Mitchell & Sloper, 2002). Furthermore, parents wanted information about planning for the future, arranging their child's leisure activities, helping with housing options, obtaining respite care, informing them of support groups and informing them of their benefit entitlements and rights. Interestingly, they also wanted information involving the whole family, not just the child with the disability. This desire for such information demonstrates the impact that having a chronically ill child can have on a family. When discussing health information needs with patients, health care practitioners should remember that the needs of parents may differ substantially from what they, as health care professionals, deem to be important (De Moor, Savelberf, & Oud, 2002). This sensitivity to parents' needs should also be maintained when parents discuss how they prefer their health information to be disseminated. Therefore, evidence exists that parents do want information and that parents would like this information to be tailored and delivered in a particular way. It is unknown how providing information that is tailored to the parents' needs contributes to how they use information.

Parents' preferred dissemination techniques. For both parents of children with and without chronic conditions, doctors are the most preferred source of health information. Parents seemed to recognize doctors' expertise (Fisher, 2001) and trusted what doctors are saying. When talking with doctors and experts about health information, parents desired "mom-level detail" (Bernhardt & Felter, 2004). Some parents found themselves in between trusting information from a doctor and the comfort of discussing information with their family (Shuster, Duan, Regalado, & Klein, 2000). Other parents desire a middle ground between information provided by doctors, and information provided from other parents. Parents called this type of information provision ‘parent-as-expert’ resources, where ‘champion’ parents who are heavily involved in the condition, illness or disease can provide health information (Jackson et al., 2008). Parents desire their health information from an “expert” in the field, but how exactly do they wish to receive this expert information? This is the question that informed the research of Khoo et al. (2008), Mulligan et al. (2010) and Jackson et al. (2008).

Parents want information in the form of guidance. Many parents indicated that they desire such guidance in accessing reliable children’s health websites (Khoo et al., 2008), ‘where to start’ and what ‘next steps’ to take, as well as which services they should access and in what order (Mulligan et al., 2010). Parents preferred this guidance to be provided verbally on a one-on-one basis, with understandable and child specific written information as a supplement (Jackson et al, 2008). These parent preferences seem to cumulate on the desire for an expert to provide information specific to their child, both in person verbally and with written material for guidance. The preferences that parents have in how they wish to receive health information also seem to contrast with how they currently receive their information, which could impact whether or not this information is used.

Where parents find their health information. Parents have been found to use a large number and wide variety of sources (Khoo et al., 2008). Once again, parents of children with and without chronic conditions seem to look for their information in the same places as one another. Parents used newsletters, conferences, meetings, magazines and television to receive health information (Huber et al., 2005). Parents also met with other parents to share and gain knowledge about their child’s health issues, creating a ‘subculture’ of information sharing (Starke & Moler, 2002). However, these sources are not preferred over sources like the internet and books. In regards to books, parents of children with autism found them to be easy to pursue at a reader’s convenience (Mulligan et al., 2010). Parents from the same study also found value in internet sources for health information, citing their convenience in access and the ability to search for specific details of their child’s condition.

Hundreds of health-related websites currently exist, and it is no wonder that health information is one of the most researched topics online (Bernhardt & Felter, 2004). On the internet, parents typically use search engines, commercial information websites and organizational/academic web pages to obtain health information. In a study examining parents' preferences in information sources relating to their children's health, the rationale parents gave about using some of the above information sources was the level of comfort they felt using the source, the accessibility of the knowledge, as well as trust in the knowledge or expertise of the source (Keatinge, 2005). Parents currently seek health information from a variety of sources, including the internet. This could result in a large amount of information, which would need to be narrowed down by the parent. This process of refining health information for use can be described by how parents gauge the quality and trustworthiness of information sources.

How parents appraise the quality of health information. Parents have placed the greatest amount of trust in traditional sources of health information, such as doctors, nurses and other health care professionals (Khoo et al., 2008). However, parents seemed to have developed their own quality criteria to judge health information. In a study about online paediatric information seeking amongst mothers of young children, parents seemed to create categories to judge the quality of online resources (Bernhardt & Felter, 2004). These categories are uncovering the motives of the website owners, identifying and evaluating sources of the information and seeing the information they found converge with other studies, as evident in repetition. These qualities in gauging the quality of sources have been seen in demographics other than parents of children with chronic conditions (Daraz, MacDermid, Wilkins, & Shaw 2009). Whether or not these criteria for quality are leading parents to finding accurate information has yet to be studied. In addition, it is unknown if these quality criteria impacts information use.

When parents search for health information. Parents of children with chronic conditions claim that their needs for health information have changed over time (Huber et al., 2005). Particularly, information seeking is greater at the time of diagnosis or when new treatment plans are being discussed. As well, information needs change depending on the age of the child. In a study involving parents of children with autism, the timing of health information was related to its perceived usefulness (Mulligan et al., 2010). According to Osborne and colleagues (2008), parents of younger children desired concise and comprehensive information immediately following diagnosis, while parents of older children desired information targeted to key junctures in their child's life. This temporality of information may affect the rate at which the information is used. Also, the fact that parents use health information at inconsistent rates could mean that monitoring knowledge use will be affected by this. Neither of these questions have been looked at in detail in research.

Why parents search for and use health information. Parents have a number of reasons why they look for and use health information. In regards to their communication with doctors, parents often sought additional information to help clarify what was said, when they were dissatisfied with the explanation or when they felt they had not received enough information (Bernhardt & Felter, 2004; Starke & Moller, 2002; Jackson et al., 2007). Parents also felt the need to use dissemination materials when it came to seeking out further support or making treatment decisions (Bernhardt & Felter, 2004). In a study of parents with children diagnosed with Turner's Syndrome, parents sought to gain knowledge about their children's diagnoses to handle others' reactions and questions (Starke & Moller, 2002). This study proposed that parental seeking of health information could also be a part of normal reflexive parenthood, as parents seek to provide the best care for their children. Lastly, parents' motives to seek more information could be to enable parental control over their health care practitioners (Jackson et al., 2007), demonstrating a strategic use of knowledge. This array of reasons to seek out health information could have an impact on the use of information. The association between why parents seek health information and how that impacts how it is used has not been explored.

What is Known about Parents of Children with Cerebral Palsy and Health Information

I performed a comprehensive literature review of the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, Psych Info, and Scopus online research databases in October 2010 and again in January 2011. My search terms were *"Parents* OR *Parents of Disabled Children* OR *Caregivers* OR *Mother* OR *Father"* AND *"Dissemination* OR *Print Materials* OR *Health Information* OR *Information* OR *Research Materials* OR *Implementation* OR *Research Use* OR *Diffusion* OR *Knowledge Translation* OR *Knowledge Exchange"* AND *"Cerebral Palsy"*, and I excluded *"neoplasms"* AND *"vaccinations"* AND *"adoption"* AND *"cancer"* from the search. I found only two articles pertaining to health literature created for parents of children with cerebral palsy exist. Both of these articles were written in the 1980s, and were very outdated. The first article, *Literature for Parents of Children with Cerebral Palsy*, claimed that none of the information available for parents of children with cerebral palsy is reviewed for quality, suitability or readability (Blasco, Baumgartener, & Mathes, 1983). This study also found that although parents frequently asked for educational literature, the information available to them was poorly written and out of date.
The second article, *Health Literature for Parents of Children with Cerebral Palsy* went more in-depth into health-specific information. In this study, parents expressed an information need for future management of their children, the causes of cerebral palsy, the assistance available to them, home management options, and current research efforts (Donovan, Reddihough, Court, & Doyle, 1989). Many parents were reported to try to seek information, but were not granted access to it or were dissatisfied with what they found.

I find it necessary to point out that these articles were written at a time when public access to the internet was essentially non-existent and therefore these findings are probably less applicable today. As well, the quantitative methodology used to conduct the research in both articles was arguably inappropriate for the qualitative research questions being asked. Even so, some of these findings resonate with the current findings expressed earlier in regards to parents and dissemination materials. These two articles on parents of children with cerebral palsy are outdated and this area of research needs to be re-examined.

There are, however, some new efforts that are addressing this major gap in the literature. Various research teams at *CanChild* Centre for Childhood Disability Research at McMaster University have identified the need to move knowledge into the hands of parents and professionals (Law & Kertoy, 2004). The current research outcomes of *CanChild* projects such as the Move & PLAY study (to be described next) and subsequent dissemination materials are reviewed here to situate the reader with an example of how one group is moving forward. In addition, this information is critical to further justifying the need to advance knowledge transfer with parents of children with cerebral palsy.

Exemplar Materials: *CanChild* and the Move & PLAY study

What is cerebral palsy and CanChild? In the Definition and Classification of Cerebral Palsy April 2006 report, *cerebral palsy* [Appendix A] is defined as “a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain” (Rosenbaum, Paneth, Leviton, Goldstein & Bax, 2007, pg. 9). Aside from motor disorders, individuals with cerebral palsy may also present with “disturbances of sensation, perception, cognition, communication, and behaviour” (pg. 9). According to the Surveillance of Cerebral Palsy in Europe, this condition affects between 2 and 3 live births out of 1000 and is thought to be the most common cause of serious physical disability in childhood (cited in Morris, 2007). Mortality is significantly declining and the vast majority of individuals with cerebral palsy are living well into adulthood.

The long-term goals of rehabilitation for individuals with cerebral palsy are to reach full social participation and to optimize long-term health. Furthermore, three short-term fundamental goals of rehabilitation for children with cerebral palsy (considering the goals identified by the children and their families) are to 1) optimize motor function, 2) prevent the development of secondary conditions (i.e. secondary impairments) that impact life-long health, and 3) promote children’s participation in their daily lives (Bartlett et al.

2010; Chiarello, Palisano, Bartlett & Westcott McCoy, 2011). The *CanChild* Centre for Childhood Disability Research has focused many research endeavours into understanding how the daily lives of individuals with cerebral palsy can be optimized and how these goals can be reached.

Within *CanChild* exists a "Motor Growth Measures" stream of research, which has produced such research products as the *Gross Motor Function Measure (GMFM;* Russell et al., 2002), the *Gross Motor Function Classification System (GMFCS;* Palisano et al., 1997) and the *Motor Growth Curves (MGCs;* Rosenbaum et al., 2002). These measures aid rehabilitation therapists in tracking motor development over time and making judgments about a child's developmental trajectory (Hanna et al., 2008). Such information can aid parents in developing more realistic goals as well as clarifying various treatment outcomes. Research by Morris, Galuppi and Rosenbaum (2004) demonstrates the reliability of family reports for the *GMFCS* [Appendix A], suggesting that parents can use the GMFCS to effectively classify their children. Research summaries were created of these measures and subsequently used by Rivard (2010) and Russell (2010) and their colleagues in researching the effectiveness of knowledge brokers in increasing access, understanding and use of these materials.

The Move & PLAY study. Recently completed, the Move & PLAY Study (**Move**ment and **P**articipation in **L**ife **A**ctivities of **Y**oung Children with Cerebral Palsy) tested a conceptual model of multiple child, family and service influences affecting the motor development, self care and play of young children with cerebral palsy (Bartlett et al., 2010, see Figure 2-1 for a conceptual model). This research was influenced by previous *CanChild* research with the GMFM, GMFCS and MGCs. Bartlett and colleagues recruited 430 children between the ages of 18 months and 5 years, as well as their families, from across Canada and the United States. These children either had a primary diagnosis of cerebral palsy, or delayed motor development, muscle stiffness and difficulty with balance and moving. At the beginning of the one-year study, information was collected by therapist assessors of children's primary impairments (balance, distribution of involvement, quality of movement and spasticity), secondary impairments (muscle strength, range of motion and endurance), playfulness and gross motor function.

Parents provided information about self-care and daily life. Six months later, parents were interviewed over the phone about their family life and the services that their children received. One year after the study onset, therapist assessors once again measured participation, playfulness and gross motor function, and parents provided information on engagement in self-care and participation. The outcomes of this research have identified the determinants that are amenable to change and which ones are likely to remain stable throughout children's early lives. Knowing this distinction among determinants will have implications on realistic goal setting for families and therapists, as well as clarifying various targets for intervention in these young childrens' lives.

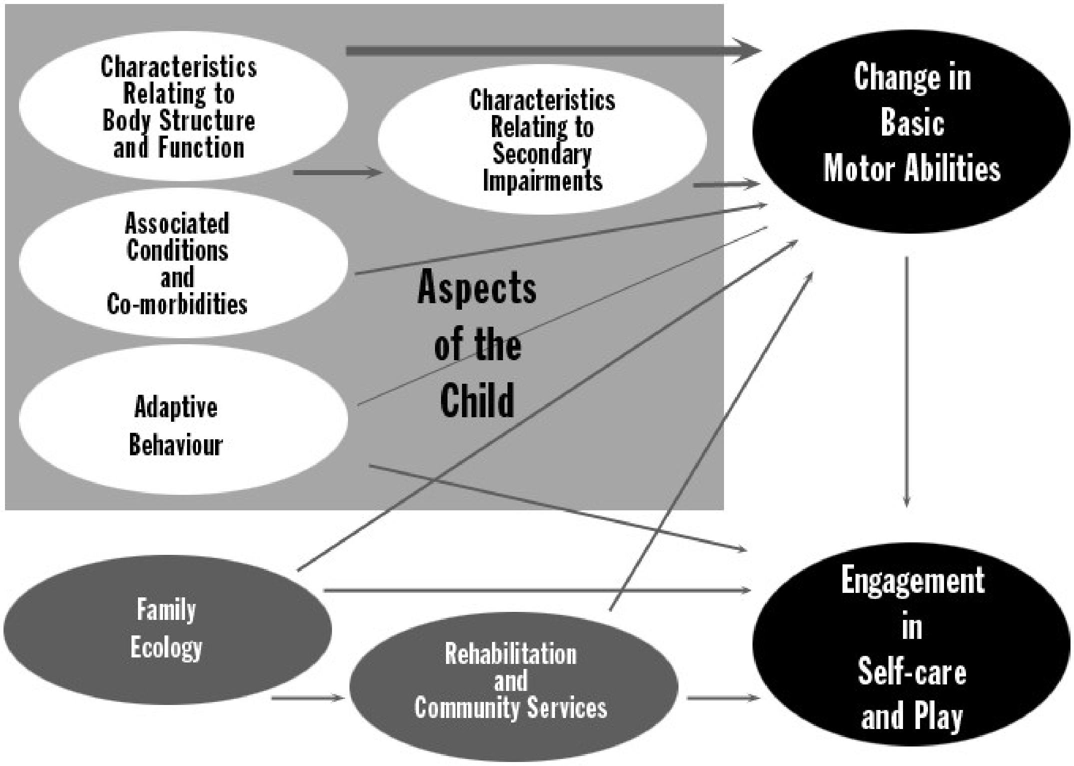

Figure 2-1. The conceptual model of the Move & PLAY study, used with permission. [See Appendix B for permission for use of figure]

Research summaries from the Move & PLAY study. Thirteen dissemination materials have been created from the Move & PLAY study (see Appendix C for examples of two dissemination pieces). The process of refinement of these materials involved parents of children with cerebral palsy and the therapists who work with them (both from within and outside of the study team), with the intention of creating relevant and valuable information for both parties (i.e., one dissemination piece is relevant for both parents and therapists). This collaboration is typical practice at *CanChild*, where "In Brief" documents contain language that is easily understandable, with recommendations for each specific target group. These completed summaries have been posted on the *CanChild* website for public viewing (http://canchild.ca/en/ourresearch/moveplay.asp). They have also been presented to parents and therapists at Thames Valley Children Centre in workshop formats. These dissemination pieces are the result of the "knowledge creation" phase of the knowledge-to-action process and were used as exemplars for the research presented in this thesis.

There are a number of reasons why dissemination materials from the Move & PLAY study have been chosen as exemplar materials. Other than the obvious fact that these are summaries of research conducted about young children with cerebral palsy and thus fit the description of "dissemination materials" for use in this thesis, these summaries have been developed and refined in a way that makes them suitable for parental use. The research conducted in the Move & PLAY study is not a randomized controlled trial design, which has implications in that it cannot establish the causality of rehabilitation services or interventions and outcomes which some deem to be of optimal importance. However, randomized controlled trials are not the most appropriate type of study to apply to broad physical therapy approaches applicable to young children with cerebral palsy. Randomized controlled studies are most feasible if the research question involves the effectiveness of an intervention that is uni-dimensional, discrete, non-individualized and controllable through a highly refined protocol (Bartlett, Macnab, MacArthur, Mandich, Magill-Evans, Young et al., 2006). Rehabilitation services, on the other hand, are typically individualized, complex and multidimensional. The Move & PLAY study employed an observational design involving a sufficiently large sample size which made use of (rather than eliminated) the natural inter-individual variability that is commonly associated with the individuals seen in rehabilitation practice (Bartlett et al., 2010). Thus, it serves as a suitable exemplar of appropriate dissemination materials for this research.

The information contained in these summaries has been tailored and modified to be of practical use for parents of young children with cerebral palsy. Parents have been involved in their creation, further ensuring that relevant material is being addressed. However, the content of these summaries may not be enough for parents to actually use them. Therefore, I decided to make use of a knowledge broker to help ensure that these summaries can be further tailored and presented to parents on a one-on-one basis and face-to-face with an information specialist. This decision is also consistent with the literature we presented in the literature review that discusses the methods in which parents wish to receive information.

Information Use with the Aid of a Knowledge Broker

The majority of research that exists on the effectiveness of a knowledge broker is in regards to health care professionals, not parents. For example, a randomized controlled trail conducted by Dobbins, Hanna, Ciliska, Manske, Cameron, Mercer et al. (2009) demonstrated that knowledge brokers were no more effective than tailored messaging in the incorporation of research evidence into public health policies and programs. Although this result could have implications for translating knowledge to public health departments, it speaks very little to the experience parents of children with chronic conditions have when accessing, understanding and using health information. Knowledge translation tends to be a context specific process that is multi-dimensional. Therefore, the experiences, contexts and daily lives of parents will differ substantially from public health departments. Hence, for the research reported in this thesis I wished to understand specifically how a knowledge broker is used when parents of young children with cerebral palsy use health information.

As mentioned before, how knowledge brokers interact with parents and whether this would be a viable decision to ensure that knowledge use could be monitored has been unexplored. However, based on what parents said about how they would like their information given to them, it seemed that a knowledge broker would be a reasonable individual to make accessible to parents. When looking at Graham et al.'s knowledge-to-action process (2006), it seemed that a knowledge broker could be effective in moving information through the first four stages of the action process (identifying problem/relevant information, adapting to local context, assess barriers to knowledge use, and selecting, tailoring and implementing interventions). Therefore, combining what is known about how parents want their health information given to them, what the role of a knowledge broker is and what the steps of the knowledge-to-action process demonstrate in regards to monitoring knowledge use, I decided to use a knowledge broker to help describe and understand how parents use health information.

What We Don't Know: How These Materials are Used

Following the literature review on parents of children with cerebral palsy (and other chronic conditions) and their use of dissemination materials, a gap in research became clear. Research to date indicated that parents wish to understand health information and has identified ways to facilitate better understanding. Parents' information needs have been examined, along with how they wish the knowledge to be disseminated to them. Research was done on where parents find their dissemination materials, as well as how they judge the quality of such materials. When and why they search for information has also been explored. However, the research on parents and dissemination materials to date has not examined *how* parents actually use dissemination materials (or health information) to make decisions. Therefore, the specific purpose of this study was to examine how parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy.

Conclusion

The literature review presented informed me as a researcher about how to focus the current study. Current research suggests that there is not only a literature gap surrounding how parents used health information, but that knowledge brokers have previously not been used to aid parents in the use of health information. The literature also informs the methodology and methods used in the data collection, analysis and interpretation in this study. The methods, methodology, ethics and my paradigmatic positioning are described in the next chapter.

Chapter Three - Methods

Introduction

In this chapter, I introduce the case study methodology and its paradigmatic fit with the research question. I also provide a brief description of myself as a researcher to contribute to the transparency as a researcher. The information on ethics is also presented. Finally, I end this chapter with a description of the selection of the units of analysis and data sources, questionnaire methods, interview methods, analysis strategies and methods used to ensure the quality and trustworthiness of the interpretations made from the data. This case study approach aimed to understand how parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy.

Methodology

This research was conducted using a qualitative case study design. The need for a *case study* [Appendix A] approach is desired when one wishes to understand complex social phenomena, as it allows researchers to retain the holistic and meaningful characteristics of real life events (Yin, 2003). Case studies are useful when the research question asks “how” or “why” something occurs (Yin, 1994). Case studies are also a useful strategy when the researcher has little or no control over the events studied and when the phenomenon to be explored is meant to be researched in its real life context (Yin, 1994). My research asks *how* information is used by parents in their real life contexts over which I have no control. Therefore, the decision to use a case study approach fits with the aims of a case study.

There are different goals of case studies (as defined by Yin, 2003): exploratory, descriptive or explanatory. My case study approach has aimed to describe “how” parents use health information and it therefore situated within the descriptive realm of case studies. Stake (1995) also has distinguished different levels of case studies. The case study in this research is described by Stake to be intrinsic, with the goal of understanding a particular phenomenon without looking for or suggesting that other cases may be similar. By adequately describing my particular case, issues of similarity between it and other cases can be discerned after the completion of this project.

Case studies can exist as single cases or as multiple cases. For this particular research project, I used a *single case design* [Appendix A]. A single case design is appropriate to use when it represents the critical case in testing a well formulated theory (Yin, 2003). Using the knowledge-to-action framework as a guide, I intended on moving parents through the steps leading up to "monitoring knowledge use" by providing them with a knowledge broker. Therefore, after applying and following the knowledge-to-action framework as my guiding theory, I intended to use my single case of parents of children with cerebral palsy to determine if monitoring knowledge use is possible and under what conditions. Another reason to apply a single case design is when the case is the representative or typical case (Yin, 2003). This study design is used when the objective is to capture the circumstances and conditions of an everyday situation. In this research, I aim to describe the typical case of knowledge use among parents of children with cerebral palsy.

The next distinction to make when applying a case study methodology is whether the case studied will be holistic or a series of *embedded units of analysis* [Appendix A]. The production of the research summaries is a context for the entire case, not a unit of analysis. In my research, the knowledge broker and each parent are considered separate units of analysis. Each of these units of analysis contributes to the overall understanding of how parents use health information with the aid of a knowledge broker. In embedded cases, the units of analysis are analyzed separately and then holistically, forming the goal of a description of how knowledge is used in this particular context by parents of children with cerebral palsy.

The case study approach can be strongly associated with qualitative research because of its emphasis on real situations and their inherent descriptive qualities (Lincoln & Guba, 1985). Therefore, it is an appropriate qualitative methodology to adopt. When using a qualitative research method, it is important to describe ones paradigmatic positioning, which is explored in the next section.

Paradigmatic Positioning

Research in the area of how research dissemination materials are used in daily life is sparse and would benefit greatly from qualitative, instead of quantitative, research. When engaging in qualitative research, it is good practice for the researcher to examine his or her beliefs about reality and how he or she views the world (also known as a *paradigm*, [Appendix A]). This research was approached from a *post-positivist* [Appendix A] paradigm. Adopting a post-positivist paradigm had implications for the ontological, epistemological and methodological positioning of this research, as well as the choice of methods.

Ontologically, a *critical realist* [Appendix A] lens was adopted. As such, I believe that a single reality exists for all humans, but it is imperfectly apprehensible because of the intractable nature of phenomena and life experiences (Lincoln & Guba, 1994). Instead, there is perceived to be multiple interpretations of one reality amongst the parents that participated in this research. Therefore, the results will be as close as possible to the reality they experience, but not a perfect representation.

The nature of the relationship between the parents and the researchers can be described using an *objectivist epistemology* [Appendix A]. This allowed me to develop an openness and willingness to listen fully to our informants in the three cases and represent their realities on knowledge use and sharing in this context as accurately as possible (Strauss & Corbin, 1998).

Yin (1994) states that case study research is not intended to be carried out with selective paradigms. Rather, researchers can examine for themselves what their particular paradigmatic positioning is and then apply it to the case study. This paradigm then helps define what the particular case study is, how it is carried out and what the results are (Jensen & Rodgers, 2001; Ragin, 1992). Clarity in defining the paradigmatic positioning of this study was provided by examining my experience and outlook as a researcher, which I describe next.

Self as Researcher

I am a masters candidate in Health and Rehabilitation Science in the field of Health Professional Education. I have an honours specialization bachelor's degree in Health Sciences, although I spent the first two years of my undergraduate career studying in the Faculty of Science in Biology. My research interests lie in knowledge translation and health communication, especially as it relates to pediatrics.

My experience with knowledge translation and health communication activities was marginal when beginning this research project. Other than participating in student council positions promoting health and wellness to peers, I had no experience in giving out health information prior to this study. However, before conducting this research I was involved in presenting three workshops at a rehabilitation centre on the Move & PLAY study. This was my first experience disseminating health-related information to an audience. I also participated in preparing the PowerPoint presentation for these workshops and raising awareness for them through posters around the centre. My beliefs are that health information and research should be openly accessible to everyone and that there should be an active participation by multiple players (including researchers and health care professionals) to give this information to parents and other patients. I believe that such health information can influence the way that individuals make decisions about their health and ultimately affect their wellbeing.

I have had experience working with parents of children as a summer school teacher and camp counsellor. I have experienced their desire for information about their children and interest in their children's health and wellbeing. I have always been curious about how they make decisions in relation to their child's care and whether or not research-based information could have a role in this process. I have worked directly with children with autism, but I had never been exposed to children with cerebral palsy. I had very little connection with these children's parents and had no preconceived notion of how such parents make decisions about the care their children receive.

These are the experiences and thoughts with which I came into this research. Because I approached this study through a post-positivist paradigm, I was committed to bracketing myself out of the interpretations of the research. Therefore, this openness of my opinions and viewpoints are to provide the reader with any backdrop that may be needed to determine whether or not I was successful in interpreting the research clearly from the parents and not tarnishing it with my own beliefs.

Ethics

Appropriate ethical standards for research involving humans were followed in this study, as outlined by the Tri council policy statement (CIHR, NSERC & SSHRC, 2010). Ethics approval was obtained from The University of Western Ontario on October 31, 2011 (Appendix D) and from Thames Valley Children's Centre on September 26, 2011.

Methods to Create Contextual Backdrop: Production of the Research Summaries

The production of the Move & PLAY summaries acts as a contextual backdrop to the units of analysis in this case study. Information on how the summaries were produced is needed to complement the findings on how or if parents used them and how to monitor knowledge use. There are different aspects of the production of the Move & PLAY summaries that need to be examined to complete this context. Firstly, the process of their development and the intentions for their use by parents needs to be understood. This is achieved through an in-depth interview with the principal investigator of the Move & PLAY study (see Appendix E for the interview guide). The second source that is needed to complete the context is the actual summaries (see Appendix C for examples of the summaries). Finally, the PowerPoint slides from the workshop presenting these summaries to the parents and therapists at the centre are needed (see Appendix F for these presentation slides). Understanding how and why these summaries were produced, what the finished products look like and how they were delivered to their intended audience provides the contextual backdrop to my research on how parents use information like this (and specifically if these summaries were used by parents).

Selection of Units of Analysis and Data Sources

The selection of cases for this research was based on the research question: how do parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy? This process of selecting the cases for this research was a very open experience (as suggested by Yin, 2003). The first unit of analysis in this embedded case is the knowledge broker. Secondly, based on my research question, I decided that each parent participant would be a separate unit of analysis in this case study. I wanted to be able to analyze each parent's unique embedded unit before looking at the overarching case. When considering parents and the knowledge broker as my units of analysis, and coupling them with the contextual backdrop of the production of the research summaries, I was studying all the aspects mentioned in my research question – health information (research summaries), knowledge broker and potential knowledge user (parents). My research question does not extend beyond these units, although there may be others involved in this process (i.e. therapists, administrators, family members). Below, I present how each unit of analysis (knowledge broker and parents) was selected and the data sources used from these units of analysis.

Unit of analysis: Knowledge broker. The first unit of analysis I discuss in this research project is the knowledge broker. The knowledge broker was chosen based on convenience, as well as by recommendation from the gatekeepers at the rehabilitation centre at which the knowledge broker worked. The gatekeepers for this project were an occupational therapist as well as the Director of Early Childhood, School Age and Adolescent Services at the rehabilitation centre. This knowledge broker works at the same centre that parent participants receive services for their children. Because the knowledge broker was aiding me in presenting the workshops at the centre, she is considered to be a collaborator for this research as well as a unit of analysis.
Three data sources were used in the knowledge broker unit of analysis: a Supports and Barriers Questionnaire (Appendix G), a Weekly Log Sheet (Appendix H) and an in-depth interview (Appendix I).

Units of analysis: Parents. The second units of analysis in this research project are the parents of young children with cerebral palsy. Each parent is considered a separate unit of analysis and was analysed as such. A convenience sample of parents of young children with cerebral palsy was collected from two workshops at the rehabilitation centre. Workshops included both a parent workshop and a therapist workshop.

Consistent with the Move & PLAY study, parents of children between the ages of 18 months to 5 years were sampled. As well, this sample was not restricted to just parents, as I acknowledge that the primary caregiver of children could mean otherwise in certain familial situations (i.e., a grandparent). The parents/caregivers that were included in this study must have attended the introductory workshop or had access to the Move & PLAY dissemination materials as well as speak and understand English. This requirement of speaking English was because we did not have a translator available for the interviews. As well, we needed to ensure that all parents had access to our "exemplar" materials prior to engaging in this research project.

Parents sampled through the parent workshop were given PowerPoint slides from the presentation and a package of the Move & PLAY dissemination materials were made available to parents. For the parent workshop, these were given directly to the parents who attended. The knowledge broker kept the list of contact information of parents who attended the workshops and got in touch with parents a week after the workshops, inquiring about potential interest in participating in the research project.

In the therapist workshop, PowerPoint slides from the workshop were distributed to the therapists. In some cases, therapists gave the research team contact information for interested parents. For parents sampled from both the therapist and parent workshops, I made contact with interested parents by phone to request a mailing address to send letters of information and consent (Appendix J) as well as Move & PLAY dissemination materials to them if they had not already received them (examples contained in Appendix C). Included in this package was a hand-written note explaining the purpose of the materials included, as well as a pre-addressed and stamped envelope to return the signed consent back to the research team, should the parents decide to participate. The research team was available for questions regarding the study up until the start of the knowledge broker phase. Signed consent (Appendix J) was obtained from parents before putting them in touch with the knowledge broker in this study.

The data sources from parents in this research include a demographic questionnaire (Appendix K), GMFCS questionnaires (Appendix L) and in-depth interviews (Appendix M).

Data Collection Methods

As mentioned in the units of analysis, multiple sources of information were used to gather information from participants in this research project. The two main methods I used for data collection were questionnaires and in-depth interviews. Each questionnaire that was used is described below, followed by a description of the in-depth interview techniques used.

Supports and Barriers Questionnaire. The Supports and Barriers Questionnaire (Appendix G) was completed to assess the perceived supports and barriers in the centre to implementing research and health information place at the centre where the knowledge broker worked. This questionnaire was adapted from Rivard et al.'s (2010) work on the activities and experiences of physical therapist knowledge brokers. The data from this questionnaire was meant to complement the contextual description of the centre. The Supports and Barriers questionnaire contains a ten-point continuous rating scale from -5 (a barrier) to +5 (a support). There are four sections on this questionnaire to be rated using this scale: organizational structure of the centre, organizational resources, health professionals at the centre and parents or families at the centre. There is also room for the respondents to give examples of supports, barriers and suggestions for each section. The questionnaire was completed by both the knowledge broker and the occupational therapist who were acting as gatekeepers for this project.

Knowledge Broker Weekly Log. The knowledge broker was asked to fill out a weekly log sheet to document her time and interaction with parents (see Appendix H for the Weekly Log sheet). This weekly log was adapted from Rivard et al.'s (2010) work on the activities and experiences of physical therapist knowledge brokers. Parents had between 1.5 to 2 months to interact with the knowledge broker. This log sheet outlining the interaction during these months was aimed to be used as a reference in the interviews with parents, as well as the subsequent interview with the knowledge broker.

Demographic questionnaire. Once I received signed and informed consent from all interested parents, and they had time to review the Move & PLAY dissemination materials, they were asked to fill out a demographic questionnaire (see Appendix K). I collected information about each parent's age, gender, marital status, relationship to child, highest level of education attained, employment status, child's date of birth, his or her primary diagnosis, the age of first diagnosis, familial constellation and information about their use of research knowledge in daily life. The information from this questionnaire helped me in creating an accurate contextual description of this research study, which is described at the beginning of the results chapter.

GMFCS questionnaire. I also asked each parent to fill out one of two age appropriate GMFCS surveys which informed me of their child's GFMCS level (see Appendix L). The GMFCS survey was created by Palisano et al. (1997) and has shown to have a high validity through nominal group technique and Delphi method testing. It is also shown to have an inter-rater reliability of Kappa = 0.55 for children under 2 years, and 0.75 for children 2-12 years. As well, the GMFCS survey has a test-retest reliability of G = 0.79 (Wood & Rosenbaum, 2000). The information from the GMFCS questionnaire also helped me in creating an accurate contextual description of this research study, which is described at the beginning of the results chapter.

Semi-structured in-depth interviews. Interviews are viewed as essential sources of case study information (Yin, 2003). All the parent participants in our study and our knowledge broker were interviewed, along with the principal investigator of the Move & PLAY study. The format of the interview was semi-structured so that it could be guided, but still allowed for elaboration and direction-change by the interviewee. Although a constant line of inquiry for each interview was pursued, the actual stream of questions was fluid and allowed for a conversational manner between interviewer and interviewee (Rubin & Rubin, 1995). The content for the researcher interview was decided in a dialogic manner with a member of my committee. I determined the content for both the knowledge broker interview and parent interviews. I conducted each interview individually and they were audio-taped for transcription and analysis. In-depth interviews allowed us to focus on one individual's experience of how knowledge is used, giving us the depth needed to produce a well-rounded description of such knowledge use.

Data Management

The data from the parents' demographic questionnaires and GMFCS surveys was extracted and put in chart form to keep track of the data. Due to the sensitive nature of this data, it was anonymized and kept in a computer folder on my computer that is password protected. The audio taped data from all in-depth interviews were transcribed and anonymized. Recorded data were then destroyed after transcription to avoid potential voice identification. The transcript was coded using unique numeric identifiers and the master list was held in a separate secure cabinet from the data.

Data Analysis Methods

Narrative description of each unit of analysis. The overarching approach to analyzing my data was through a qualitative and iterative process. According to Yin (1994), there are two general analytic strategies when conducting case studies: theoretical propositions and case descriptions. I reviewed multiple sources of data for each unit of analysis in this case study to develop case descriptions of each embedded unit of analysis. I created this narrative description for each case to understand the general characteristics and relations of each unit (Yin, 1994). Specifically, I aimed to produce a narrative that described how the knowledge broker described knowledge brokering in the centre and how parents use health information. The information on the Move & PLAY summaries was not analyzed, it was only presented to form a context. I used visual mapping methods as part of my analysis to understand the complex relationships these individuals have with health information and the social processes inherent in their use of health information (Charmaz, 2003).

Analysis of the knowledge broker. As mentioned in the previous section, the sources of data that informed the knowledge broker unit of analysis were the Supports and Barriers Questionnaire (Appendix G), the Knowledge Broker Weekly Log (Appendix H) and the semi-structured in-depth interview (Appendix I). The results of the Supports and Barriers Questionnaire and the Knowledge Broker weekly log, along with the description of the knowledge broker and her context, were combined to create an introduction into knowledge brokering at the centre. The interview data collected from the knowledge broker, combined with this introduction, was used to create a narrative description of what knowledge brokering looks like in this centre. Two diagrams were created to help visualize the flow of knowledge in the centre and to exemplify what the knowledge broker was describing in her interview.

Analysis of Parents. Each parent was treated as a separate unit of analysis in this case study. This is because I aimed to provide an in-depth description of each parent's knowledge use. To provide this depth, I wanted to have a complete narrative of each parent's interactions with health information before combining them into the overall case. The sources of data that informed each parent's narrative were the demographic questionnaires (Appendix K), GMFCS questionnaires (Appendix L) and the semi-structured in-depth interviews (Appendix M). I used these sources to create diagrams outlining the sources of parent's health information, the management of that health information and the uses and outcomes of the health information. This was consistent across all parent groups. I also used these sources of data to describe the parent's opinions on knowledge brokers and the Move & PLAY summaries.

Interpretation of each unit of analysis and overarching case. After providing a narrative description and diagrams for each unit of analysis, I engaged in a dialogic review process with my master's thesis committee to inform my interpretation of each unit of analysis and the overarching case. As prescribed by Yin (1994), I made sure these interpretations relied on all relevant evidence and that the most significant issue of the study was addressed. A second diagram was produced to depict a deeper interpretation of each unit of analysis.

My committee members independently reviewed the transcripts from each parent and the knowledge broker; I then held a peer-review of my initial and then in-depth interpretations. The peer-review of the initial analysis of each unit was to ensure that it was clear, consistent and coherent with the data and as comprehensive as possible. The peer-review of the in-depth interpretations was to identify patters of information use. A dialogic process was used in which I shared my interpretations and the advisory committee members shared their insights. This was an open process and each member gave reasons for their interpretation of the flow of information. Questions were asked from the committee members for clarity and substantiation of how I arrived at an interpretation based on the different sources of data. The reason why I presented an interpretation after each narrative description was that it enabled a deeper understanding of the concepts in each person's journey in health information use. I subsequently used these interpretations in part of the preparation of a provisional model for monitoring knowledge use and to answer the overall research question.

Finally, all units of analysis were combined to inform the overall case of how parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy. This was achieved by what Yin calls "explanation building" (1994). Explanation building is when, through a series of iterations, underlying explanations are applied to the patterns apparent in the narrative description of a case (Yin, 2003). It is most frequently associated with exploratory cases, but can be applied to descriptive cases as well (Yin, 2003). My process is considered to be iterative because of the interpretation stage that occurred for each unit of analysis before bridging all of them to form the overarching case. I was able to suggest underlying themes for each narrative in each interpretation. These themes could then be analyzed again to contribute to an overall explanation in regards to the entire case. I also brought in relevant literature to this step to inform my interpretations and proposed explanations.

Quality and Trustworthiness Criteria

There are two forms of quality criteria that were addressed in this research: paradigm-transcendent trustworthiness criteria (as outlined by Morrow, 2005) and naturalist criteria for determining rigour (Lincoln & Guba, 1985). In regards to case studies, Yin recommends a set of quality criteria related to the empirical grounding of a research study. These criteria are construct validity, external validity and reliability. However, considering the qualitative nature of this research and the quantitative underpinnings of Yin's quality criteria, I have decided to use the parallel criteria suggested by Lincoln and Guba. According to Lincoln and Guba (1985), their naturalistic criteria for determining rigour are meant to be equivalent to the typical quantitative criteria that Yin has suggested. Lincoln and Guba's quality criteria are: credibility (instead of internal validity), transferability (instead of external validity), dependability (instead of reliability) and confirmability (instead of objectivity). I discuss my adherence to dependability and transferability because Morrow's quality criteria address confirmability (Morrow's "subjectivity and reflexivity") and credibility (Morrow's "adequacy of interpretation").

Lincoln and Guba's (1985) criterion of *dependability* was adhered to by the provision of the step-by-step process undertook by my master's committee and me to analyze the data. By providing a transparent and detailed summary of how analysis was conducted provides an audit trail to help ensure dependability. *Transferability* was adhered to by providing a thick description of the narratives of each unit of analysis. Multiple data sources were used in the construction of these narratives to ensure an ample and deep description of each person's context in regards to using health information. Morrow's (2005) trustworthiness criteria include social validity, subjectivity and reflexivity, adequacy of data and adequacy of interpretation. *Social validity* is the importance of the research to the greater social community, that is, the end users. By involving parents and a knowledge broker in this research (i.e., anticipated end users), I elicited a context that resonates with our end users.

The research team used *subjectivity and reflexivity* to interpret and manage our own perceptions, values and feelings of what was being researched. Our goal to remain unbiased meant that our own personal values were meant to be absent from the interpretation of the research. This would not have been possible without the ability to acknowledge the possibility for subjectivity and try to remain objective by being reflexive and recognizing our own personal biases so we could identify and remove them if they appear in the interpretation. This was achieved through my dialogic data review sessions with my master's committee members. *Adequacy of data* was achieved by using multiple forms of data collection through the initial array of surveys and in-depth interviews. Lastly, the criterion of *adequacy of interpretation* is concerned with the ability to accurately interpret the data. The research team adopted more of a "witness" role in the research than an "author" role, providing ample direct quotations in this paper to support the grounding of our interpretation in the words of our participants. We also discussed emergent themes and interpretations of the data together as a research team, to keep each other as focused on the actual data as possible.

Conclusion

This research was conducted using a qualitative case study approach, modeling the methodology after Yin (2003). This case study is considered a single case approach, using embedded units of analysis. The paradigmatic positioning of this case study project is post-positivist. All necessary ethics approvals were obtained before the start of this project. The study participants include a knowledge broker (recommended to us) and parents (recruited through a convenience approach). The knowledge broker completed a supports and barriers questionnaire and helped the researchers conduct the workshops. Parents were interviewed and asked to complete both a demographic questionnaire and GMFCS survey. They were then given health information from the Move & PLAY study and provided with access to a knowledge broker. The knowledge broker was interviewed about this experience at the end of the interaction and was asked to fill out a weekly log sheet. The researcher also participated in an in-depth interview to provide a context of the production of the Move & PLAY summaries. All data were audio taped, transcribed and went through a series of analytic iterations both on an individual and didactical group basis. The quality criteria that we used to ensure the trustworthiness of our research was Lincoln and Guba's (1985) naturalistic criteria for determining rigour and Morrow's (2005) paradigmatic transcendent criteria. In the next chapter, I present the results of these methods and methodology and the interpretations of this research.

Chapter Four – Findings

Introduction

In the findings section of this thesis, I begin by giving the contextual background of the development of the research summaries from the interview with the principal investigator of the Move & PLAY study. This context sets the stage to present the data and themes that emerged as well as my interpretation of each interview with the knowledge broker and all three parents. The knowledge broker and each parent are the embedded units of this case study. I also present the overarching case; that is, how these embedded units came together to inform the research question *how do parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy?*

Study Background

Introduction. This section of the findings chapter serves to outline the development process of the Move & PLAY summaries and their intended use that informed my research. The sources of data that have informed this study background included the summaries, my role in the development of these summaries as a research assistant and the semi-structured interview with the principal investigator of the Move & PLAY study.

The principal investigator is a physical therapist and has worked with *CanChild* Centre for Childhood Disability Research at McMaster University for a number of years. I have been involved in the creation of the Move & PLAY research summaries, and therefore had some prior knowledge of the process when conducting this interview to inform the data collection process and provide insight into the project. The principal investigator's research with *CanChild* prior to the Move & PLAY study was mostly examining and describing the trajectories in motor development of children with cerebral palsy. The principal investigator indicated that she was interested in looking at the bigger picture of motor development; the multiple determinants that affected this development. She and one of her colleagues began by creating a conceptual model of some of the determinants that contribute to motor development in children with cerebral palsy.

Through connections at *CanChild* and conferences, the principal investigator was soon joined by other investigators interested in adding other determinants and outcomes to the model. As this model grew, encapsulating these multiple factors, the Move & PLAY study was formed.

Currently, funding for the Move & PLAY study has ceased, but the dissemination process has not. The research team is still working on research papers from the study in addition to the 12 research summaries. Right now, most of the dissemination is taking the form of peer review papers and scientific conferences, and is expected to continue for the next year or so. The part of the Move & PLAY study that my research is concerned with are the 12 summaries, which were provided to the parent participants and knowledge broker and presented at the centre through workshops. The next section explains what these summaries are, why they were created, how they were created, and what the Move & PLAY research team's intentions were for these summaries.

Move & PLAY research summaries. The decision to create summaries from the primary research conducted through the Move & PLAY study was a relatively easy decision for the principal investigator and her research team to make. Aside from creating peer review papers and conference presentations, members of *CanChild* also feel an obligation to create documents meant to inform study participants, service providers and funding agencies. This obligation is enacted by creating research summaries (also known as *Keeping Current*, *Project Reports,* and *In Brief* documents). Although this is common practice at *CanChild*, the principal investigator also has a history of creating research summaries throughout her other research endeavors.

Summaries from the Move & PLAY study were created by taking the usual format for creating research summaries from *CanChild* and adding on various steps. The addition of steps (mostly involvement of end users) was made possible by receiving an "End of Grant Knowledge Translation" supplemental grant from the Canadian Institutes of Health Research. In "end of grant knowledge translation", the researcher develops and implements a plan for making knowledge users aware of the findings from a research project.

The starting point for creating these research summaries was using the guidance of the *Knowledge Transfer Tip Sheet: Written Communication of Research Findings* (Law & Kertoy, 2004). This tip sheet was created by an occupational therapist and a speech language pathologist affiliated with *CanChild* and is used by the organization whenever creating research summaries. The Move & PLAY study followed the guidelines from the *In Brief* section on the tip sheet. The main points that were followed were:

- Use language that is easy to understand
- Include target recommendations for each group (i.e. parents and service providers)
- Provide one paper for both audiences
- Use questions for headings

Typically at *CanChild,* the research investigators would prepare the summaries, and pass them through an extensive review process at *CanChild* involving review from the knowledge translation committee. The summaries would then be sent to members of the target audience for review. The principal investigator and the rest of the research team wanted to make the link between the target audience and the research team more apparent.

The Move & PLAY research team's first step in the process to achieve this was to have the project co-coordinator for the Move & PLAY study create the initial summaries. This project co-coordinator has over 30 years' experience working in research and developing summaries for parents. The second step was to have multiple iterations with the research team. After these iterations, the third step was to have two parent consultants assess the materials. These parents were from Canada and the United States, both had a child with cerebral palsy, and are well-educated. Ten champion assessors were also asked to review materials. These assessors were therapists who were involved in data collection in the Move & PLAY study who were recommended by their peers for going over and above what was expected of them during the research. There was a teleconference among the parent consultants, champion assessors and research team to discuss the clarity and understanding of the research summaries. These summaries were refined again. The fourth step after this teleconference was a review of the materials with regular assessors which was completed through survey monkey. After all this feedback, the summaries were further refined. The fifth step was to conduct two focus groups with therapists and parents not involved in the study. These focus groups were conducted at the centre where my research took place. These focus groups yielded minor revisions. This final step concluded the revision period with the research summaries. These summaries were then translated to French and are currently posted on the *CanChild* website.

The research team's intentions for these summaries were to give back to parents and therapists, especially those who participated in the study. I have created Figure 4-1 to describe this intention. As a result, the summaries were sent to everyone who had participated. The main goal of creating these summaries was to increase understanding about the study and increasing awareness of the multiple determinants of a range of child outcomes that need to be considered when planning care. The Move & PLAY study was not meant to provide specific treatment suggestions or "*magic bullets on the proper intervention or a cure*", as the principal investigator articulates. Also, these materials are intended to act as "*boundary objects*" between parents and therapists (indicated as the double sided arrow in Figure 4-1). What the principal investigator means by this is that because there is one piece for both groups, they will both have access to the same information and have the same reference point on which to discuss.

The principal investigator anticipated that parents would use these summaries in a variety of ways, depending on their relationship with health information in general, and where they are specifically with their children in regards to milestones and transitions. Parents could either use these as a resource to reference at a later point when it is relevant in their lives or as a talking point with therapists in regards to goals for their children's development. On the other hand, parents may not use them at all and instead wait for their therapists to discuss their content. All of these possibilities are presented in the "parent" box on Figure 4-1.

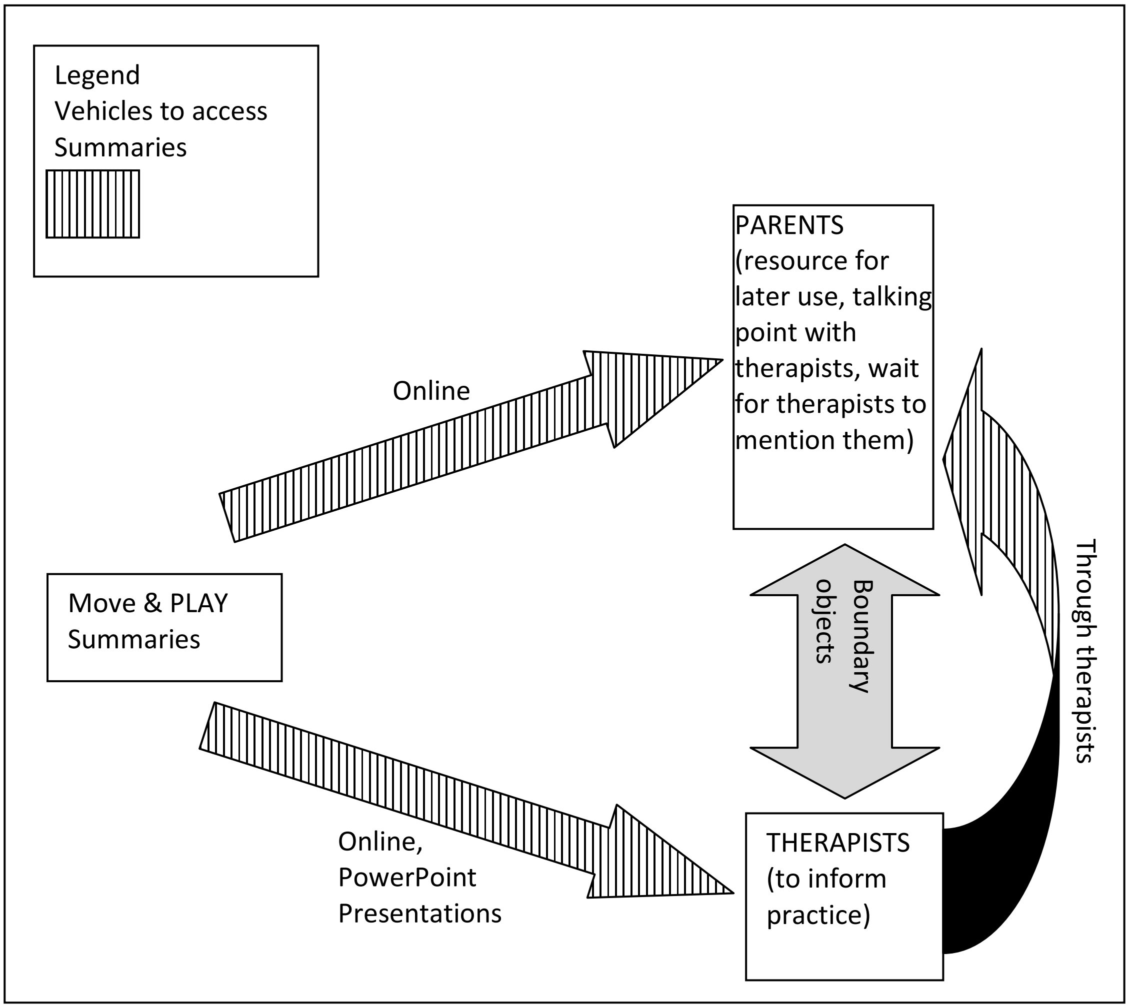

Figure 4-1 Intended use of Move & PLAY summaries by principal investigator

Parent involvement in Move & PLAY study. As mentioned above, two parent consultants helped to refine the summaries. In addition to this, these parents also:

- Reviewed the Move & PLAY grant before it was submitted,
- helped refine the conceptual model of the study,
- reviewed training materials to help ensure relevance to parents,
- trained interviewers in sensitivity when interviewing parents of children with cerebral palsy,
- and produced commentaries about family-centered care and their involvement in this research in scientific journals.

In addition to the two parent consultants, parents were also included in this study through the parent focus group at the end of the study for the final refinement of materials.

Packaging and access to summaries. These summaries were intended to be primarily accessed online or through therapists. In Figure 4-1, there are two arrows leading the summaries to the parents: online, or through the therapists. To this point, they are still being presented by the Move & PLAY research team at workshops and conferences to spread awareness, and posted to the *CanChild* website so they can be downloaded. In addition to hard copies of the summaries, PowerPoint presentations have been created for assessors who participated in the study to present them at their centres as in-services. For therapists who were not involved in the study, PowerPoint presentations are being created so they can present them as well (demonstrated by the line from the summaries to the therapists in Figure 4-1). The principal investigator acknowledges the complexity of doing more than providing access in regards to uptake. She gave examples of research that was completed provided access to years ago that is only currently being used and questioned.

According to the principal investigator, there is more than making these summaries accessible to ensure their use. How this information is packaged is critical, and more information isn't necessarily better. She said that "*they are just scratching the surface on how to give this information to parents*". In regards to disseminating to therapists, she says that "*since therapists are busy, they had to find a way to package information to serve them*". The issue of the level of interaction that readers have with the material is another issue. There are no cases in these summaries, as there are in other Move & PLAY dissemination materials. According to the principal investigator, "*this information needs to be accessible in different levels, for different reasons and at different times*".

Evaluation of Summaries. Evaluation of the effectiveness and quality of these summaries was built into the refinement process. The review of the summaries at multiple levels acted as an evaluation. In addition to this, the research team is attempting to provide users of the electronically posted summaries an interactive discussion board to share their experiences. Contact information was also provided at the bottom of each summary if readers wished for more information or clarification.

Involvement of the centre in the Move & PLAY study. The involvement of the rehabilitation centre (hereafter referred to as 'the centre') in the Move & PLAY study was minimal. At the time the Move & PLAY study began, the centre was already involved with another *CanChild* project and did not participate in the Move & PLAY study. Centre involvement began during the final focus groups during the refinement of the research summaries.

The main reason that the centre was chosen to participate in my research was convenience, because the centre was local. The centre is a research intensive child development centre, with a dedicated research department and active research program for over 25 years. The key leadership of the centre has supported research, even during tough economical times when research endeavors wouldn't typically be supported. This centre has a culture of wanting to be evidence-based, supporting research activities, and supporting the uptake of research, thus providing what might be perceived as an optimal site for my work.

Conclusion. All of the data sources relating to the contextual backdrop of this study provide a good insight into the intentional preparation of the Move & PLAY summaries and an integrated approach to knowledge translation development. In the next section, I present the first unit of analysis in this embedded case analysis looking at how parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy.

The Knowledge Broker

Introduction. This section describes the knowledge broker who was involved in my study; she will be referred to as "Susan". This section begins by giving a background of the centre at which the knowledge broker works and that the parents all visit. The decision to use this centre and this particular person as a knowledge broker are also explained. To further strengthen the description of this context, a Supports and Barriers questionnaire was filled out. The results of this questionnaire are presented in this section, along with the results of the Knowledge Broker Weekly log sheet. After presenting this data, I explain how Susan describes knowledge brokering in this centre. Finally, I provide an interpretation that further examines knowledge brokering in this setting.

Description of centre and knowledge broker. The centre is a large regional rehabilitation centre for children and young adults with physical disabilities, communication disorders, developmental delays and autism spectrum disorders, living primarily in Ontario. The centre serves more than 6,900 children and their families, ranging from newborns to young adults, every year. Some of the disabilities that are serviced by this centre include birth defects, cerebral palsy, cleft lip & palate, developmental delay, orthopaedic conditions, brain injury, spina bifida, speech & language disorders, and autism spectrum disorders. Some of the services and therapies that are provided include specialized medical clinics, physiotherapy, occupational therapy, intensive behavioural intervention, psycho/social services, communication development, augmentative communication, seating and mobility, leisure, recreation and fitness. This centre's mission is to provide the aforementioned services and therapies to children and youth while focusing on the strengths of these individuals and their families at home, school, workplaces and in the community. As a centre, the staff is committed to pursuing research, education and advocacy, as well as partnering in a local and regional system of services.

Working with this centre was a natural decision in this research process given their dedication to both the families of children who use their services, along with their determination to contribute to research activities in and around the centre. A number of the centre's guiding principles outline providing meaningful information to families to answer their concerns and questions that also supports family decision making. The centre encourages a collaborative working relationship between their health care providers and families, which further enhances this "information sharing" attitude of the centre. Recent organizational restructuring to create the new CEFD (Communication, Education and Fund Development) program is tangible evidence of the centre's dedication to information mobilization and sharing. This new program (initiated in early 2011) brings together the Resource Centre Co-ordinator, Education & Program Co-ordinator, Community Relations and Computer Support under one umbrella, so information sharing can be a more streamlined process.

In addition to organizational structure and mission statements, the centre has created a number of vehicles for the exchange of information in the centre. *Facts To Go* and *Focus On...* are free, brief, easy-to-read summaries of research findings and topics of interest published and distributed by the centre. The Family Link Newsletter is full of client stories and information about special events, activities, programs, workshops and research. Opportunities to Participate online brochure has a little bit of everything: Arts, Aquatics, Play and Learning, Sports, Recreation and Specialty Programs to name a few. These resources can be accessed in-person at the centre or through the centre's website. The website is a major information hub, providing a comprehensive description of the centre and its services.

There is also information about the centre's resource centre on the website. The resource centre is located in the main atrium of the centre and is home to a number of helpful resources for parents. The resource centre has books, magazines, DVDs and brochures, information packages to meet parents' individual needs, a disability news bulletin board, a computer and colour printer for public use, a link to community information sources and access to the latest journal articles. On the centre's website under the resource centre link, there is information for parents in regards to how to access online journal articles and tips to improve online searching. The co-ordinator of the resource centre is also the knowledge broker for this research project (see Appendix N for a description of her job duties at the centre).

Supports and barriers questionnaire. At the beginning of this research, Susan and an occupational therapist from the centre were asked to fill out a Supports and Barriers questionnaire to assess the perceived supports and barriers in the centre to implementing research and health information (see Appendix G for the questionnaire). The reason Susan and the occupational therapist filled out this questionnaire was that they were both gatekeepers in this study. They worked with the research team supporting my master's work since the inception of this project, and were instrumental in integrating my research study into the centre. Because they were helping to distribute information about this study's workshops and research within this centre, we wanted their opinions on the Support and Barriers that they currently face within the centre to better tailor our research and to initiate discussion. They filled out the questionnaire together and then returned it to me.

The Supports and Barriers questionnaire (Appendix G) contains a ten-point continuous rating scale from -5 (a barrier) to +5 (a support). There are four sections on this questionnaire to be rated using this scale. Three out of the four categories were rated as a 4 on the scale (meaning almost a full support), which were: organizational resources, health professionals at the centre and parents or families at the centre. The supports that were listed across-categories were:

- Parents and families highly respecting therapists' help,
- having programs available like the resource center and the research department
- and having publications like Focus On (easy reading summaries of research), Family Link (newsletter for parents), OTP (opportunities to participate for children and youth recreation, therapy groups, family support and education).

The least supportive aspect of the centre, as ranked as a three on the scale, was the organizational structure of the centre. Some of the barriers listed were "*being a large centre with many departments with different organizational needs*" and subsequently "*inconsistent information sharing*". However, the "*new CEFD (Communication, Education and Fund Development) program brings together Resource Centre coordinator, Education & Program Coordinator, Community Relations and Computer Support under one umbrella*" at the centre. The aim of this program is to have *"one person would be responsible for co-ordinating all the dissemination materials"*, which was also the strategy proposed in the questionnaire to overcome this barrier. Other barriers across-categories noted in the questionnaire were:

- Financial constraints,
- time constraints in finding and tailoring health information,

- information not in an easy-to-read format; information is usually tailored to clinicians,
- difficulty in gathering information from different departments in the centre,
- and lack of a single person to oversee the collection and tailoring of health information.

The knowledge broker weekly log. Susan was asked to fill out details about her interaction with parents in a knowledge broker log (see Appendix H). However, in the month and a half that parents had access to a knowledge broker, there was no contact made. Therefore, the knowledge broker log was not filled out, and has not been used as a source of data, other than to accentuate the lack of connection between the knowledge broker and parents.

The Knowledge Broker Interview – Narrative

In the previous section, I provided a context of the centre in which Susan works and where the parents in this study receive their services. Within this context, there is a pattern of information flow and use between Susan, therapists, and the parent-clients who use the centre. To begin this section on the description of knowledge brokering at the centre as according to Susan, I present Figure 4-2. This figure was created using Susan's interview to provide a visual representation of knowledge flow at the centre between Susan, therapist and clients. The components of this figure will be explored in this section.

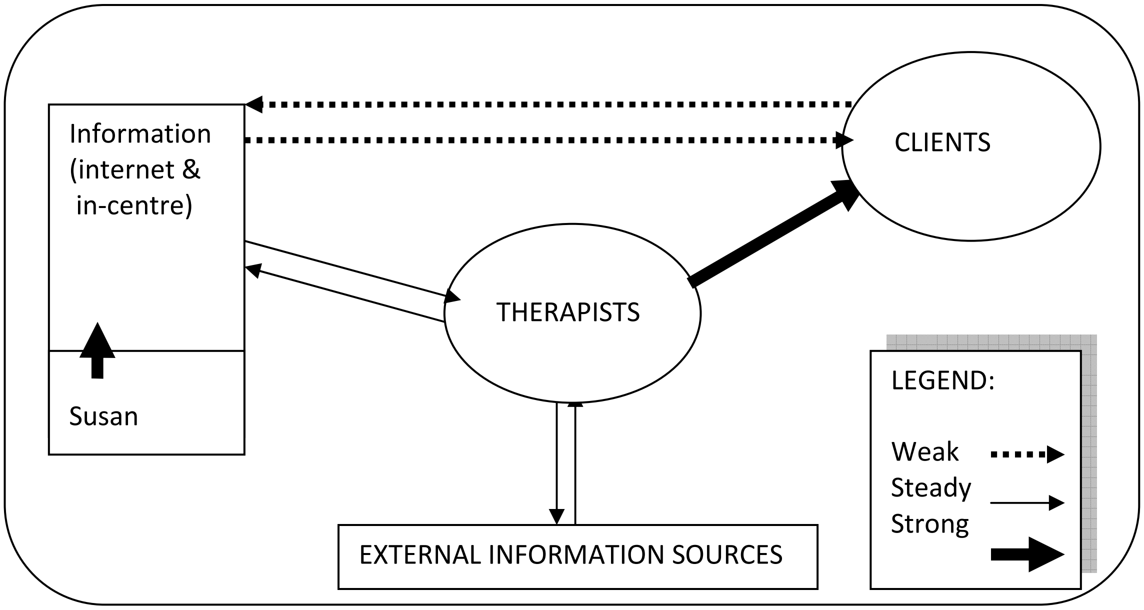

Figure 4-2. Current Information Flow and Knowledge Brokering at the Centre.

Information flow at the centre: Lines and arrows on the diagram. Information flow at the centre is represented by lines and arrows in Figure 4-2. The arrows show directionality on where information is going, as perceived by Susan. In addition to the direction of the arrows, there are three different classifications of information flow as indicated in the legend in Figure 4-2: weak, steady and strong. These classifiers correspond to the intensity and concentration of effort in regards to giving or receiving information. Therefore, a dotted line indicates a low concentration of information sharing, while a thick line indicates a strong concentration of information sharing.

Susan's role in the centre. Susan is the resource centre coordinator at the centre. Not only does she consider herself to be a knowledge broker while carrying out her role as resource centre coordinator and prior to this study, but her job responsibilities align with the definition of a *knowledge broker* (Appendix A). Susan is responsible for the resource centre, including its books, journals and other content that it has at any given time. She is also responsible for the website, and what information is presented online. This is shown with the solid arrow moving from Susan to information in Figure 4-2, because this is her major role and responsibility in the centre. However, Susan also has a major role in providing accessibility to health information for the clients and therapists at the centre. Although Susan says it's mostly the therapists and staff who use her services, she also provides information to parents and clients directly, both through the resource centre and through the website. However, because Susan has indicated that therapists use her services more than parents, the line linking Susan's information to clients is dotted in Figure 4-2 (indicating a weaker concentration). Information sharing with clients is in contrast to her information sharing with therapists, which is more constant and indicated with a solid line.

Susan's approach to knowledge brokering is twofold: making the information readable and being approachable. Susan says that "*a lot of the information we deal with is not the kind of information that parents are going to take away and find something valuable in, so it has to be toned down*". In addition,

> "*When we are talking with clients, it is about the approachability... they have to feel like you are not the 'librarian', they need to feel like you are a regular person and they can go up to you and talk with you.*"

However, according to her, it is the therapists who provide direct information to the clients most of the time.

Therapists in the centre. In addition to acting as a knowledge broker in this setting, Susan is joined by the therapists who work at the centre. Susan considers the therapists to be knowledge brokers along with her. According to her, the process right now at the centre is that she is "*usually connecting with the staff who are connecting with the clients*". She explains that "*the staff will come down to me and look for stuff and then pass it on to the clients*". This relationship is shown by a solid arrow linking the therapists to the clients in Figure 4-2, as this is a strong concentration of information flow. In describing the various knowledge brokers in this setting, she also addresses who does what in terms of knowledge brokering.

According to Susan, therapists get their information from a variety of sources, including the resource centre and various external outlets. Susan believes that these therapists actively visit these sources of information to get their resources, as opposed to having the information brought to them. Each therapist has his or her own information that is usually specific to the area of therapy in which they work. According to Susan, depending on what other therapists may need, they share among one another. In addition to this, they share their information with their clients. Susan says therapists do not give their information directly to her. In Susan's words, "*the therapists are holding on to a lot of the information... they say things like 'this is my information and I will hand it out*". Although they go to Susan to receive information, they do not give Susan ownership of their information in return. In Figure 4-2, the arrows from the therapists go to the information in centre and online, and not to Susan. This path is because while they use the information that Susan provides, and they are not currently involved in the process of sharing information with Susan that she can post online or in the centre.

Changes in information sharing over time at the centre. Information sharing at the centre is a dynamic process that has slowly been changing over time. Therefore, Figure 4-2 may not have been applicable in the past, or useable in the future. According to Susan, she hasn't been able to reach her full potential as a knowledge broker yet because "*it is a process and it hasn't gotten to that point at [the centre] yet... they are making small steps towards that, but they are very small*". For example, the information sharing tendencies have changed over time for doctors, but not therapists in the centre. Susan says "*when we first started, we were concerned about the doctors holding on to a lot of information.... they have let loose a bit but the therapists are still holding on to it*". Also, Susan's role as resource centre coordinator has changed over time. She "*started out not [connecting with others] at all, and then all of a sudden [her role] was growing*". Despite this slow yet steady process of change at the centre, there is currently a process in place right now that is about to change the way information is shared.

As mentioned before, therapists tend to come to Susan for information which they communicate with their clients. However, they do not seem to give Susan access to the information they have accumulated from other sources for Susan to make available online and at the resource centre. According to Susan, the centre is going to be pushing for therapists to "*hand over a lot of their hand outs down to the resource centre*". According to Susan, this will mean that parents "*are going to have to come down to the resource* *centre*" to get information. She also says that because she mediates what is put on the website, the information she receives from therapists will be put there as well. That way, "*parents won't necessarily have to talk to [Susan] in person... they can just go to the website*". Susan wasn't able to comment on how this change was initiated, just that she "*could have told them to do this years ago*". This change will be an extension of Susan's current role at the centre and a big step for information flow within the centre that Susan has "*been waiting for years*" to hear. This extension in information flow is indicated in the Figure 4-3 by the "strong" shadowed arrow between the therapists and Susan.

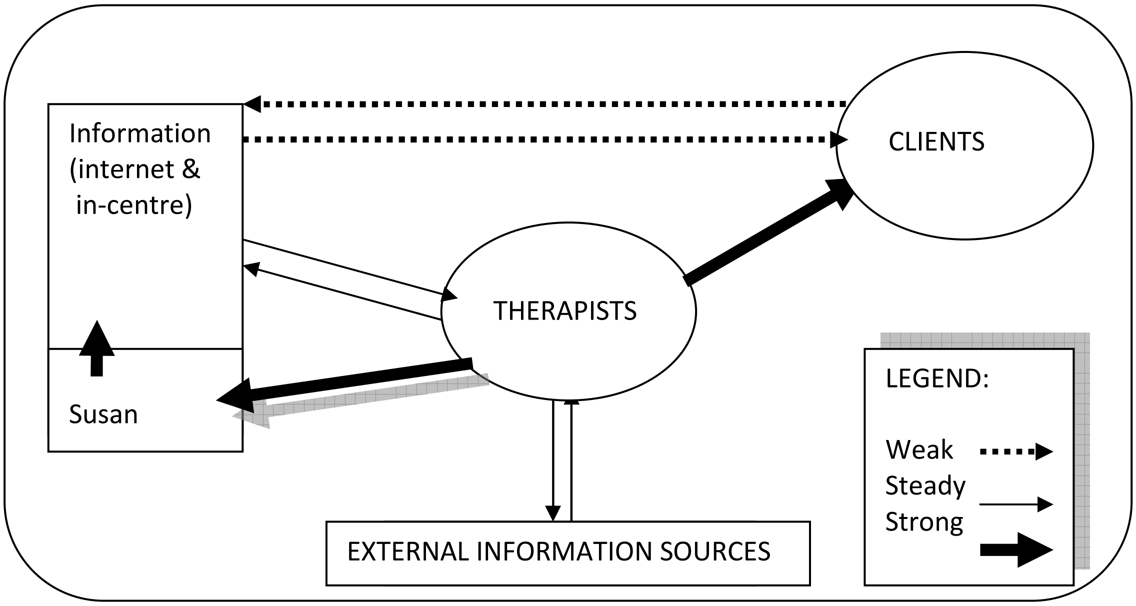

Figure 4-3. Susan's proposed amendment to the flow of information sharing at the centre, demonstrated by the addition of the black arrow between therapists and Susan.

Interpretation of Susan's Knowledge Broker Case

To remain consistent with Yin's (1994) definition of a descriptive case, I aim to provide an interpretation of the concepts that underlie the patterns and approaches to knowledge brokering in the setting of this centre. These concepts are informal versus formal knowledge brokering, temporality, and interactive versus trans-active knowledge brokering. Each of these terms will be defined, as well as explained, as they relate to Susan's portrayal of knowledge brokering at the centre.

Formal versus informal knowledge brokering. At any time at the centre there are different individuals and groups involved in knowledge brokering. Susan, being the coordinator of the resource centre and therefore mandated by the centre to organize and provide access to health information, has a more formal knowledge brokering role. Everyone else aside from Susan is considered to be informal knowledge brokers. Susan is mandated to run the resource centre and also the website. She is meant, by the centre, to co-ordinate the central repository of health information. However, as Susan discusses the role that therapists have in knowledge brokering, it becomes clear that these more "informal" knowledge brokers are also players in the knowledge flow within the centre. That is, Susan discusses how therapists find, manage and share their own information (and sometimes Susan's information) with clients.

The reason these therapists are considered to be more informal knowledge brokers when compared to Susan is that the acquisition and sharing of health information is not their primary role within the centre, as recognized by the centre. Although as therapists, providing information is very much a component of providing exceptional care to clients who use the centre and seek their help. Because they are not formal knowledge brokers, and not seemingly mandated by the centre to manage health information like Susan is, they seem to operate under the centre's health information radar. Because the centre has not recognized the therapists' role in knowledge brokering, they continue to perpetuate this "informality" in therapists' roles with health information. However, despite holding the label "informal", these therapists seem to have a very strong role in the information sharing dynamics in the midst of practice or provision of care. Formal knowledge brokers and informal knowledge brokers work in parallel to one another in this centre when it comes to sharing health information with parents and children.

Temporality. This case of information sharing between therapists and Susan becomes more complex when the issue of temporality is considered. I define temporality as time-based and progressive. Therefore, there are two ways of looking at how knowledge brokering and translation occurs at a setting like this: at an instant in time, and over the course of time. This study examines both information sharing at a certain time at the centre and describes some of the changes in information sharing that have occurred over time. As explained by Susan in the section above, therapists have been holding on to their own information for a number of years, while other health professionals have opened up and shared their information with her. Therefore, information sharing and knowledge brokering in a setting such as this one changes over time. However, only recently has the centre taken notice of this gap or oversight in the connection in information sharing. According to Susan, the centre's solution to this is to foster the information sharing between her and therapists. As explained by Susan, this recent development of fostering the information sharing connection between her and therapists will be a very big step for the centre towards better information sharing. Susan's relationship with therapists is anticipated to evolve over time as a progression of information sharing.

Interactive versus trans-active. In addition to the temporality of information sharing between Susan and therapists over time, there is a multi-level way in which Susan acts as a knowledge broker. She shifts between being trans-active and interactive as a knowledge broker. Trans-active knowledge brokering activities typically take place behind the scenes. These roles are seldom seen as knowledge brokering, but are very important to set the stage for interactive knowledge brokering. Interactive knowledge brokering occurs through interactions with others, and the sharing of knowledge. How both of these types of knowledge brokering apply to Susan is discussed below.

When Susan is being trans-active in her role as a knowledge broker, she is providing access to health information by maintaining the resource centre and continuously updating the website. She actively searches for information from around the centre and elsewhere, and also waits to receive information from others. Once Susan has health information to work with, she decides what information to post online and in the resource centre. This filtering is done based on her perceptions on what is needed by the therapists or clients or what has been requested by either group. After deciding what information to make available to therapists and clients, Susan manages the resource centre and website on a regular basis. This involves updating materials, posting relevant announcements, and modifying the content of the resource centre and website based on the demand of the centre and its clients.

In regards to interactive knowledge brokering, Susan interacts with whomever comes to her for her health information. This is usually therapists and clients. She always holds an active presence in the resource centre and is ready to interact with and direct individuals to appropriate information. This is a broader form of tailoring than she describes what the therapists do. For example, the therapists will provide clients with specific information that is tailored to individual children because they know these children well. Susan tailors information to what the parent asks for, but she does not refine this information any further.

Susan's face-to-face meeting with clients and therapists is more interactive than the previous steps Susan took to get the information to the shelves of the resource centre or the website. This process is what is visible to the centre and its patrons. It also seems as if this interactive part of knowledge brokering is what Susan aims to increase. Her description of therapists giving her access to more information will increase her interactive knowledge brokering with them as she will be working face-to-face with them more regularly. More interaction with therapists will also provide Susan with another source of information which she will manage and allow access to via trans-actional knowledge brokering. This increase of available information may allow Susan to have a wider pool of available knowledge to draw from when interactively tailoring information to parents in the resource centre. As well, if Susan is privy to the same information that therapists currently hold, Susan believes that this will increase the amount of client traffic in the resource centre, thus enabling her to interact more frequently with clients (boosting her levels of interactive knowledge brokering).

Conclusion

Although the knowledge broker never interacted with parents in this study outside of the workshops, the information she has given on the context of health information sharing within the centre is very valuable to this study. This information provides insight into the context of the centre environment when examining how parents use health information. Because parents are interacting with their therapists on a regular basis, they have a lot of contact with the centre. After understanding the dynamics of health information sharing and possession within the centre, I present how parents interacted with the health information provided by the research in the context of their daily lives and their interaction with the centre.

The Parents

In this section, this case analysis compares three parents who were recruited though convenience sampling. It is important to note that all three parents are mothers. For the duration of this thesis, I will be referring to these mothers as parents. The characteristics of these parents are presented in Table 4-1. The parents' pseudonyms are Jessica, Monica and Bridget. I present the results and interpretations of my interviews with Jessica, Monica and Bridget in the order they are listed. The parents are listed in this order to present a progression of increased involvement in information use. Each parent is presented and analyzed separately due to the intricacies and differences of each respective embedded unit in this case. Monica attended one of the workshops that were held at the centre. Jessica and Bridget were referred to me through their therapists at the centre, who attended the therapist workshop. Jessica was interviewed at the University; I traveled to the homes of Monica and Bridget to interview them there.

Table 4-1
Demographic Information of Parent Participants

DEMOGRAPHIC	PARENTS		
	JESSICA	MONICA	BRIDGET
Age of Parent	29	32	38
Marital Status	Married	Common Law	Married
Highest level of Education Achieved	University Bachelor Degree	Community College	Community College
Employment Status	Part Time	Full Time	Full Time
Age of Child with Cerebral Palsy	3	2 ½	4
Primary Diagnosis	Cerebral Palsy	Cerebral Palsy	Cerebral Palsy
Time of Diagnosis	Shortly after birth	Shortly after birth	In utero
GMFCS level of Child*	III	III	I
Other children	5yr old	No	10yr old and 8yr old
Self-Reported Research Use (least 1 – most 7)	3	1	5

**Note.* GMFCS = Gross Motor Function Classification System (I representing the greatest functional ability and IV representing the least voluntary movement).

Parent One – Jessica's Narrative

Introduction to Jessica. Jessica is a married mother of two children: a 5-year-old and a 3-year-old who has cerebral palsy. Jessica is 29 years old, holds a university bachelors degree and works part time. Her child was diagnosed with cerebral palsy shortly after birth, and is classified by Jessica to be in GMFCS level III. Jessica rates her use of research information to be a 3 out of 7, meaning she sometimes uses research information. Jessica's narrative on how she uses health information is presented first in the following section.

I begin by discussing Jessica's sources of information: online, through family and friends, and her therapists. I then discuss Jessica's information management with the aid of her therapists. Jessica's uses and outcomes of information use is described next, followed by her opinions on knowledge brokers and research-based health information. Jessica's narrative of her interaction with health information is presented on the following page in Figure 4-4.

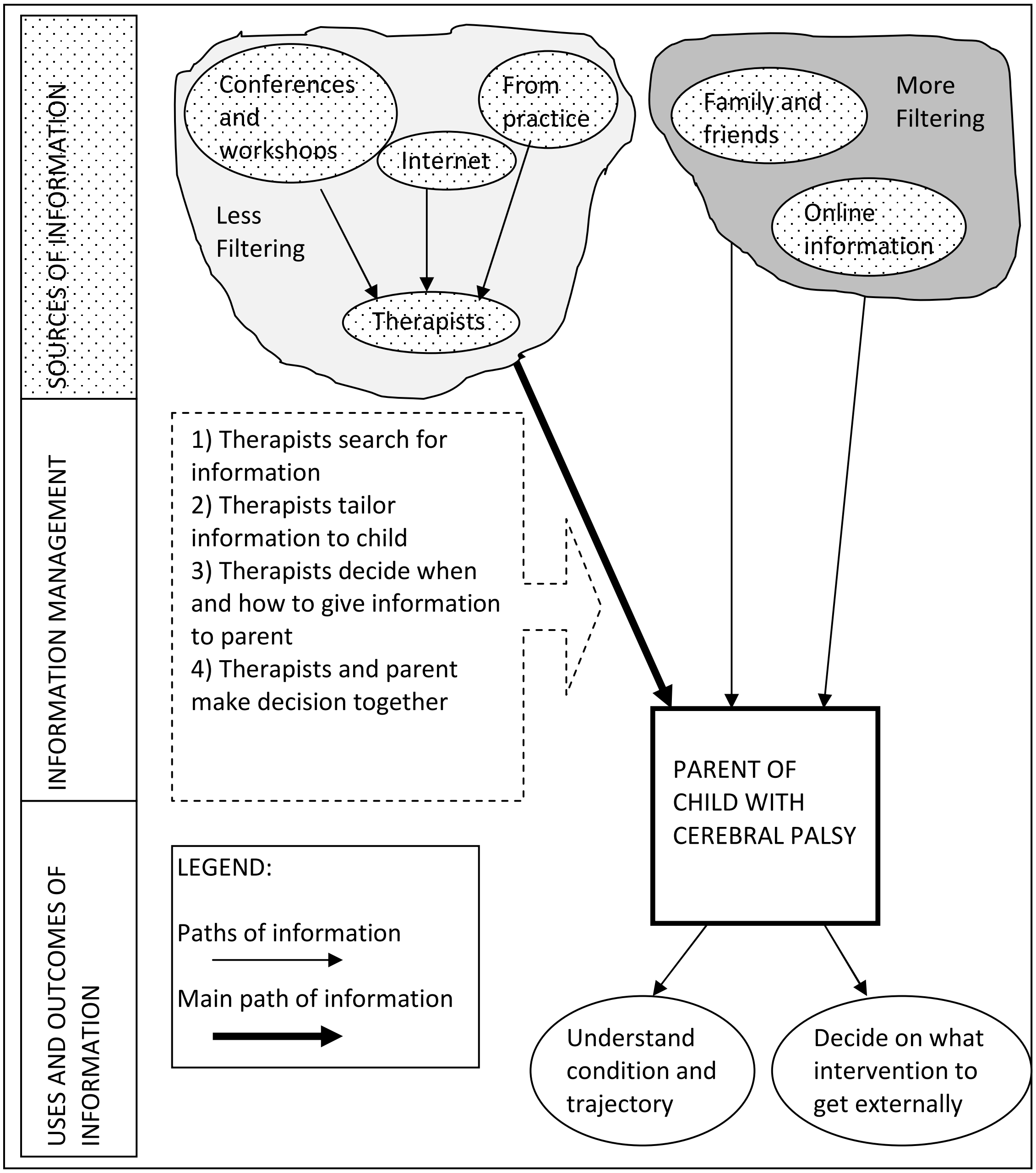

Figure 4-4. Jessica's interaction with health information.

Jessica's sources of health information. As represented in Figure 4-4, Jessica has three main sources of health information. Initially, when Jessica first received a diagnosis for her child of cerebral palsy, she searched for information on the internet. When she used the internet, she "*used Google and then whatever sites popped up*". However, according to Jessica most of these sites contained "*mostly studies because his condition is rare*". Jessica does not "*like going through [studies]*" because "*a lot of it is* *confusing*". In addition to Google searches and looking through studies, Jessica also went on "*some forums from Google and Yahoo*" but "*they were irrelevant*" because her child "*is so different, it's hard to compare it with other parents and their children*". As a result, Jessica filters this information more than other information she may come across. Jessica's online information searching significantly slowed down when she was given access to a physical therapist and occupational therapist. However, she has consistently received intermittent information from family and friends over the course of her child's life. For example, she says "s*omeone from our church community mentioned something about neuromuscular massage integration or something like that… it's a different kind of therapy. So we started doing it and I mentioned it to my therapist"*. Another example she gave of family giving her health information was her mother-in-law who mentioned stem cell transplantation and "*that cerebral palsy kids could potentially benefit from it so I did research on it and brought it to my neurologist"*. Jessica always brings information that she receives from family and friends to her therapists. This is one way that she determines its quality and usability. As such, she filters this information just as much as the information she finds online.

Jessica's primary source for health information, indicated by the thick arrow in Figure 4-4, is her child's therapists. According to Jessica, "*most of my information comes from my physical therapist and occupational therapist*". She has "*a lot of confidence in [her] therapists that if there is something out there that [she] should know about, they will tell [her]*". She says her health care practitioners "*never brush anything off, and they want to help [her child] as much as possible*". In addition to this, if they don't have the information she needs, she feels "*confident they would direct [her] to the right place*" to find it. She says that "*they are the experts*". Because of this, she doesn't tend to bring information to her health care practitioners. Instead, they "*usually just come with something like papers and say 'oh, have you heard about this' or 'we went to a conference and this came out' or 'hey we sometimes do this'*". In the examples given in the previous section (information given to her from a person in her church community and her mother-in-law), she described the different ways her health care practitioners reacted. These are the only two examples of her bringing health information forward to her doctors or therapists. Figure 4-5 describes these two examples.

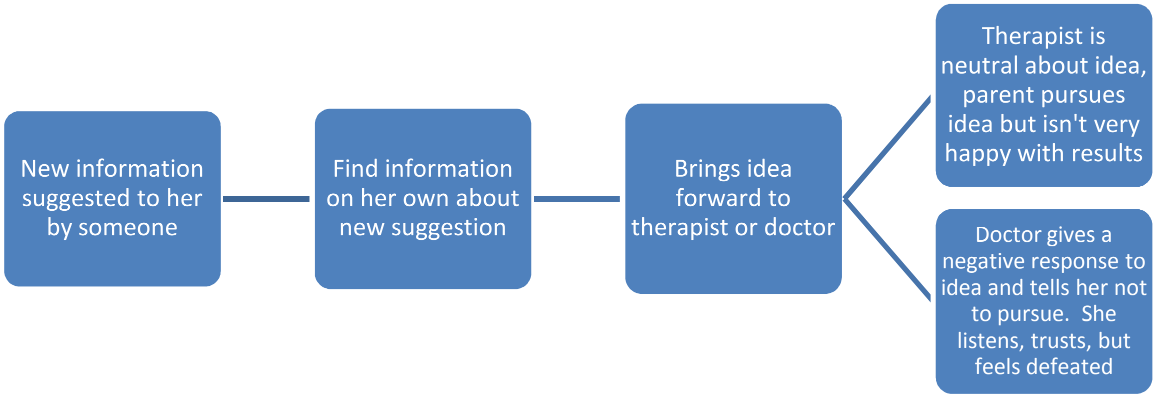

Figure 4-5. Jessica's experience when bringing information to health care practitioner.

When she received advice from a church member on neuromuscular integration, she asked her therapists about it. According to her, "*the therapists didn't really say anything about [it]… because it's something totally different than what they do. So they said yeah, definitely try it, and if it works, great. They think different things are good*". She started this type of therapy for her child, and isn't happy with the results. This is one of the outcomes demonstrated on Figure 4-5. On the other hand, when she asked her neurologist about stem cell transplantation, the response she received was much different. Jessica says her neurologist said "*it's not really proven to be effective yet*". As a result, she shares that her and her husband "*were really disappointed about that because there were a lot of personal anecdotes online about how effective it was, so [they] thought it might be something*". However, despite this disappointment, she says that "*when [her neurologist] said it wasn't proven and wouldn't be effective, [she] obviously trust[s] him because he's the expert*". This is demonstrated as a second outcome in Figure 4-5. Figure 4-5 adds some depth to the information relationship Jessica has with her therapists, demonstrated on Figure 4-4 by the solid line. Because therapists are Jessica's primary information source, this relationship was something she was able to elaborate on (which is demonstrated in Figure 4-5). Therapists are integral in Jessica's information management, which is described in the next section.

Jessica's health information management. Jessica expects therapists to find, tailor and deliver health information to her. She "*does not know what [information]is out there so [she] trusts [the therapists] to find it*". She also incorporates them into her information filtering techniques, by trusting their opinions on information in regards to her child. In both of the examples mentioned above, Jessica involved her health care practitioners in her decision to use health information given to her by family and friends. Having her therapists comment on the quality of the information given to her by family is a method of filtering for Jessica. She recommends that other parents also get their information from their therapists and health care providers because they are "*people who are in direct contact with the child. Because every child is different and [the therapists] would know what they are going through.*" Jessica gives the following example of working with her therapists to make a health care decision for her child:

> *"Our therapist asked us what our goal was, and I said I would really like to see [my child] stand. So [the therapists] got someone to bring in standers, I think we had three standers all together. They lent them to us for a couple of weeks to see which one we liked. And obviously the therapists have their input too. And then we ordered one, it was joint decision making. But the therapists are the ones who know what's out there, they are the experts. To set it up, I let them do it because they know what they are doing. Obviously it was a joint decision because I'm still making the decisions for [my child] but on their recommendations and expertise".*

In this example, therapists went out to find the information (different stander options), tailored some options to their needs (only brought in a few standers), and made a joint-decision with Jessica and her husband on which stander to choose. In addition to this joint decision making, Jessica talks about her experience with information when it goes against what she thinks is right or natural.

> *"We were talking about casting. Then I sort of stood back and said 'do I really want this?' It definitely makes you think. Even with orthotics… The new pair aren't as comfortable, so they said have [my child] wear them at nighttime… but*

> *that wouldn't be comfortable for him! But whatever, I try it… if they think it's going to help. As long as that doesn't hurt or harm I'll try it".*

Jessica gives two examples of outcomes of her information use: choosing a stander and casting her child's legs. These outcomes are elaborated on in the following section.

Outcomes of Jessica's health information use. Jessica uses health information to make decisions about the interventions that are applied to her child. This decision is mostly made with the aid of a therapist, as described above. This is one of the outcomes in Figure 4-4, "decide on what intervention to get externally". I use "externally" because she does not mention providing therapy or interventions on her own at home. The second use of health information for Jessica on Figure 4-4 is "understanding the condition and its trajectory". This process is a continuous endeavour for Jessica as her child grows and develops, but it was especially important for her at the time of her child's diagnosis. She says that the internet "*was our main source of information, just to see what was going on*". This was before she had access to a therapist for help. The following section discusses Jessica's opinions on using someone external to her therapists as a knowledge broker.

Jessica and the knowledge broker. According to Jessica, the main reason she did not make use of the knowledge broker was that "*I'm not looking for information. If I do need information, I have enough people*". This coincides with what she was saying about not having to look for information ever since she was put in touch with therapists. In regards to who she seeks information from the most, she says that it's mostly the therapists because she does not have her "*neurologist or higher readily accessible*". However, she says "*the physical therapist, the occupational therapist, I can be in touch with them weekly*". She is "*quite confident in [her] physical and occupational therapist*" and doesn't think she "*would go to someone [she doesn't] really know*" for health information for her child. Even though Jessica foresees she will need more guidance in the future as her child is ready for school, she says that she already has access to a social worker who she anticipates will help her with that transition. According to her, "*that's* *why I'm satisfied… I've got the physical therapist, occupational therapist, speech language pathologist, neurologist, social worker… everything under the sun!*" With supports like these and little information searching on Jessica's behalf, she does not see the need to make use of a knowledge broker now or in the future. In the next section, I describe Jessica's opinions on the Move & PLAY research summaries.

Jessica and the Move & PLAY summaries. When asked about how she felt in regards to the Move & PLAY research summaries, she said that "*they were quite confusing… I found them hard to go through and I didn't understand them a whole lot*". This is similar to her perception of research information that she found online when doing research about her child's diagnosis. Jessica does not seem to mind if health information is based in research or not. When asked about the sources of the information she receives from her therapists, she says "*I never ask where they found it, I just trust them to give me the right information*". She adds that the information she received from her therapists is "*definitely practical*". She is unsure how to use the summaries from the Move & PLAY study right now. My interpretation of Jessica's narrative is presented in the following section.

Parent 1: Interpretation of Jessica's Narrative

The underlying concepts that describe Jessica's patterns of information sources, management and use are presented in this section. These underlying concepts are the instrumental use of therapists as knowledge brokers and the intermittent use of information from sources external to her therapists. These interpretations are defined and explored in this section and represented on the Figure 4-6.

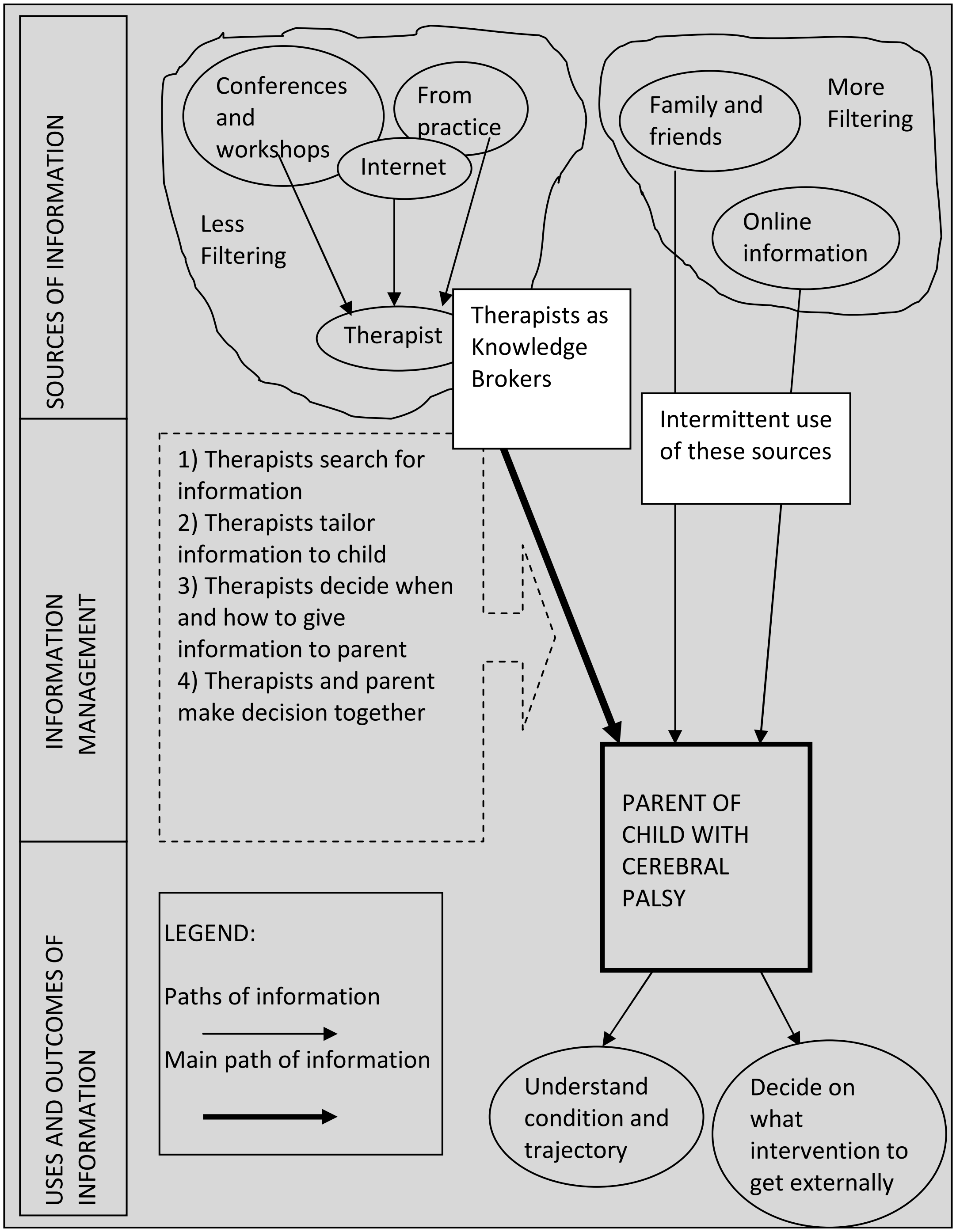

Figure 4-6. Interpretation of Jessica's use of health information.

Use of therapists as knowledge brokers in Jessica's information management. Jessica has a pattern of bringing all the information she finds on her own or that is given to her by family and friends to her therapists. Her intention is that the therapists will help her filter which information she should use and which she shouldn't. In addition to bringing information to her therapists, she relies on her therapists as knowledge brokers in regards to finding and tailoring information for her child. This pattern of knowledge use is exemplified in Figure 4-4 in the box which outlines Jessica's information management and can be seen again in Figure 4-6. She has stated in her narrative that she relies on her therapists to know what information is available that is applicable to her child and to give her that information when she needs it. This reliance on her therapists to filter information from others, search for the majority of her information, tailor it to her child and deliver it to her when appropriate are the patterns in her narrative. The underlying concept of these patterns is that Jessica uses her therapists as knowledge brokers.

In regards to bringing information to her therapists, Jessica has past experiences which inform her current opinions. These experiences are described in Figure 4-5 in the previous section, as they elaborate on the solid line describing the information sharing relationship she has with therapists in Figures 4-4 and 4-6. In both cases Jessica received health information from an external source. In both cases, she brought this information to her therapists and health care professionals. In one case, the therapists knew little of the intervention and weren't able to provide much guidance. It turned out that Jessica was not very satisfied with her decision to perform this treatment. In the other case, she did research on the proposed intervention prior to bringing it to the attention of her health care professional. She had already formed a positive and hopeful opinion of the intervention, and was disappointed that her health care professional said it wasn't a very good intervention to try. Jessica has a history of bringing information to her health care professionals and therapists and not having particularly positive outcomes and feeling dissatisfied in her independent searching of health information. This may potentially explain why she is comfortable with therapists and health care professionals searching for and bringing her health information instead.

The examples that Jessica gave of where her therapists find their information show that they use multiple sources when finding relevant information for her to use.

These sources can be seen in Figures 4-4 and 4-6, where therapists have access to conferences, workshops, the internet and from experience in their practice. Jessica also has said that they know her child best, and are able to give her information specific to her child's condition. She sees her therapists on a weekly basis, so she has access to them regularly to discuss her information needs. In all of these ways, the therapists act as Jessica's knowledge brokers. They find, tailor and give Jessica access to health information. In addition to this, they also filter information for Jessica that she has found elsewhere. All of her information needs are met by their knowledge brokering, in so far that she does not see the need for another person (such as Susan) to act as one. Jessica does not currently need, or anticipate needing, a separate person aside from her health care professionals to act as a knowledge broker for her. Her satisfaction with her health care professionals' handling her health information and the outcomes she has experienced in the care of her child have been enough to build a large trust between herself and these professionals.

Jessica did not find the research summaries from the Move & PLAY study useful. They were too difficult to understand without someone guiding her, and she did not see their applicability to her child. However, it seems that when Jessica encounters health information that is not of use to her, she feels comfortable in discarding it. She trusts that if health information is worth using for her child, then her therapists and health care providers will present such information to her.

Intermittent use of information sources external to therapists. Jessica used the internet as a primary information source before she had access to a therapist. Once she was given access to a therapist, she started using the internet only occasionally. Now, with her frequent visits with therapists and satisfaction in their information sharing, she only uses the internet when she wants to learn more about something that family or friends have suggested. In addition to the internet, Jessica received intermittent information from family and friends. She cannot predict when she will receive this information, as it only occurs when her family or friends find something interesting or applicable to Jessica's child. These are patterns of Jessica's health information use; using the internet more heavily at certain points, and receiving information from family and friends at an inconsistent rate. Intermittent use of information is the concept that underlines these patterns, which is demonstrated in Figure 4-6.

This "intermittent use" can be defined as an occasional use of information that occurs in a periodic fashion. Jessica's intermittent use of information external to her therapists is not done in a step-wise fashion and can be somewhat unpredictable. The concept of intermittent information is reinforced right away when Jessica talks about how she previously handled her health information before her therapists were accessible to her. When her child was first diagnosed, Jessica wanted to find out information about the diagnosis. She performed general searches on the internet although her child had a very specific and rare condition. The general, cerebral palsy online support groups were of no use because she could not find guidance specific to her child's needs. Even though Jessica describes this independent information seeking as a negative one, it still serves to demonstrate Jessica's drive to find information for her child. Intermittently, this will happen only if she does not have access to a therapist to help her.

The intermittent use of health information that is not sourced from therapists occurs when she receives information from family and friends. Every so often, when Jessica is presented with a period of information sharing from family and friends, she goes online to do her own information searching before bringing it to her health care professionals. This occasional use of the internet and inconsistent interaction with information from family and friends is peripheral to her interactions with these health care practitioners. That is, her information sharing and receiving with these professionals is constant and somewhat controlled by the therapists. The therapists decide when to give Jessica access to information depending on their perception of her child's trajectory or her particular rehabilitation goals. Jessica feels comfortable with the predictability of this information source. Intermittent use of information is involved when Jessica is encountering information on her own and managing it without therapists. She decides whether or not to bring the information forward to her therapists so they can help filter its usefulness and quality. This pattern changes over time, as she is inconsistently presented with health information external to her interaction with her therapists. However, she has developed a system of bringing this health information to her trusted therapists when she is presented with it, in an attempt to make these intermittently used information sources more regulated.

Parent 1: Conclusion to Jessica

Jessica's relationship with therapists and their impact on her health information management, as well as the intermittent use of her independently-sourced information describes how Jessica navigates through the complex world of health information. The next part of this chapter explores Monica's relationship with health information.

Parent 2: Monica's Narrative

Introduction to Monica. Monica is a common-law mother of one child; a 3-year-old who has cerebral palsy. Monica is 32 years old, holds a community college degree and works full time. Her child was diagnosed with cerebral palsy shortly after birth and is classified by Monica to be in GMFCS level III. Monica rates her use of research information to be a 1 out of 7, meaning she rarely, if ever, uses research information. Monica's narrative on how she uses health information is presented first in the following section.

I begin this section by describing the sources of Monica's health information: online information, extended family, conferences and workshops, doctors and therapists. I then discuss Monica's information management, and how this involves therapists. I present the outcomes of Monica's health information use, which are to understand cerebral palsy and the trajectory, to provide interventions herself and to decide on what treatment to get externally. Finally, I present Monica's opinions on knowledge brokers and research-based health information. Monica's uses, management and outcomes of information use are depicted in Figure 4-7.

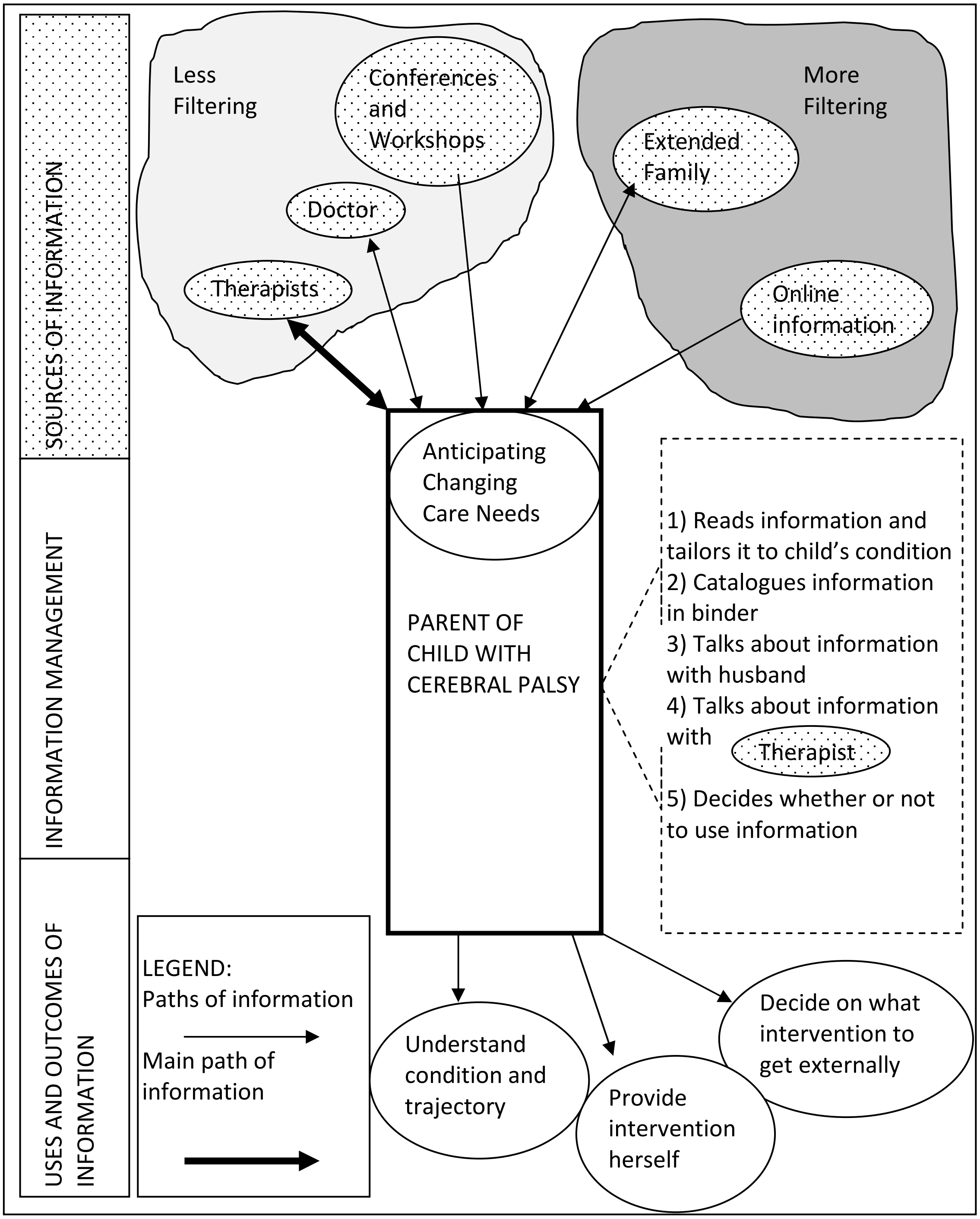

Figure 4-7. Monica's interaction with health information.

Monica's sources of health information. Monica uses information from websites online to get health information. Monica said that "*if we get stumped somewhere, we Google it*". When asked about any specific search strategy, she says that "*it's just random. Like I'll wonder what we can do about something and I'll just type it in and wherever it takes me, it takes me*". She does not believe that information from online sources are always accurate, so she uses some filtering when using these resources, as shown in Figure 4-7.

Monica isn't the only one who uses Google to search for information for her child. She talks about her mother-in-law and how she "*Google's stuff and she'll come across something and if she thinks it's of interest she will send it our way*". According to her, "*our family is really good. If they hear anything, if someone tells them something, they will share it with us. It's a good little resource circle that we have*". However, since Monica brings this information from extended family to her therapists to gauge its quality, "extended family" is placed in the "more filtering" section of Figure 4-7.

Monica likes to share information with friends, family and her health care providers when she can. This information flow is demonstrated by bi-directional arrows in Figure 4-7 between Monica and these sources of information. Monica says that she "*doesn't know any other parents in this situation, but I do share information in general. When people ask me questions about my daughter, I'll tell them so that if they know somebody they can pass it on*". In regards to sharing information with her family, Monica says that "*we always fill them in so they know what's going on. It's a two-way thing, we share all the time*". Monica is not only open to receiving information, but she is very interested in sharing it with others. Monica is aiming to foster connections with health information, in which she receives and gives information freely.

In addition to information from the internet and her extended family, Monica likes to attend workshops and conferences when she can. In regards to the workshops that were held for the Move & PLAY summaries at the centre, Monica says "*workshops like that we tend to participate in when we can*". She also talks about a conference she went to last summer saying "*that was a first for us, and we just thought it was awesome. I'm really hoping that's something they can continue doing because that gives us knowledge on what could happen in the future, things they are working on, that kind of stuff*".

Monica mentions later in her health information management that she tends to trust information from the centre (including workshops, conferences and from health care practitioners) more than her other sources of information, classifying this as a source that requires less filtering, as demonstrated in Figure 4-7.

Monica's primary source of health information is her therapists, as she says that "*the information that we use we get from [our child's] physiotherapist. If we have any questions, they have been a huge resource. Most of the time, whenever something comes up, it's just the therapist that I'll usually ask*". She goes on to explain that the frequency of visits with her therapists help make them her number one source for health information. This frequency is indicated by the thicker arrow in Figure 4-7. She says "*they are the ones we see more regularly, the ones we keep in contact with*". In addition to this face-to-face time with her therapists, Monica also says that:

> *"If I have a question they are pretty good at answering right on the spot. If not, they will send me an e-mail. Or, if I can't attend my physio appointment, I will send them an e-mail. I email them regularly with updates from my appointments and then if I have any questions they will just email me back like 'OK, that is something we will look into and then we will let you know at our next appointment'".*

This frequency in access is coupled with the fact that when her therapists give her information, they are giving it in the context of her daughter's specific condition. She says "*they know our situation; they know [my child's] situation. We feel that they are our 'go-to' people if we have any questions or concerns*". She adds later that "*I use our therapist for all those information questions because she just knows my daughter best. She knows her strengths and capabilities and where she is struggling. She is just the most appropriate person to go to answer any of my questions*". There is a high level of trust and a strong relationship between Monica and her therapists when it comes to the quality of information that they provide her with. This is demonstrated in Figure 4-7 by indicating that Monica uses less filtering when using information from her health care providers than when she uses information she acquires without their involvement.

Monica also uses the information that comes from her therapists as a way to gauge quality and usefulness of information. She explains that "*I try to stick with the information from our therapists, the centre and the workshops that they provide. I know that's a lot of good information there that I can utilize back home*." Monica sometimes has the opportunity to meet with multiple health care professionals at the same time. She describes her experience with these health care professionals:

> *"All of them work really closely together so they share information. If I have a question about something, say I'll ask the occupational therapist. If she doesn't know, she will pass it on to the speech therapist who will get back to me and answer my question. They all work very well together. Sometimes we have visits with all three of them so it works very well together, I can bounce things off everybody!"*

When asked specifically how she uses her therapists in regards to information she finds on her own, she says "*I ask my therapists questions and they fill in the blanks for me*". In this sense, Monica looks for completeness in her understanding of health information. This open communication between her therapists is accentuated by Monica's willingness to bring them information that she finds. For example, when her mother-in-law sent them a link about a new kind of physiotherapy, she went to her therapists for their opinion on the treatment.

In addition to therapists, Monica also uses doctors as sources of health information. Monica comments of the differences between working with her therapists and working with her pediatrician:

> *"I do take [my child] to the paediatrician, he knows of [my child's] situation but not to the point that therapists do. If I have a concern that is health related, I take it to the pediatrician. If it's because of [my child's] condition, I take it to the therapists. I feel like the information they are going to give me is more geared towards [my child]. And the information [the pediatrician] would give me would be general information".*

In addition to being selective about where she sources her information when it comes to health professionals, she notices there is a difference in the way the information is given to her in both situations. She says:

> *"I think it's because of [the therapists'] jobs and their responsibilities, it's always uplifting. It doesn't matter what my concern is, they are always reassuring, saying that 'it's ok, and this is just a phase'. They always just make me feel like it is going to get better. Than just say, talking to her pediatrician it would just be general information like 'this is how it is' sort of thing whereas [therapists] are like 'oh she's doing fine, and this is what's expected'. It's really uplifting, and makes me feel really good. So I kind of like that vibe instead of the 'this is what you get'."*

In the next section, I will explain how Monica manages her health information.

Monica's health information management. As demonstrated in Figure 4-7, Monica reads health information, tailors it to her child, catalogues this information in a binder, discusses the information with her partner and therapists and then makes a decision on whether or not to use it immediately. She also anticipates her child's changing care needs, which acts as a lens when managing her health information. This process will be elaborated on in this section.

Monica says that all this information that is being shared with her is valuable. She says that "*all the information we've gotten through friends, through resources, through anybody, it's all been beneficial*". Monica seems to use all the information she is given or that she finds. She welcomes new information saying that she "*can't get enough! The more I know, the better I feel and the more competent I feel in being able to help her. So I try to absorb everything I can*". However, this desire to find and keep as much information as possible is a daunting task. Monica explains:

> *"There is never enough time. I could spend hours on the internet just looking things up. I try not to because it can be a little discouraging sometimes depending*

> *on the information that you get. So I try to avoid that. There is just too much, and I try to absorb it all. I do a lot of research, and it is a little discouraging with all the information, what's good for us, what's not good for us".*

Monica seems to have a system in place when it comes to using health information. As outlined in Figure 4-7, she receives new information, she talks it over with her partner and if it is something worth looking into, she will bring it to her therapist. She says "*of course we look into [the information] and if it interests us, we bring it to the therapist. It's like 'Hey! What do you guys think about this?'*". Monica gives a more in-depth explanation of what she does when she encounters new information. She says that "*what we would do is take the new information and try it out, combine it slowly step-by-step with what we already know and see how it goes*". When asked about whether or not she will come back to information that she does not immediately use, she told me about her "process" with written health information. She explains:

> *"And that's something that I usually do so like with information, every so often I will go through and read them again just so I understand them again and so that I know there is a reason for what's happening. So there are resources that I do use regularly, just so I can freshen up my memory."*

In addition to using written information to refresh her memory, she keeps them so she can go back to them when she needs help understanding the reason for what her child is experiencing. She keeps all this information, including the summaries, in a binder. As she says, "*we hold on to everything, and it's always useful. There hasn't been anything where we were like 'oh, this sucks' and then throw it aside*". Monica is very cognizant about her current health information management process, and also about what may possibly happen in the future as her daughter encounters more transitions.

Monica's child is still quite young and according to Monica "*when [my child] is five or ten, we'll have a few more years under our belt to have a bit more experience, just because [my child] is still so young. We're still kind of new and fresh, so we don't really know what's out there yet*". She acknowledges that this process of information searching and use may change as her child gets older. According to Monica, "*I know it's going to happen soon because [my child] is almost school-aged and we're going to have to make some big decisions then*".

The biggest transition that Monica has had to face was "*choosing an adequate daycare that was going to support her*". When asked about this process, and how information played a role, it seemed as if Monica went about deciding which daycare to put her child in like any other mother would do. She explains that "*basically I interviewed a couple of babysitters saying 'OK, our child has cerebral palsy, this is what we need to have done, can you accommodate this?' And we found one who was willing and that's where she is*". Aside from the decision of which daycare to send her child to, Monica is preparing herself for an upcoming transition: sending her child to junior kindergarten. She says:

> *"We are trying to pick a school that can accommodate [my child's] needs, so that is something that we are looking into. [My child] has to be potty trained before going to school… it's overwhelming! It's what's on my nerves right now… like it's in two years, and it's on my mind every day! And this is something that I'm going to be talking about to my therapists".*

Choosing a daycare and school that can accommodate her child's needs are outcomes of Monica's information use. These outcomes, along with two others, will be described in the next section.

Outcomes of Monica's health information use. Monica uses information to fulfill three main needs: understanding her child's condition and trajectory, to provide interventions herself, and to decide on what interventions to pursue external to her home. These three outcomes are depicted in Figure 4-7.

In her health information management, Monica has mentioned that the more information she can get, the more she feels prepared to be the best parent she can be for her child. Monica uses all of this information to help her understand what her child is going through, and what she can expect for her child's development in the future.

Monica also uses health information to decide on what interventions she can apply at home. While I was at Monica's house conducting the interview, she was showing me different toys that she bought to try and enhance her daughter's muscular control. She used health information to inform what movements she should be working on with her daughter and bought toys that would encourage those movements. Lastly, Monica uses health information to decide what interventions to get external to her home environment. For example, she is using information to help her decide which daycare and school will have the most supporting environment for her child. The next section describes how Monica feels about the role of a knowledge broker.

Monica and the knowledge broker. Monica did not make use of the knowledge broker. We began the discussion about the reason why with Monica re-iterating what she felt a knowledge broker would be used for:

> *"My perception of a knowledge broker was that if you had questions about information you came across… say you came across this website and it had some information that you were unsure of, you could ask them and they could explain it in a more simple language".*

After hearing her perception of what a knowledge broker did, she explained why she didn't make use of the knowledge broker provided. Her first reason was that "*personally, in my life right now, it has been pretty hectic. I haven't had the chance to utilize it right now the way I could have. But over time it might have definitely come in handy*". Monica only had access to a knowledge broker for a little over a month, and in addition to being busy, she did not encounter anything that she felt she needed help with in this short period of time. However, she did say that "*I personally don't have a need for it just yet. But that doesn't mean it wouldn't change over time. I mean, as [my child] gets older, things change. We might run into other questions or things we need help with*". Monica acknowledges that as things change in her child's life, the way she uses information may change, and her need for a knowledge broker may change as well.

Monica is skeptical about using someone external to her child's care for health information. She says that "*most of my questions are just specifically about my daughter. If I have a concern about something that she is not doing or something like that, I didn't know if that was something I could talk to the knowledge broker about*". This lack of understanding about the role of a knowledge broker, as well as her comfort in talking with her therapist is another reason Monica did not make use of a knowledge broker. She says "*I have a lot of personal questions about [my child] but I didn't think I could ask personal questions like that or if it was moreso information in general*". Clarifying the role of a knowledge broker could have helped Monica decide whether or not she wanted to bring her concerns to this individual.

I asked Monica if there were any other resources missing from her circle of support that she would like to have when caring for her child. She shared:

> *"Actually, what I think would be helpful is someone who, I could contact them or they could contact me and tell me about upcoming seminars or workshops or big play groups or places I could bring [my child] or just things for my husband and I to attend so that we could meet other parents and share information or gather information. Kind of like your workshop, I was sad that nobody else showed up! I thought that was awesome, and we don't get to experience that ever, right? Things like that I would really like to know about."*

Monica's desire for information goes over and above written information that is delivered one-on-one from family members, her therapists or the internet. She is very passionate about trying to connect with other people who have children with cerebral palsy. Monica sees the value in interactions like this, and sees it as another way to get information, and as a resource to help her use information. In the next section, I describe how Monica perceived our written information sources, and how she intends on using them.

Monica and the Move & PLAY summaries. Monica read all 12 summaries that we gave her at the workshop. She says that "*a lot of it I kinda already had an understanding of, but some of it was new. It was definitely helpful and some of that stuff* *we definitely used*". She also commented on the number of summaries, saying that "*it was a lot of little booklets to go through, but it was interesting*".

Monica believes that all information is good information, and in addition to this, she does not rank information stemming from research as more useful than information not from research. In fact, she is sometimes skeptical about the relevance of information from research. She says:

> *"Well the only problem is that research, when it's usually conducted, is a big group, and the age range usually varies. So you get mixed results, when I just want to know about [my child]... So the information is good, we just kind of have to pick out where she kind of fits. Like 'your daughter is two years old, she's in level two, this is what she should be doing this is where she should be at'. But that's, like, impossible to do. So I guess that's why they give you the big groups just to give you an idea of what's going on... it's just so big it's hard to do."*

Monica acknowledges that most of the research she has encountered has given her information for a wide range of children, and she doesn't like that she does not get specific guidance for her child. In most cases, she is presented with all possible outcomes and cases, and sometimes these can be negative. As she says, "*it's just hoping for the best in most cases*". The personalized information she receives from her therapist is one of the main reasons why she goes to these individuals first when it comes to health information needs. It is also the main thing she suggests to other parents of children with cerebral palsy: "*talk to your health care provider, talk to the therapists, go to the centre. They are all great resources.*" In the next section, I present my interpretations of what Monica is describing about her relationship with information.

Parent 2: Interpretation of Monica's Narrative

Monica's sources of health information are online searching, from extended family or friends, by attending conferences or workshops, and from her doctors and therapists. She uses all of these information sources consistently, and uses information from her therapists the most often. Monica has a process of managing health information.

She searching for information, tailors it to her child, catalogues it in a binder, and then talks with her partner and therapist in deciding whether or not to use the information to make a decision. The outcomes of Monica's information use are understanding the condition and trajectory, knowing what interventions to provide at home and deciding what interventions to get external to home. These sources, management and outcomes of information use create patterns in Monica's interaction with information. These patterns are underlined by three major concepts: temporality in information use over time, self-efficacy in cataloguing and using health information and her relationship with therapists. I explore and define each of these concepts in this section. These interpretations are depicted in Figure 4-8.

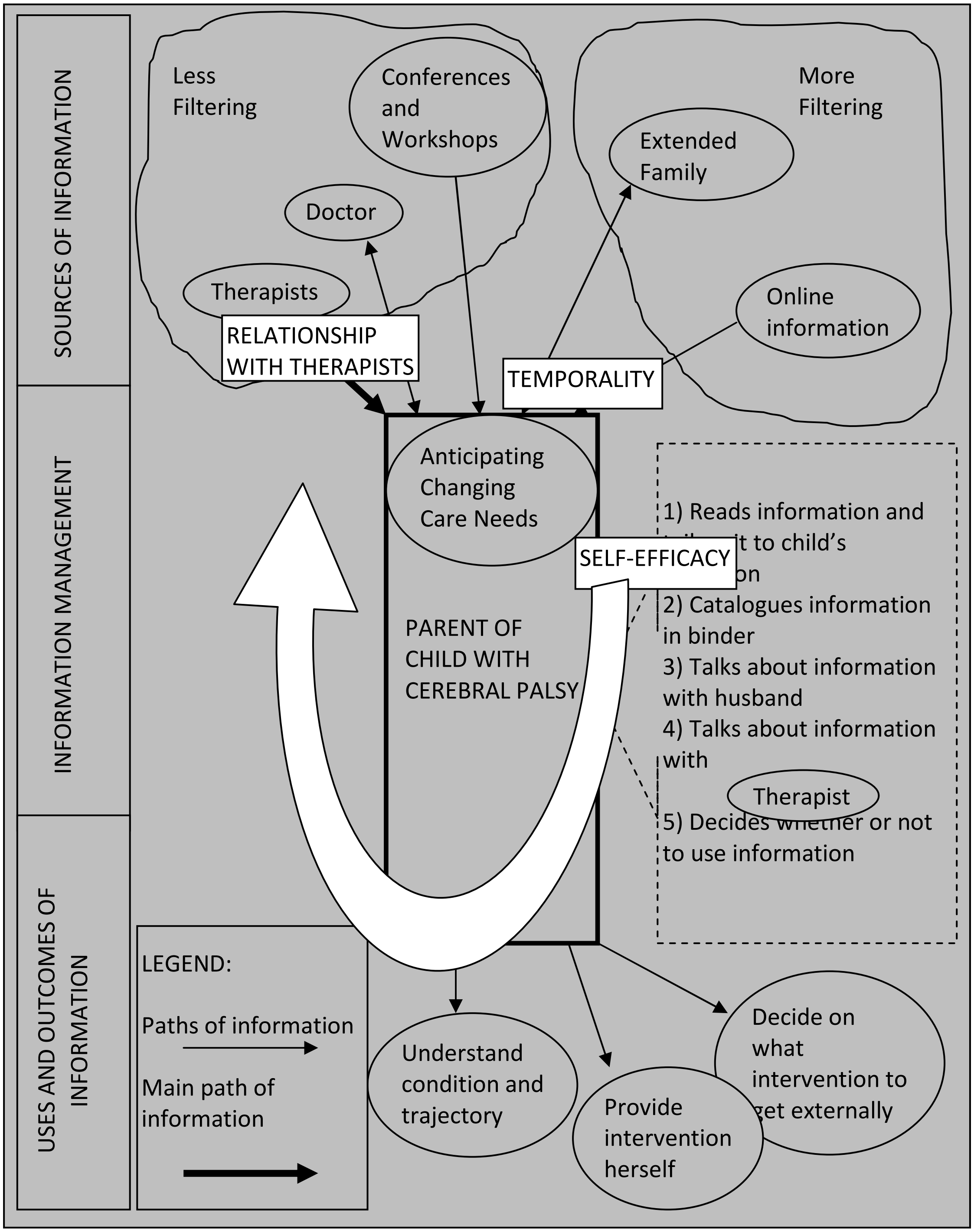

Figure 4-8. Interpretation of Monica's use of health information.

Temporality of health information. In Monica's narrative, she shares that she anticipates her relationship with information to change over time. She described her current sources of health information, but says that since she is a new parent she anticipates that she will learn of more sources and may manage the information she receives differently. She also shares that as her child experiences new transitions in life, she may require more help with than what she currently has. Therefore, Monica's current pattern of the sources and management of information may change over time, with temporality underlying these patterns.

In Monica's case, temporality is defined as anticipating change over time and progression. It describes the realization that as things progress in her and her child's lives, the way she comes to acquire and use her health information will change. In Figure 4-8, temporality is placed across the arrows indicating the information sources that Monica has currently identified. I have done this to show that these sources, as well as her current relationships with them and frequency of use may change over time. For example, Monica did not need the help of a knowledge broker at the time of my study because she was not experiencing any major transitions that she needed help with. However, she anticipates this will change as her child grows and perhaps as she enters school. Monica says that she is already preparing for this change by teaching her daughter how to write. This is a very big transition for Monica, and she is already getting ready to face it. She said that she will go to her therapists for help on how to approach this transition, and she acknowledges that as she experiences this new transition, she may look for help elsewhere (as in using a knowledge broker). She admits that she is still a new parent, and doesn't really know what else is out there for her, information-wise. She understands that her experience with her child's condition is hard to predict, and she acknowledges that things will change over time. She uses her catalogue of information to help her with handle this temporality and increase her self-efficacy as a parent, which is described in the next section.

Self-efficacy as a result of gathering and holding information. Monica has a pattern of collecting as much information as she can and cataloguing it for reference at various points. She says that she never turns down information and that she believes all information to be useful. Sometimes she feels overwhelmed at the amount of health information available, but that does not stop her from collecting all the health information that she can. Monica has said that having access to a lot of information on a consistent basis makes her feel competent to support her daughter as she grows and develops. When Monica receives information, she reads it and catalogues it in her binder. She says that this helps her in the future, because this information may come back to inform her as she experiences new things with her child. Even if a piece of information does not seem valuable to Monica at the moment, she still believes in its ability to be valuable and things change down the road. The concept of self-efficacy underlines Monica's pattern of collecting and holding on to information.

In Monica's case, self efficacy is defined as her belief in her own competence to care for her child. In Figure 4-8, self efficacy is placed under step two in Monica's information management process. This is the action that reinforces and promotes her self-efficacy to care for her child. In Figure 4-8 the effects of Monica's self efficacy loop down and effect the outcomes of her health information use, such as her ability to understand her child's condition and trajectory. Finally, her self-efficacy from understanding her child's condition and trajectory cycles back to the top of the figure to inform how she searches for information.

The information that is given to her and that she seeks out is empowering to her as a mother. This could be why Monica never turns down information, and considers every information source to be valuable. Her binder of information acts as a resource and tool for her to succeed as a mother. She owns that binder of information and it is always accessible to her. She refers to it often when she needs help understanding what is going on in her child's life and it enables her to share information with others. She mostly shares this knowledge source with her therapists and family, but has a strong desire to share what she knows with other parents of children with cerebral palsy.

Often in our interview, Monica mentioned her desire to attend more workshops and conferences. She said that she would appreciate someone who could tell her about events and opportunities to connect with other parents. This desire could be to share what she knows, allowing her to feel like she has contributed positively to another parent's knowledge of managing their child's cerebral palsy. It could also be to access another source of information which Monica can use to add to what information she currently has. In either case, Monica embraces multiple information sources, and desires an outlet to share what information she has. However, the large amount of available information overwhelms Monica, who feels upset that she cannot possibly know all that is out there for her child. To fill this gap she relies on her therapists' help, who act as Monica's knowledge broker.

Relationship with therapists. In Monica's narrative, she describes her relationship with her therapists. The patterns in this relationship is that she prefers their information over other sources; she trusts the information that they give her and she trusts their opinions on the information she presents them with. She also describes their role in helping her make health care decisions with this information when she describes her management of health information. These patterns are underscored by the relationship that she has built with her therapists, to the point where they act as her knowledge brokers. This is demonstrated in a white box over the line that connects Monica to her therapists in Figure 4-8.

Monica says that her first sources for information are her therapists. She says that they know her child the best, and that they can give her health information that is specific to her child. This tailoring that therapists can perform when giving their clients information appeals to Monica. She trusts that they are giving her valuable information, and she says it is very practical advice too. The type of tailoring of information by therapists that Monica desires is hard to get from research. Monica has said that when she reads research, she notices that it is mostly about a group of children. She knows that children are all different, and she finds the broad results of such research to be difficult to apply in her life with her child. This opinion on research is one reason why Monica prefers information that comes from her therapists; they can act as knowledge brokers in the tailoring of health information.

Monica's therapists also provide ample access to health information. Therapists do this through frequent visits and communication via email. Sometimes, Monica has meetings with multiple therapists as once, allowing her to ask questions and get information from all of them. She says that if her therapists don't know the answer to a question she has, they will find someone who does. This referral saves Monica from having to go through different sources herself. Of course, she does not rely solely on therapists for her health information. However, Monica always brings her information that she is considering on using back to her therapists. She rarely makes a decision without first consulting therapists. The trust that she has built with them and her history of satisfaction with their work and results has led her to create a strong relationship. Therapists have a very large role in the use of health information with Monica. Therefore, when examining how Monica uses health information, it is prudent to ask how she uses information with the aid of her therapists (her knowledge brokers). This is not to say that she would not make use of a knowledge broker who isn't her child's therapist. However, at this point in Monica's life, with her current level of self efficacy and her relationship with her child's therapist, she does not feel the need to add another individual to her resource circle yet.

Parent 2: Conclusion to Monica

In this section, I presented Monica's narrative about her relationship with information, how this is affected by the inclusion of therapists, what she thinks about using a knowledge broker and her opinions on research-based health information. The main concepts underlying the patterns in Monica's information use are temporality, self-efficacy, and her relationship with therapists. The next section of this thesis explores the third and final parent's patterns of use of health information.

Parent 3: Bridget's Narrative

Introduction to Bridget. Bridget is a married mother of three children: a 10-year-old, 8-year-old and a 3-year-old who has cerebral palsy. Bridget is 38 years old, holds community college degree and works full time. Her child was diagnosed with cerebral palsy *in-utero*, and is classified by Bridget to be in GMFCS level I. Bridget rates her use of research information to be 5 out of 7, meaning she often uses research information. Bridget’s narrative on how she uses health information is presented first in the following section.

I begin with the sources of Bridget’s information, which are others with a similar condition, participating in research, by living with a chronic condition herself, written information sources, the internet, her intuition as a mother and person and health care providers. Bridget’s information management techniques are discussed next followed by the outcomes of Bridget’s health information use. These outcomes are keeping health care practitioners and other people up to date, providing information to others with a similar condition, providing interventions herself, understanding the condition and trajectory, and deciding on interventions external to the home environment. These sources of information, information management and outcomes from using information form Bridget’s pattern of information use, and each one will be described in this section and outlined in Figure 4-9. Following these descriptions, I discuss Bridget’s opinions on the use of a knowledge broker and research summaries.

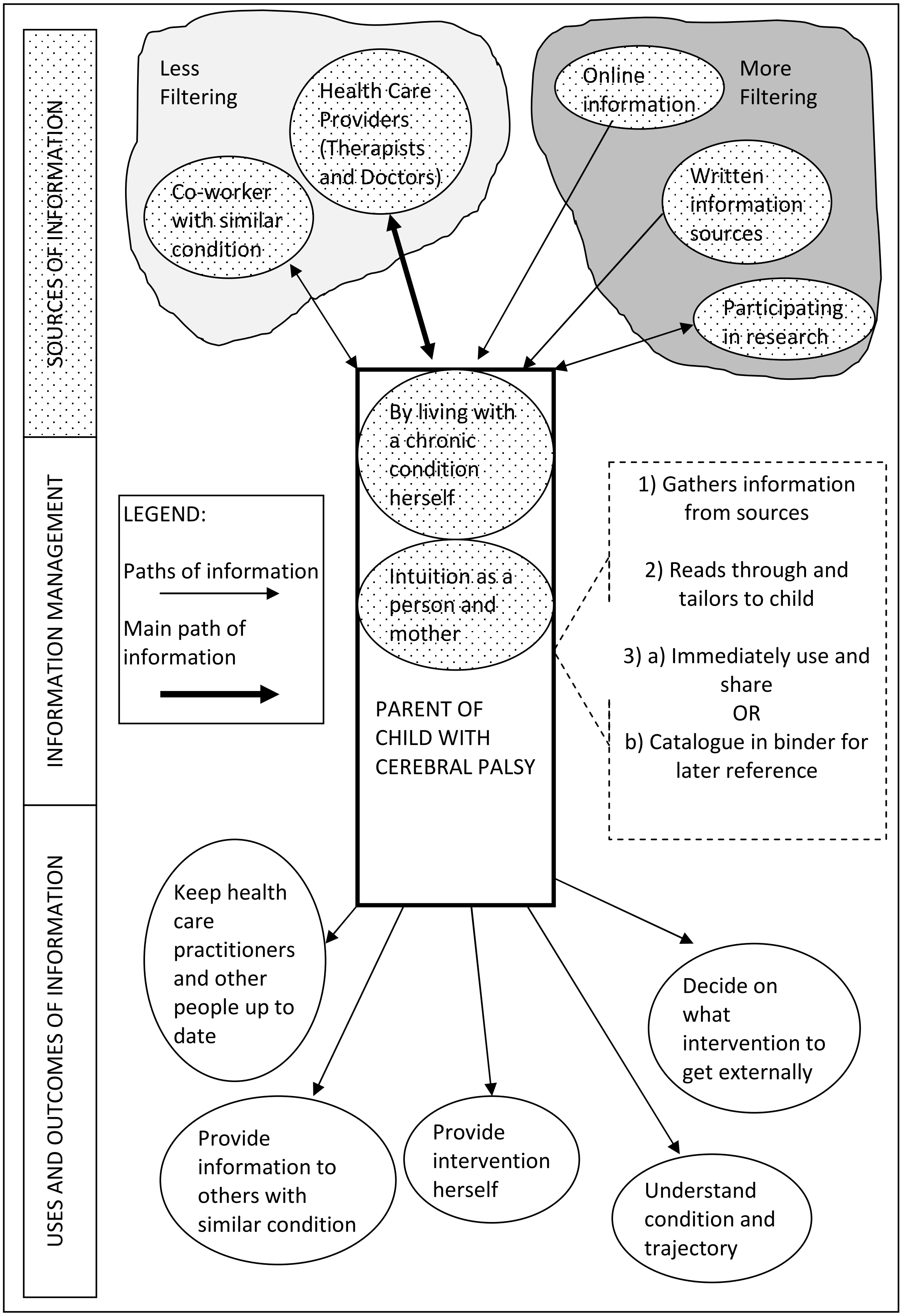

Figure 4-9. Bridget's interaction with health information.

Bridget's sources of health information. Bridget receives some of her health information from others who have a similar condition. She works with someone whose husband has the same condition as her child, and they share information often. She says "*he's come back about certain things he reads from books and talks. He actually sees the same doctor [my child] sees and he's like 'oh, yeah, that doctor, he's great, he'll be thorough' so it was really great to have that there*." In addition to this co-worker, she also received information from another mother when she was expecting her child with cerebral palsy. Bridget shares that this mother told her:

> *"To document everything... what you say at your appointments, when she takes her first step, because that will all come back to help you. She had a daughter who was having problems like a sleep apnea, but it turned out to be seizures. She said I wish someone had told me that when we were going through this with our daughter."*

Bridget not only receives information from other individuals who have experienced a similar condition, but she shares it as well. This is demonstrated through the double-sided bold arrow in Figure 4-9. According to Bridget, "*anything that we find that worked for [my child] or tricks that we've done, I definitely share them, and they can take it away. I'll say 'this is something someone told me, give it a try because it worked for us'*". She gives an example of sharing information with another friend who found out there was something wrong with her baby's brain *in utero*. Bridget says it was on a similar scale to what she experienced with her child, except when she was experiencing it, she had no one to prepare her for what to expect. She tells the following story about her conversation with her friend:

> *"I told her 'you know what, look at my child, you've seen her, there's hope, like don't go in thinking the worst, keep yourself busy and go from there'. And you know she was saying MRI, and I was like 'well this will happen and this will happen and this is what you can expect when she wakes up' because my child had an MRI at 6 months so I was like 'she'll look like spaghetti, it will be this, it will*

> *be that'. Because it's scary when you're going in there and you don't know what to expect. At least that way when I've been through it and this is what they can expect it's a little more comforting for them as well. So if we can share, either way, we do it."*

In this sense, Bridget receives information from what she perceives to be reliable sources, documents everything, shares what she can with others, and uses information to address unknown outcomes.

In addition to these connections with individuals with similar conditions, and the sharing of information between these people, Bridget also connects with researchers by participating in research studies. She gets valuable tips and information from participating and provides researchers with information to complete their study (demonstrated by double-sided arrow in Figure 4-9). Recently, she has a researcher come to her house with a Wii game console, and she said "*the student suggested a game for Wii, a dance game where you can specify the hand to have the remote in... so the right hand so she can move that hand*". In regards to her son who has the same chronic condition as herself (that is not cerebral palsy), she combines her desire to help others and her desire to contribute to research:

> *"So whenever there is anything for research I am right there, first in line, if I can help then I will. Especially if it is going to help someone else or benefit my son down the road then I'm there. I'll jump in with both feet. And I said to my husband, even if we didn't have our son, if it would still help somebody, I'll do it. It doesn't hurt me. It's a drive down here, we have family down here, so if we can help, we will."*

Bridget has expressed that living with a chronic condition herself, and having a son that has inherited it, has provided her with previous experience of handling information to apply to her child with cerebral palsy. This source of knowledge and experience is embedded in the "parent box" in Figure 4-9, since it is a part of Bridget. Bridget says "*I think it's fortunate for my child to come from a family like this. Like you know what, you* *can do it*". Bridget has a very positive and strong attitude when making decisions about the care her child receives. In fact, after experiencing a chronic condition herself, when she reads information from online resources she "*wonders if it is just more a 'woe is me' case... some of the reading I did for my child was saying different things and I was like 'that doesn't apply, she has been dealing with this her whole life'*". She goes on to say "*there are websites about my neuromuscular disease, and I don't want to read it because it's not upbeat, it brings you down. It's a different case, you know?*". In this sense, Bridget actively filters her information, discerning whether it is overly negative or inappropriate to use for her daughter. This appraisal of the information Bridget reads is consistent across her written and online sources.

Bridget says she "*uses both medical books that I have purchased and the internet... but the internet is more detailed*". In addition to the internet being more detailed, Bridget feels that she needs to "*take the information with a grain of salt because obviously some of it is not as bad as they make it out to be on the web*". As she says, "*it's all about deciphering everything, because you don't want to read it and be depressed*". Bridget adds that "*every scenario is different, and there is a huge window of information online and we don't know where she is going to be*".

When Bridget' child was diagnosed before birth, they did not know too many details about the condition. Bridget says she "*did research on the diagnosis when my child was first diagnosed*". However, without many details about where her child fit on the spectrum, Bridget shares that "*it was a massive spectrum and a scary one*". Bridget recounts her experience in the following passage:

> *"It's just that it's so much information, and 'here's the best case and the worst case'. But it's too much! I know you have to tell us and tell me all this, but holy geez! How am I supposed to take this all in and not stress out and affect the baby and still go on! So it was like, that's enough. It's just too vague, it's that huge gap that they give you and you don't know where you're going to be. And when you don't know, you're hoping for the best case but then there's the worst case and it's just enough! Just whatever happens, happens and we'll take the hand we're dealt but I can't keep reading this stuff."*

Online information at this point in Bridget's experience did not help her because she wasn't able to use it. Instead, it created a bigger uncertainty. Bridget looks for information to "*reduce the uncertainty and to know what we are dealing with and where we are going*". At the diagnosis of her child's condition, her online and written information were not effective for her. Another point at which information failed Bridget was during her daughter's first MRI. She recounts her disappointment at the information provided:

> *"I didn't know what she was going to be like when she woke up, I wish someone would have told me. She's not going to be able to hold up her head, she's going to be coughing, she's going to have semi-breathing problems because the tube has been taken out. I wish somebody was there to say all that. They just said they were giving her an MRI and then sedate her and that was the end of it! Nobody really said anything. And they were like 'this is to be expected' but it was like you guys didn't tell me! I could read a pamphlet but it wouldn't detail it as much as somebody saying 'well this is what you can expect'".*

These experiences may have underlined the patterns of appraisal that Bridget currently uses when looking at health information. That is, after experiencing information that was not helpful and not predictive, she is now more critical when deciding which information to use. This is demonstrated by being categorized in the "more filtering" side of Figure 4-9. At these points, and at points along the way, Bridget has learned to rely more on her intuition as a mother and as a person to handle this uncertainty.

One of Bridget's main recommendations for other parents of children with cerebral palsy was to trust their instincts with health information. She says that "*with all three [of my children] it's the same... just give me information! Even before they were born I read the information for nursing, what's going to happen in the pregnancy, what to expect when they get here*". Bridget's consistent desire for information and to know what's going on in her children's lives has led her to make many health-related decisions without waiting for her therapists or health care practitioners to make them with her.

Sometimes she just relies on her own intuition. For example, she tells the story of having her son tested for the same chronic condition she has:

> *"Like my son, before he was even diagnosed I knew he had the disease by the way he was walking. My husband was like 'no, it's this, this' and I was like 'no, I'll put money on it'. So we went to the doctor and I was like 'could we get him tested' and she was like 'we don't normally test before they show signs but because you are the way you are, I will test him' and sure enough he has it."*

In relation to her daughter, Bridget has acted as an advocate for her daughter's care by trusting her intuition on what felt right, and asking for help. She shares:

> *"At the children's hospital, they discharged her after 6 months and I noticed that right side wasn't working properly, and I said to the doctor 'she looks really stiff'. And he was like 'she might need some physiotherapy', and I was like 'I want a referral now'. I was the one who started it, and stayed on the ball about it, and did the follow up to see how do we get the therapist into the house."*

These instances of intuition guiding Bridget to make health decisions influences the patterns of the information she applies and the information that she doesn't. Bridget's intuition is an active component when making health care decisions, and is embedded in the "parent box" along with "living with a chronic condition herself" in Figure 4-9. Bridget gives many examples of how she works with her health care providers, to achieve desirable outcomes with health care and treatment decisions.

Bridget uses health care providers to provide her with information and advice. With Bridget, it seems as if she uses her therapists just as often as her doctors. She says that "*our pediatrician has been wonderful throughout the whole thing*". Bridget also says "*the physiotherapist is more like a case worker, she gave me information on how to work with my child, exercises and stuff. But the therapists are wonderful with ideas of what to work on her, study groups, courses*". Bridget feels very comfortable asking her health care providers for information, even if it is information that parents would not usually be privy to. For example, in working with her son who has a speech condition, she says that the school board only works with him so far before they discharge him. However, Bridget has come to know the speech-language pathologist in her son's school by volunteering there. According to Bridget, as a result:

> *"[The speech language pathologist] just went to a seminar about different techniques. She photocopied the entire PowerPoint presentation and gave it to me so I could continue to work with him at home with the different techniques and tongue placement. And she knows it's because I've researched the information, and we've always done speech therapy."*

This relationship with her health care professional allows her to have access to information so that she can take control on her son's therapy. Specifically in regards to the doctors that Bridget works with, she has a particularly positive information sharing relationship. In regards to addressing Bridget's concerns at appointments, she says "*we were asking about her eye because her eye was rolling. He was like 'I don't think it's serious, but maybe you should see here and here'. He was on top of things and shared that information*." In fact, Bridget is so comfortable in working with her various doctors that she feels she can liaise with them outside of appointments. As she describes, "*those appointments are so short, so I will just go home and research it. If I can't find anything I'll call the family doctor and say 'OK, what do you know? So I just go home, and if I need to, I can call the office*". Bridget feels comfortable in her own information searching abilities to involve the health care providers minimally in this process. When she does need help making a decision about the quality or trustworthiness of a piece of information, she tends to mention it to a few health care providers. Finding agreement amongst the doctors she works with helps her verify her health care decision on a piece of information. This is not to say that she does not use health care providers to help her make decisions about her child, or help decipher the information that exists. Rather, she does not solely rely on them as her primary source of information. Therefore, they are represented as a source of information on Figure 4-9, and not involved in Bridget's information management.

Bridget's health information management. Bridget gathers information from a number of sources, as described in the previous section. After she gathers this information, she seems to read and tailor to her child herself. She does not rely on therapists to do this with her. She also filters her own information without the aid of a therapist. This means that she is gauging the quality and truthfulness of what information she is retrieving. After this step, Bridget seems to either catalogue it for later use, or apply it right away. Applying the information right away involves sharing it with others, such as individuals with a similar condition. Her explanation of this system is as follows:

> *"I like going everywhere for [information], printing it off and reading it. And then going 'oh this applies' and then highlight it or 'this doesn't apply'. And even pamphlets- it's information, so if anything happens like surgery or something I have it here [gestures to binder on table] in [my child's] binder of information. And all of her reports, like her MRI and everything, I'll request for a copy to be sent to me so I have it on file. So if we get sent to a new specialist or whatever I've got it. And I can revisit it so I can understand what's going on and what they're saying."*

As mentioned above, Bridget will read and keep her information, even if it doesn't currently apply. She keeps it catalogued in case she needs it at a later point in her child's life. Since Bridget has a chronic health condition herself, she provided a certain perspective on her patterns of health information use over time. She was able to comment on her information use before she had children (when she was just handling her own condition). She also provided information on what information use was like before her child with cerebral palsy was born and still *in utero* and diagnosed with cerebral palsy. This adds complexity when describing Bridget's health information management; that is, her health information management and use is underscored by time.

Bridget has talked about what it was like to search for information on her child before she was born. This was a point at which she didn't know much about her child's diagnosis, and the information she was receiving was scaring her instead of helping her. On the other hand, when asked about her current information searching, she says "*because [my child] is so good, I haven't done a whole lot of research. I mean, I did get some information on her arm, but she is using that arm so much now, it's not like she's not. So I don't go into a whole lot of detail with that*". Another example is when her doctor suggested Botox for her child. Since she was unsure of what that therapy meant in the context of cerebral palsy, she did some research. She says

> *"Now I'm understanding why we're injecting my child with stuff people get in their face! We haven't done it yet, but I have done the research so that if next year, I can understand why we are using... and is it painful? And how do we do it? So I've looked into that now."*

It seems as if Bridget's drive to search for and use information is mirrored by what is currently going on in her child's life. The next section describes Bridget's uses and outcomes of information.

Bridget's outcomes of health information use. As mentioned above, Bridget likes to catalogue all of her written information. This allows her to refer to it when necessary to keep her health care practitioners and others up to date. For example, when I was interviewing Bridget at her home, she had her binder of information on the table to fill out forms for school for her child. Aside from providing information to health care practitioners, she provides information to others with a similar condition. For example, she will share what interventions worked and which didn't with a co-worker, or what to expect after a certain procedure with a friend whose child is experiencing the same procedure. Bridget also provides interventions herself at home. She gave me the example of providing speech language activities to her other children when the program was ended in their schools. Bridget also decides on what treatment to get externally, such as which therapies to pursue at what time for her child. Bridget also has a continuous desire as a parent to understand her child's condition and trajectory, which she does by using health information and connecting with others. In the next section, I describe Bridget's opinions on using a knowledge broker.

Bridget and the knowledge broker. The issue of time affecting Bridget's search for and use of information is also a concept that emerges when she discusses usefulness of a knowledge broker. She says:

> *"Well, I guess at that point there wasn't really anything. I mean, now I would love to access her because there are things going on with [my child's] eyes that I would love to see some more information on. But I think in that month there wasn't a whole lot going on. Everything was kind of covered, and we already knew what we were doing."*

Bridget is open to having someone to help her find more information for her child. In fact, Bridget did not know much about how the centre could help her find health information until this study. She shares "*I was like 'geeze, there is a person I could be talking to?' It's good to know! Because I didn't know there was a knowledge person who could actually talk to me and tell me stuff.*" When she goes to the centre, she sometimes picks up pamphlets, but she wasn't aware of the other more personal resources that the centre offered. She seemed very eager to start taking advantage of the resource centre and the knowledge broker now that she is aware. When asked if she could have used any other resources other than a knowledge broker, Bridget said that she thinks the role of a knowledge broker for parents is a great idea. She explains:

> *"I think that person could maybe help point you in some more directions. Like to narrow down that internet search when you're hit with all that information, where it's overload. At least a body could say 'you might want to look down this path more' because she's obviously got that resource and that knowledge. Whereas I'm just somebody on the net saying 'Ok, let's see what we can find!'*

Bridget indicates that she would use a knowledge broker to help her with the issue of being overwhelmed with information, so that she would be better able to use her information. In the next section, Bridget talks about her use of the Move & PLAY summaries, and information like them.

Bridget and the Move & PLAY summaries, Bridget was very eager to tell me that she "*read the whole [package of summaries], front to back*". She says that "*some of it went over my head, but I read it before I even filled out the [consent form]*". Bridget says that "*they were definitely an interesting read, and I saw where [my child] fit in and where she didn't*". She has "*never seen anything like that before*", and is ready to cycle them through her system for written health information. She mentioned that the summaries are "*on the computer table, ready to be put in the binder!*" The next section goes into detail about my interpretations on Bridget's information use.

Parent 3: Interpretation of Bridget's Narrative

Bridget's gathers her information from a variety of sources, reads through to tailor and filter the information herself, and then will immediately use or share the information or catalogue it in her binder for later reference. These patterns in Bridget's narrative are underscored by several concepts: she acts as a knowledge broker for herself and others, has built trust with her health care providers to meet her goals, is critical of negative information, has the self-efficacy to act as an advocate for her child's care, and the way she uses health information is underscored by temporality. These patterns are explored in this section, and I have added feedback lines to Figure 4-9 to create Figure 4-10.

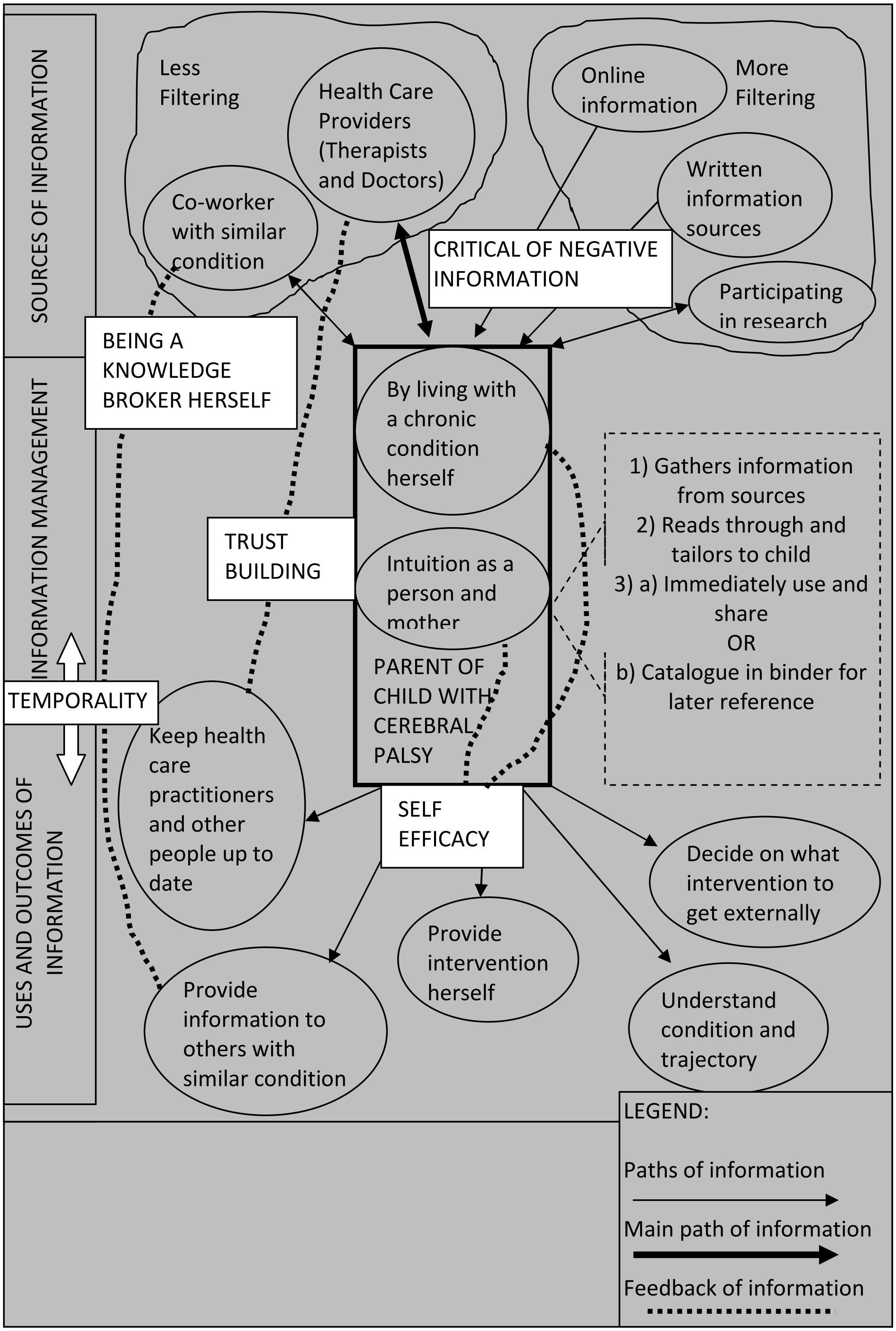

Figure 4-10. Interpretation of Bridget’s use of health information.

Acting as a knowledge broker for herself and others. Bridget seems to be brimming with health information at any given time. She involves herself in the daily lives of her children's health care by gathering and keeping as much information as she can access. She is passionate about finding and organizing her information and wants to share what she knows with others. She gives multiple examples in her narratives about connecting with various individuals in her life who are going through similar experiences as she is. She seems to be driven to share information with these people partially because she wishes that someone had gone out of their way to share information with her when her child was diagnosed. She shares negative experiences of finding things out the hard way, when all she wanted was some guidance through information. Therefore, whenever she feels like she has valuable or useful information for somebody, she will go out of her way to share it (as the dotted line in Figure 4-10 suggests). Bridget tailors that information to whomever she is sharing it with, and will explain it to them in a way they understand. This further suggests that she may be acting as a knowledge broker for these individuals.

In regards to acting as a knowledge broker for herself, Bridget has built up a community of information resources where she is granted access to information (the sources of her information in Figure 4-9, many of which including a double-sided arrow indicating open sharing). If she has trouble understanding something, she is not afraid to go to her health care professional for help (again, indicated by a double sided arrow in Figure 4-9). She also tailors what she reads to her child, easily seeing in most cases where her child fits and where she does not. She does this alone, without the aid of a therapist. This finding, understanding, tailoring and later using of information is a system that Bridget uses consistently when managing her child's condition. In this way, she is acting as a knowledge broker for herself.

Trust building with health care providers to meet goals. Health care providers are Bridget's primary source for health information. She has always had positive experiences with them, and feels very comfortable accessing them for information on a regular basis. Bridget also brings her questions and concerns about health information to them. This regular pattern of referring to therapists for her health information needs has strengthened the relationship between her and these individuals.

Bridget has built a very solid and trustworthy relationship with her child's health care providers. This high level of trust between Bridget and her health care professionals is indicated by the feedback line between Bridget's information outcome of informing health care providers and her source of information from health care providers on Figure 4-10. Bridget relies on her health care professional network to refer her to other sources when needed, and she expects that these health care professionals will reveal high quality information to her. She uses this information to provide therapy herself at home and to advance her children's treatment plans, and conveys this intention to her health care practitioners. This involves a high level of trust, as Bridget is using their information without subjecting that information to much filtering or criticality. Although she cites therapists as being a primary source for her information, she also talks a lot about the information searching she does independently from them. Perhaps the large amount of independent information searching she conducts helps her feel more at ease with trusting her health care providers so fully.

Self-efficacy in acting as an advocate for her child's care. As mentioned in the narrative, Bridget had a neuromuscular condition herself that one of her sons has inherited. This history of managing her condition and her son's condition has empowered her to take charge in her children's health care when she feels it is needed. She has given examples where based on her history or her intuition, she will request a certain intervention or hasten a timeline of when an intervention is supposed to be given. As such, Bridget has a high self-efficacy when it comes to making decisions on behalf of her children's health care needs.

Bridget's self-efficacy is indicated on Figure 4-10 with the dotted line connecting her intuition as a parent and experience with living with a chronic condition herself with the outcomes of her information use. Bridget's intuition and experience with chronic conditions has led her to make certain decisions about the care her child receives. Experience and intuition are two inner components of Bridget's being that she has fostered and uses regularly. These combine with her decision making self-efficacy to make appropriate health care decisions for her child. “Self-efficacy” is placed above all the outcomes on Figure 4-10 to indicate that this self-efficacy affects all the decisions that are made by Bridget.

Bridget seems to have a good grasp of what resources and supports are out there, and expects her options to be open when choosing care for her children. When Bridget sets her mind on wanting something for her children, she finds a way to obtain it. Her positive relationships with her health care practitioners do seem to help her when she is advocating for her children’s care. That is, she has made it known that she is well-versed in the current information climate surrounding an issue and takes care to explain exactly why she thinks a certain direction should be taken. For example, Bridget said that the reason her son’s speech-language pathologist gave her information to perform exercises at home was that the therapist knew that Bridget was well-versed in the literature. Also Bridget’s self-efficacy helped her in her insistence to have her son tested for her chronic health condition, and to start physical therapy early with her daughter. In both these cases, Bridget had the outcomes she anticipated (her son did have the same condition as her, and her daughter needed to start physical therapy early). Bridget’s self-efficacy is strong and contributes to her advocacy for her children’s care, which has so far yielded positive outcomes for Bridget and her family.

Critical of negative information. Over time, Bridget has learned that she should be critical of the negative information that she receives from her sources. This approach to using information is evident in Figure 4-10 by the box across Bridget’s health information sources.

When describing her relationship with information, Bridget shares a particular dark period of her life when her child was first diagnosed with a brain condition *in utero*. The diagnosis was not definite, and there was little guidance on what to expect upon birth. The doctors could only give her a “window” of possibility on where her daughter could end up. With this background of guidance, Bridget set forth on her own to try and research her daughter’s condition. The online information she found mirrored what the doctors were saying, that it is too wide of a window to give any specific guidance on what to expect.

As a parent with a strong desire to be informed about her children's health issues, this initially did not stop Bridget from searching for some guiding information. However, as the weeks leading up to her child's birth passed, she decided she had to stop searching. Bridget demonstrated though her examples that when she is given a wide window of possibility on her child's health, information can be hindering instead of helpful. Without specific guidance on what the cause, classification and trajectory of her child's condition, the information available is too broad. She says that of course the best and worst case scenarios were presented, but without knowing anything about the condition, she was unable to place her child along the continuum. As a worried mother, she was hoping for the best but expecting the worst.

The fact that her child ended up being on the less-severe end of the spectrum drives the point home further for Bridget. That is, after expecting the worst for so long because of using the wrong information, she knows how stark the contrast is between accurate and helpful information that is predictive, and information that is incorrect and sparks unnecessary worry. This experience has changed the way Bridget interacts with information. Now she always views information criticality in that information that is viewed as overly negative may not necessarily be true for her child's case.

Temporality in Bridget's health information management and outcomes. As mentioned when discussing Bridget's health information management, Bridget's method of receiving, organizing, tailoring and using health information has changed over time. The concept of temporality underlines these differences, as indicated in Figure 4-10 overlapping the "information management" and "uses and outcomes of information" boxes. Temporality in this case means both chronological and progressive information use over time. Bridget describes different patterns that occurred before she had children and was dealing with a chronic condition herself, while her daughter was *in utero* and after her daughter was born. These different patterns and interpretations are described in Table 4-2.

Table 4-2
Bridget's Management of Health Information Over Time

	As an adult, 2 kids already born without CP	***In utero*, before birth**	**After birth, growing child**
DIAGNOSIS	Neuromuscular disease earlier in life	Fluid on brain, unsure of cause	Cerebral palsy
BIGGEST FEAR	That her children will get the disease she has, that she will be at the negative end of the spectrum	Not knowing if the baby will come out alive	Not knowing the trajectory of development or how to best help her manage
INFORMATION AVAILABLE	Negative disease-specific information, predicting trajectory of her disease	Very broad, sometimes scary, pessimistic worst case scenarios	Very broad, sometimes scary, sometimes helpful
WHAT TO DO WITH INFORMATION	Uses it to make decisions about herself, to manage her disease	Can't take action with it, could decide to terminate or not, otherwise must wait and see	Uses it to make decisions about her child
ABILITY TO UNDERSTAND WHAT IS GOING ON	High - she has dealt with it her whole life, and she has had experience with working with the information available	Low – information not helping, unsure of cause of fluid, unsure what result of fluid will be	Medium- through information and concrete diagnosis, and health care practitioner's help, but still has time to learn more
EXTERNAL HELP	Has control, with possible help from doctor	Doctor has control	Parent has control along with doctor and therapist because of ability to know what is going on and ability to take actions into own hands
LVEL OF INFORMATION SEARCHING	Looks at information regularly because she is a mother, also looks for information sporadically regarding her condition	High because of uncertain stressful time. Soon to cease because of poor information guidance	Steady mostly, because child is developing fine. Speeds up when something happens.

In Table 4-2, Bridget describes three distinct points in her life when she was searching for health information. The first row I would like to discuss is “biggest fear”. Whatever Bridget’s biggest fears are at each interval in the table drive her health information search. Essentially, as Bridget’s information goals change over time, so does her interaction with health information. In the next row, “information available”, Bridget perceived the information that was available to her when handling her condition was overly negative. She knew this because she was currently managing her condition, and over time the negative things she read about didn’t happen. Likewise, while her daughter was *in utero* and the information that Bridget was looking through was negative and tended to be worst-case scenarios. This negative information also turned out to be unpredictive of the outcomes she observed with her daughter. These two experiences have been described in the concept of being critical of negative information. Her third experience with information, while her daughter is a developing child, is that although negative information exists, there is also positive and helpful information out there for her.

The fifth row, “what to do with information”, demonstrates that when Bridget has a concrete and searchable diagnosis of a condition, she is able to act on the information that she receives. However, if she is not given a broad explanation of a health situation, as she was given while her daughter was *in utero*, she finds it harder to use health information to make decisions. At these points when the diagnosis or condition is too broad, Bridget does not feel comfortable moving information into her decision making process because information does not narrow this void. This coincides with row 6, “ability to understand what is going on”. I interpreted Bridget’s ability to understand the current phase of her life staged by her narrative on how she interacted with health information over time. This approach is ranked as high, medium and low in relation to one another. The longer she was able to get familiar with a condition, the more ability she had to understand what was going on. Understanding a particular stage in her life allowed her to use health information more fully. This familiarity seems to be driven by chronology, in that she must experience the condition for a period of time before she is able to feel comfortable understanding what is occurring.

In row 7, “external help”, I comment on Bridget’s control over her or her child’s situation. This also coincides with temporality, as her control of her information use is synonymous with how comfortable she is with her familiarity in managing the condition, and subsequently what kind of information is available to her. Her control over information progresses over time, as she is able to build self-efficacy to use health information to handle more familiar situations.

The last row, “level of information searching”, includes my interpretation of the amount of information searching Bridget conducts at any point in time. Bridget’s pattern of information searching is steady before and after her daughter was *in utero.* This is because at these points she was not experiencing any major milestones or problems in development. However, when Bridget experienced a negative and broad diagnosis of her developing child *in utero*, she had cause to search for information at a high pace. In this sense, Bridget’s information use is tied to temporality. That is, where she is in the chronology of her life, or how her child is progressing influences the information searching that she conducts and therefore affect the amount and kind of information she has to apply in her life (hence the placement of “temporality” on Figure 4-10).

Parent 3: Conclusion to Bridget

Bridget’s ways of finding, managing, and using information is multifaceted. She involves many different individuals in this process and it changes over time. The main themes of Bridget’s narrative were acting as a knowledge broker for herself and sharing information with others, working with and trusting health care professionals to meet her goals, using self-efficacy to be an advocate for her child’s care, being critical of negative health information and the temporality in Bridget’s health information management and use. In the next section of this findings chapter, I bridge all three parent narratives together and posit a provisional model relevant to monitoring knowledge use by parents. I also incorporate the narrative of the knowledge broker to answer the overall research question of this case study: *how do parents use health information when living with and caring for their young children with cerebral palsy*?

Overarching Case Study: How do Parents use Health Information with the Aid of a Knowledge Broker when Living with and Caring for their Young Children with Cerebral Palsy?

Introduction. In this section, I aim to bridge all the embedded units of analysis (the knowledge broker and the three parents) together to answer my research question. I will be doing this with the aid of relevant literature on family-centred care (Chiarello, 2012), the Social Cognitive theory and self-efficacy (Bandura, 1986), cerebral palsy (Rosenbaum et al., 2007) and the knowledge-to-action framework (Graham et al., 2006). First, this section is an interpretation that aims to explicate differences in parents' use of health information. This is accomplished through the use of figures that will act as spectrums to examine the differences and similarities among Jessica, Monica and Bridget. After this, I link these spectrums to how a knowledge broker is perceived and may be used by these parents. I then comment on how this is particular to parents of children with cerebral palsy. Finally, I present a provisional model to depict potential areas for monitoring knowledge use and its relevance to the knowledge-to-action cycle.

How do parents use health information? The parents in this research study use health information differently. Jessica, Monica and Bridget's experiences can be mapped along different spectrums of health information use. The first spectrum I present is Chiarello's *Role of Family Members Spectrum* (2012). This spectrum attempts to order the extent and type of participation by family members in the care of their children (Chiarello, 2012). The spectrum (on the following page) acts as a continuum in which family may be placed depending on varying factors unique to each family at any time (Chiarello, 2012):

Non-Involvement
Passive Involvement
Information Seeking
Partnership
Service Coordination
Advocacy

Figure 4-11. Chiarello's *role of family members* spectrum (2012) which demonstrates the extent and type of participation by family members in their care of their children.

Figure 4-11 describes family involvement in care as Chiarello suggests, but also parents' involvement in the seeking, tailoring and use of health information for their children with cerebral palsy. As outlined in the individual cases in the previous sections of this chapter, Jessica, Monica and Bridget have differing opinions when it comes to their role in information seeking, tailoring and use. In Chiarello's model above, I have placed Jessica between "passive involvement/information seeking", Monica between "information seeking/partnership" and Bridget between "service co-ordination/advocacy". In the following spectrums that I have created to add to Chiarello's model of family involvement, Jessica is represented on the far left, Monica in the middle and Bridget on the far right.

Sources of health information

Jessica	Monica	Bridget
Mainly health care providers, family members, occasionally the internet	Mainly health care providers, family members, the internet, conferences and workshops	Health care providers, others with similar condition, participating in research, written and online information

Figure 4-12. Parent's sources of health information

As demonstrated in Figure 4-12, parents' information sources can vary from very few to a larger number. Parents retain these information sources consistently; as they tend to be satisfied by the information they are receiving from them at this point in their children's lives. In Figure 4-11, parents who are less involved may not feel compelled to use numerous information sources. However, parents advocating for their child's care may feel it necessary to obtain as much information as possible, from a variety of sources, on their children's care. Jessica primarily uses her therapists as an information source, who have their own sources of information. Occasionally, Jessica may receive information from a family member and do some research online on her own. Monica not only uses her therapists, family members and online sources, but also attends workshops and conferences to connect with other people who share information. Bridget, an advocate for her child's care, uses all the sources that Jessica and Monica use plus others with a similar condition and by participating in research. She also manages a chronic condition herself, and uses that experience to help her find information for her child.

Finding and tailoring information

Jessica	Monica	Bridget
Therapists find and tailor information to parents' needs	Therapists mostly find and tailor information to parents' needs, but parent also attempts this alone	Parent finds and tailors information to her own needs, with occasional help from therapists

Figure 4-13. Parents' levels of information searching and tailoring

Consistent across all parents was their appreciation of and satisfaction with their health care professionals, which is demonstrated in Figure 4-13. Jessica, Monica and Bridget trust the information coming from these professionals to be accurate and applicable. These parents also trust their doctors' and therapists' opinions on the information they find alone. Parents like Jessica on one end of the spectrum, feel very comfortable having therapists find and tailor their information, and see no need to do it themselves. This could coincide with the fact that they are not as actively involved in using information to make care decisions. However, as one moves along the spectrum, it becomes clear that a parent on the advocacy end seems to have more self efficacy to find and tailor their own information, without the aid of a therapist. Bridget uses the therapists as an information source and as an aid in making health care decisions, but not to the extent of Jessica and Monica who rely on their therapists more heavily.

The Social Cognitive Theory (Bandura, 1986) describes how parents may use information differently depending on external factors such as prior experience or family composition. Self efficacy is a major component of this theory, meaning that as parents feel more comfortable and experienced with using health information, they will do it more often (Bandura, 1986). In the context of the Social Cognitive Theory and self-efficacy, the parents in this study have shared information about past experienced and current contexts that contribute to their use of health information. For example, their experiences searching for information alone, usually on the internet, have been negative at the time of diagnosis for their children. This negative experience has influenced the parents' current beliefs in their abilities to effectively search for and use health information and has also influenced their involvement of their therapists in this process. Furthermore, individuals like Bridget have experience managing their own chronic health conditions and chronic conditions of their other children. The experience and history of using health information effectively in this case informed their self-efficacy to continue searching for and using health information independently of their therapists.

Managing health information

Jessica	Monica	Bridget
Does not keep or catalogue health information	Keeps all health information to personally reference at a later date	Keeps all health information to reference at a later date and to inform others

Figure 4-14. How parents manage their health information

Figure 4-14 demonstrates the differences in health information management among Jessica, Monica and Bridget. Jessica does not keep health information that is not perceived to be useful to her. This is aligned with her reliance on therapists to find and tailor her information in that if she ever needed anything information-related, she would not have to rely on herself to provide it. Monica does keep all her information to reference at a later date, regardless of its current perceived usefulness. Bridget also keeps all her health information, but uses it to help effectively advocate for her child's care. On Bridget's end of the spectrum, the more she gets involved in her child's care and gathers information, the more she wishes to share what she has with others. By cataloguing her information, she makes it easier to share it with others.

Use of research-based health information

Jessica	Monica	Bridget
Dislikes research-based information	Skeptical of research-based information	Impartial to research-based information

Figure 4-15. The use of research-based information by parents

None of the three parents particularly seek out information that has been sourced from research, as demonstrated in Figure 4-15. When presented with the Move & PLAY summaries, all three parents mentioned that they were hard to understand. Aside from that comment, Bridget was the only parent to express interest in applying them. Monica said that she might one day be able to apply them, and would keep them catalogued. Jessica did not find them useful, and made no mention of keeping them for later use. In regards to the perception of the quality of information that is from research, the parents seemed to not associate research information as applicable or usable by them. When parents get information from their therapists or doctors, they do not question their sources. Information from their therapists that is tailored to their child and can be practically applied is more important to these parents than information from research. Monica went so far as to bring up the generalized nature of research, and how numbers, figures and findings from such research is usually synthesized from a somewhat heterogeneous group. She does not think that information from such a source could be practical for her child.

Different kinds of information use. Graham et al. (2006) distinguish three kinds of information use: the conceptual use of knowledge (changes in understanding, knowledge, or attitudes), the instrumental use of knowledge (changes in behaviour or practice), and the strategic use of knowledge (to attain power or profit goals). All three ways of using information have been demonstrated by parents in this study.

Conceptual use of knowledge was observed in all three parents when they used health information to help them understand their child's condition and trajectory. Parents conceptually used knowledge more often than instrumentally or strategically. This is because parents were constantly aiming to understand what their child was currently going though, and to prepare them for what they could encounter in the future.

Instrumental use of knowledge occurred in all three parents when they applied what information they found on their own, or received from others, when deciding what treatment or management they were going to choose for their children. Often times this was done with the aid of a therapist, but it can still be classified as instrumental use of knowledge on behalf of the parent, as they had to make the final decision.

The least demonstrated use of knowledge was strategic, which was only demonstrated by Bridget when interacting with health professionals. This strategic use of knowledge may be underlined by the fact that she is on the advocacy end of the family involvement spectrum and has a high self-efficacy. Bridget takes action in making decisions and has a wish to help others understand information as she acts as a knowledge broker for other parents.

In the next section, I explain why parents did not use a knowledge broker, and whether they may in the future.

Information use with the aid of a knowledge broker. As mentioned in the previous sections, none of the three parents in this study used the services of the knowledge broker. The main reason for all three parents was that there was not enough time to make use of the knowledge broker. The parents had access to the knowledge broker for a month and a half, and there were no major transitions or issues in their child's care that caused them to seek for information or change their current information seeking behaviour. However, there was a difference among parents in their willingness to use a knowledge broker in the future. Figure 4-16 illustrates these differences.

Jessica	Monica	Bridget
Will not use a knowledge broker in the future. Will use therapists and other health care providers.	May use a knowledge broker in the future. May just use her therapists.	Will use a knowledge broker in the future in addition to her other information sources.

Figure 4-16. Parents' opinions on the usefulness of a knowledge broker.

As presented in Figure 4-16, Jessica does not feel the need to add another information source to her repertoire. She will continue to use her therapists and other health care providers. Monica may use a knowledge broker, depending on what she is faced with in the future. Currently, she is satisfied with her therapist as a primary source for information. Both Jessica and Monica have mentioned that they use their therapists like knowledge brokers. These parents said that their therapists find information, filter and tailor it to their child, and then deliver it at the appropriate time. All three parents trust their therapists, and have built relationships with them over time. For parents, trust and a relationship are important qualities to have in someone who provides them with information for their child. In addition to this, all three parents said that when compared to an external individual acting as a knowledge broker, their therapists know everything about their child and their specific conditions and trajectories. To Jessica, Monica and Bridget, this means that they are giving them the most appropriately tailored information. Furthermore, this means that the parents can access the therapists in a comfortable way when they have sensitive concerns about their children. In this sense, even Bridget's willingness to use a knowledge broker in the future will not be as a replacement for the tailored and sensitive information that she receives from her therapists. Instead, it will complement that information relationship she already has with her therapists.

In the next section I discuss how parents use health information specifically with children with cerebral palsy.

Living with and caring for young children with cerebral palsy. Cerebral palsy is classified as a group of permanent disorders, and can have a wide variety of physical manifestations and secondary conditions associated with it (Rosenbaum et al., 2007). Because cerebral palsy is such a broad and diverse condition, parents of children who have cerebral palsy have to manage this wide possibility of outcomes. In the interviews with these parents, it became clear that when their children were first diagnosed with cerebral palsy and they were not given a lot of guidance on the specifics of the condition, their own information use was affected. They were driven to use information as a way to comfort their fears of how their children would progress and they attempted to find information to clarify what their children were experiencing and what they should do to prepare their children for the future. Without this guidance, however, they found information to be negative, scary and not applicable to their child's nuanced form of cerebral palsy. The nature of cerebral palsy then affects the use of information by these parents. The relationship between broad conditions like cerebral palsy and information use is only subtly touched on in the information gleaned from my interviews with Jessica, Monica and Bridget. The next section explores a topic that was a main focus of this research, and that is how information can be monitored in parents of children with cerebral palsy.

Monitoring knowledge use: The Knowledge-to-Action Framework. In this section, I revisit Graham et al.'s knowledge-to-action framework (2006) that was initially presented in my introductory chapter. This framework influenced this research in a number of ways. Research summaries were chosen that resembled information resulting from the knowledge creation phase in the middle, knowledge was adapted to the local context of these parents' children's rehabilitation centre, the supports and barriers to information use were addressed, and a knowledge broker was provided to help tailor information to the parents' daily lives. I explored how knowledge was used by these parents after progressing through these initial steps of the knowledge-to-action framework.

Graham and colleagues acknowledge that there may be feedback between the dynamic stages in this cycle and they may influence each other (Graham et al., 2006). These researchers also give the disclaimer that because the process of moving knowledge into action is complex and dynamic, the boundaries between knowledge creation and action and the phases that comprise each one are fluid and permeable (Graham et al., 2006). Regardless, after exploring how parents use health information it became clear that a more refined model needs to be formed to demonstrate how to monitor knowledge use in parents of young children with cerebral palsy. I present a provisional model to describe this in the next section.

Monitoring knowledge use in parents of young children with cerebral palsy. Figure 4-17 is in response to the knowledge-to-action framework that has guided this research. It is also a result of interpreting and explicating the multi-faceted way in which parents use health information.

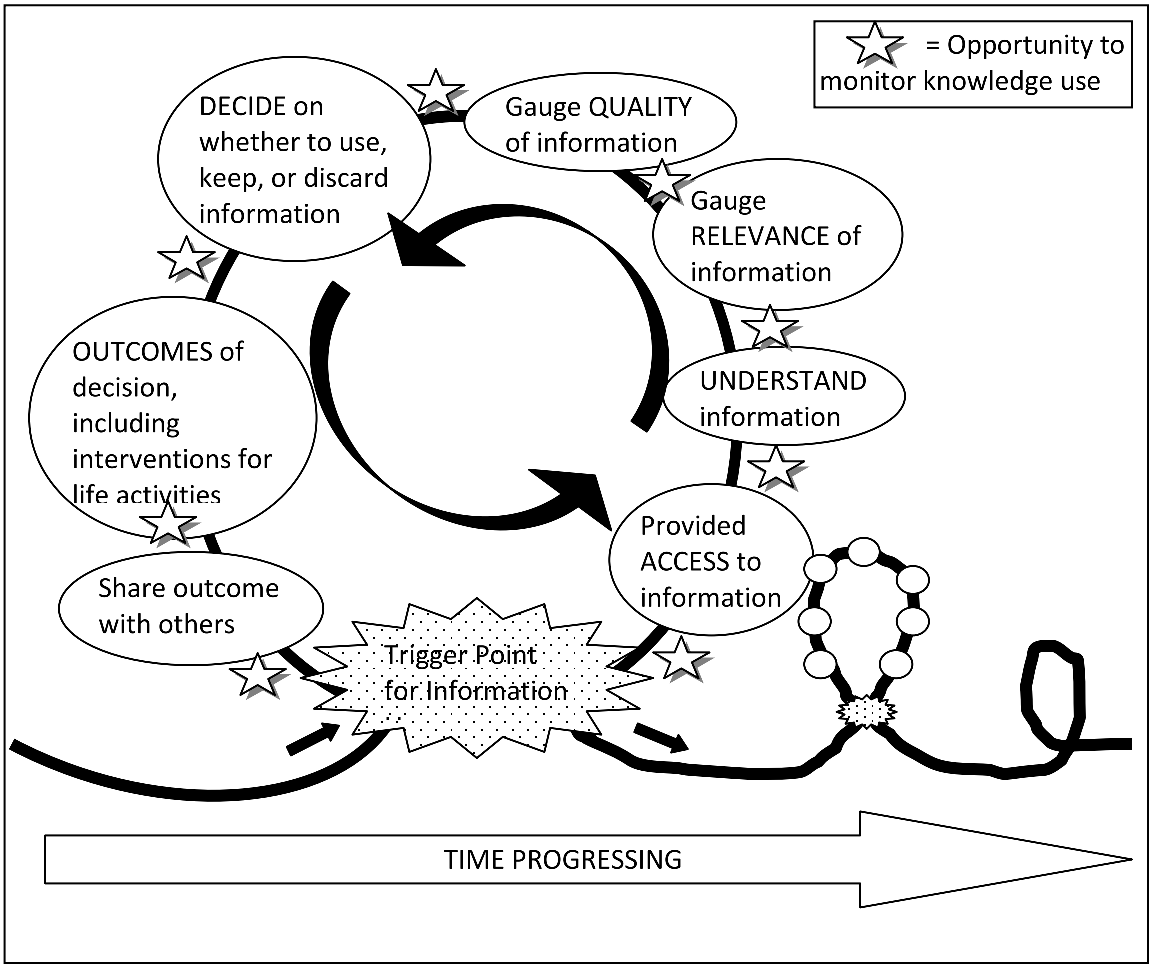

Figure 4-17. Monitoring knowledge use of parents of young children with cerebral palsy.

Monitoring knowledge use of parents of young children with cerebral palsy is characterized as a temporal endeavour. That is, to effectively and accurately understand how to monitor knowledge use in these parents, it must be understood that knowledge use will be connected to whatever point that parent is in their life (or their child's life). This temporality is why there is an arrow denoting the time in Figure 4-17, and why the cycle of knowledge use is not contained, but rather evolves over time. Each "spiral" on Figure

4-17 indicates a separate knowledge-use cycle. I was able to fill in the initial knowledge use cycle knowing how Jessica, Monica and Bridget currently use health information at this point in their lives. I have included phases in the next cycle, however I am not able to comment on what these phases might be as they could change at that later point. As these parents encounter different transitions in their children's lives, they will enter another cycle on this figure. The subsequent cycle may be similar to the one displayed up front in Figure 4-17, or it might be different. In any case, the cycle will represent a complete transition through the health information, from first encountering it to eventually using it (or not using it).

I have begun the initial cycle in Figure 4-17 with a "trigger point" phase. This represents a point in time characterized by an even or occurrence in the parent's life that causes them to use health information. Such an event may be planning for a major transition such as preparing for kindergarten, needing information to provide to a health care provider or fill out a form, or just wanting information on a general aspect of cerebral palsy to understand the condition better. Whatever the trigger, it will propel parents into the proposed version of parents' knowledge-to-action process.

The following phases in Figure 4-17 after the trigger point occur in a particular order for these parents, but may be repeated or skipped as well, depending on their personal context and the particular trigger that has made them enter the cycle. The first step is to acquire information. Next, parents have to understand the information they are receiving or they will not be able to progress further. The third step is to gauge the relevance of the information to their child's current condition, their family context, and their child's personal trajectory with cerebral palsy. The fourth step is to gauge the quality of the information, including whether it is too negative or goes against their personal beliefs on what is right. The fifth step is to decide on what to do with this information. I have given the three options mentioned by Jessica, Monica and Bridget. These are to discard the information due to its inability to be used right away, to keep it for later use or reference, or to immediately apply and use. These initial five steps in this cycle will either happen independently (for parents such as Bridget), with the aid of a therapist (for parents like Monica) or mostly done by the therapists themselves (for parents like Jessica). Although parents have not used a knowledge broker in their current information use, a future cycle could include a knowledge broker aiding parents in these steps.

The "outcome" phase is what occurs as a result from the decision of their previous phase. If it is to use the information, then the outcome is the treatment or management decision that parents have made as a result of the information (instrumental use), or the change in understanding as a result of the information (conceptual use). This could also include the strategic use of knowledge, if that was the initial goal. If parents choose to not immediately use the information, but catalogue it for later, this includes the placement of such tangible information into the binder of the parent. If the parent decides not to use or keep the information, then the information is discarded and the parent may go back to the first phase to find other information instead. The phase after this, sharing outcomes, indicates that parents will discuss their decision or the result of their decision with therapists, their family or other individuals invested in their children's care. For parents like Jessica, this could just mean informing their therapists of their decisions. For parents like Bridget, this could mean giving their information or insight to others with a similar condition. After this phase, a new cycle may begin, or parents may remain on the straight path before a cycle for a longer period of time (or until they are presented with another trigger point).

The stars in Figure 4-17 indicate places in the cycle where knowledge use could be monitored. Unlike the knowledge-to-action framework which only indicates this after information has progressed through the initial phases of the cycle can it be effectively monitored, my figure indicates that monitoring can occur at multiple stages. The primary difference here is that I classify monitoring knowledge use as more than just a quantitative technique to see if knowledge was ultimately used or not. In contrast, I believe that knowledge "use" is a process, and not an outcome.

Depending on where one may monitor knowledge use, one may be presented with different things. For example, monitoring knowledge use when gauging the quality of information will look different than monitoring knowledge use when sharing the results of their information use or lack of use. Not only will monitoring knowledge use be different depending on where the parent is in the cycle, it will be different depending on the parent in the cycle and what their context and background is. With these two conditions in mind, it becomes clear how complex monitoring knowledge use is, especially among of children with complex and wide-spectrum of involvement health conditions (such as cerebral palsy) who change over time as they grow and develop. Therefore, the entire cycle displayed in Figure 4-17 is considered to be “the use of knowledge” in that it is not restricted to one phase of a cycle.

In the following chapter, I discuss the implications of the interpretations of this case and how it may inform monitoring knowledge use, practice and education, and future research. I end with a conclusion of this research project describing how parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy.

Chapter Five - Discussion

Introduction

In this chapter, I discuss the implications of the research I conducted. I begin with the implications of my provisional model on monitoring knowledge use and the relevant research surrounding this process. I then discuss the implications of this research for practice and education in regards to health care professionals and rehabilitation centres. Furthermore, I will extend my suggestions for further research on this area, based on the outcomes of my findings and the methodology used to conduct this study. Finally, I will conclude this thesis with what we can describe about how parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy.

Implications of my Provisional Model of Monitoring Knowledge Use

Figure 4-17 is a provisional model of monitoring knowledge use in parents of young children with cerebral palsy. That is, it is singularly based on the research I have conducted with Jessica, Monica and Bridget and is expected to be different in different cases with different parents (and would also be different for parents of older children). Figure 4-17 is a magnification of what happens at the "monitor knowledge use" phase of Graham et al.'s knowledge to action framework (Figure 1-1). In Graham and Tetroe's 2010 article, they state that "the [knowledge-to-action] framework does not prescribe specifically what needs to be done at each phase in the process, nor populate each phase with theory that might direct action at each phase". Hence, my provisional model provides one description of what might occur at the monitoring knowledge phase in parents with young children with cerebral palsy. My model does not explicate who should be monitoring knowledge use (such as knowledge brokers) and at what stage. I have suggested places where monitoring knowledge use could be done based on the data from each parent participant, but this is not a prescription of where to monitor knowledge use or what monitoring knowledge use might look like.

The implication of my model on monitoring knowledge use is that it is a process that will look different over time. Parents of children with cerebral palsy have a complex relationship with health information based on the broad and general nature of the condition. As time progresses in Figure 4-17 and children with cerebral palsy develop, so does the potential to monitor knowledge use and the different outcomes that this will yield, making monitoring knowledge use complex in this case. In an article by Straus, Tetroe, Graham, Zwarenstein, Bhattacharyya and Shepperd, current conceptualization of monitoring knowledge use is discussed (2010). Most of the article gives examples of how to monitor instrumental knowledge use with research techniques. A further examination of monitoring conceptual and strategic use of knowledge needs to be given, as well as monitoring knowledge use with qualitative techniques. Monitoring knowledge use is especially important to examine based on the complexity of information use by parents of young children with cerebral palsy, as described in my study.

Implications on Current Knowledge Brokering Practice

Despite the fact that parents did not use a formal knowledge broker (such as Susan) over the course of this research, they were able to offer their opinions on whether they would use one in the future. Answers ranged from never using a knowledge broker to being very interested in using a knowledge broker. In all cases, parents valued the abilities of their therapists to broker knowledge to them. However, the centre where these therapists work (alongside with the knowledge broker involved in this study) recognizes them as informal knowledge brokers. One implication of my research on practice in centres such as this one is that therapists need to be re-conceptualized as formal knowledge brokers. Literature suggests that therapists (and other health care professionals) are typically considered to be formal knowledge brokers (Booth, 2011). If therapists can be recognized as formal knowledge brokers at the rehabilitation centres where they work, they may be provided with more resources and support to conduct this aspect of their jobs. According to Ward, House and Hamer (2009), knowledge brokers need the time and resources to effectively broker knowledge. If therapists aren’t recognized as formal knowledge brokers by the centre, they could be lacking the supports they need to more effectively broker knowledge to their clients. Because therapists are regarded very highly by parents of young children with cerebral palsy, and these parents heavily rely on these therapists for accurate and useful information, it is in the centre's best interest to re-evaluate how they define knowledge brokers in their context.

In regards to this research's implication for the practice of knowledge brokers, there is much more that can be discovered though later research. However, what my research does examine is that parents' desires to use a knowledge broker exists on a continuum. That is, some parents do not want to use a knowledge broker and others do. Overall, parents would rather have health information that is very specific to their child, which is best provided to them by therapists. Parents also feel more comfortable approaching therapists for health information because of their frequency of interactions and the relationship of trust they have built over time. This relationship between therapists and parents may inform how centres wish to use knowledge brokers in their contexts. The most logical connection to foster in centres appears to be between therapists and knowledge brokers. In this case, knowledge brokers could help therapists in their roles to provide information to their clients. Knowledge brokers would still be finding and tailoring information, but therapists would be able to deliver the information to their clients (when they can do so at specific times and with specificity to the child they are applying the information to).

Implications on the Education of Health Professionals

This research carries implications for how health care professionals could be better prepared through their education to work with parents effectively when it comes to using health information. In the case of therapists, their abilities to broker knowledge effectively need to be fostered in their education. If parents are saying that they rely heavily on their therapists for health information, as well as to appraise and tailor information that they find on their own, therapists need to be trained properly on how to fulfill these expectations. A component of therapists' education should be on how to find, gauge the quality of, tailor and deliver health information to consumers. Essentially, this expertise that therapists seem to already have while working with their clients in regards to health information needs to be refined, strengthened and explicitly recognized and valued.

Knowledge brokers who are working in rehabilitation centres should be trained to work with parents of children with cerebral palsy and other complex chronic conditions of childhood. Knowledge brokers should be able to understand the conditions of the clients they are providing information to, just as they should understand the culture of the centre in which they work. Parents may feel more comfortable approaching a knowledge broker with their health information needs if they feel the knowledge broker is knowledgeable about their children's condition. In addition to working with parents, it is essential that knowledge brokers are able to liaise with therapists to provide clients with information. Knowledge brokers should understand the roles and responsibilities of therapists, and understand where they may need to step in to aid therapists in providing their clients with health information. This could be achieved with site-specific knowledge broker training, where knowledge brokers contracted or hired to a certain site would be trained on the information dynamics at that site. Essentially, knowledge brokers should be sensitized to the kind of clients they are providing information to, and the individuals (such as therapists) they may have to liaise with to provide that information. In addition, monitoring knowledge use may be a responsibility that knowledge brokers wish to adopt. If knowledge brokers take on the role of monitoring knowledge use, it would be helpful for them to be familiar with how parents use health information which could be achieved by being sensitized to these clients.

Implications on Future Research Directions

Methodological suggestions. This research was conducted using a qualitative single embedded case study approach. This case involved three parents and a knowledge broker as embedded units of analysis. Future research should also consider involving therapists in this case to understand information sharing from their points of view. Therapists can offer unique perspectives on the information flow in the centre that may complement or coincide with what the knowledge broker was describing. Furthermore, therapists would also be able to comment on their perspective of their relationship with clients and their information management and knowledge brokering techniques could be explored. In addition to involving therapists in the research design, knowledge brokers could be provided to parents for a longer period of time before examining their interactions. This would allow for the temporality inherent in parents' information use, and increase the probability of parents encountering a transition or issue with which the knowledge broker could help. It would also allow researchers to examine information use at various points in time in these parents' lives. Finally, more parent participants could be included in this study to produce more examples of health information use. The spectrums I presented in the findings chapter of this thesis could be more well-rounded and representative if they were based on more parents. This could be accomplished by applying a grounded theory study design. Involving therapists in this case study, giving knowledge brokers more time to interact with parents, and recruiting more parents are methodological modifications that can be added to this study to yield a wider spectrum of results.

Conceptual suggestions. This research brought forth many interesting issues that were not able to be addressed due to the scope of my thesis. For example, the change in information use over time that was described by parents was not able to be observed in this research. Although it is a component of Figure 4-17, it is not able to be explored in depth. Parents' changing relationships with information over time and how this affects their knowledge use and the ability to monitor knowledge use needs to be addressed further. In addition to this, the change in information flow in the centre over time was also brought forward by the knowledge broker, but not elaborated on. The expertise of knowledge brokering done by therapists needs to be examined further, as does the knowledge brokering that parents engage in as a result of their self-efficacy in health information use and advocacy in their children's care. Another aspect that can be explored is whether evidence-based practice can be applied to parent populations, where research-based information is not typically used. Finally, the parents in this study all anticipated changing care needs over the next few years as their young children enter school. How these parents use information in the midst of these transitions should be examined and compared to information use at more static points in their lives (such as during this research project).

Conclusion

In this thesis, I aimed to examine how parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy. I conducted a qualitative case study involving a knowledge broker and three parents. The major findings of this study were:

- Parents' health information sources, management and outcomes differ depending on the parent, family, and child;
- cerebral palsy is a complex and broad condition with various outcomes, which affects knowledge use by parents of children with cerebral palsy,
- a knowledge broker is only useful to some parents, while others prefer to use their therapists as knowledge brokers,
- therapists or parents themselves can act as knowledge brokers,
- research-based information is not necessarily valued by parents,
- therapists are instrumental in the use of health information for parents,
- monitoring knowledge use is complex in parents of children with cerebral palsy.

These findings inform the practice of knowledge translation, and the movement of research-based health information into the hands of users. My provisional model (Figure 4-17) is a description what "monitoring knowledge use" may look like in the context of parents of young children with cerebral palsy. However, much work is still to be done on understanding how to monitor knowledge use in this population.

My research adds to a little-known area of knowledge translation: monitoring knowledge use in parents of children with a chronic condition. After conducting a final search of available research on knowledge translation and monitoring information use in parents of children with a chronic condition, it is still evident that very little information exists on this topic. In the future it is anticipated that the importance of health information use by front-line users will be examined more fully. This increase in research will lead to providing these parents with more useful information that will impact their lives and the lives of their children.

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Appendix A: Glossary of Terms

Term	Definition
Case Study	An empirical inquiry in which the focus is on a contemporary phenomenon within its real life context and when the boundaries between the phenomenon and its context are not clearly evident (Yin, 1994).
Cerebral Palsy	A group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain (Rosenbaum et al., 2007).
Client-Centered Care	A partnership between the client and therapist that empowers the client to make informed treatment decisions (Sumison, 2005).
Critical Realist Ontology	Reality is assumed to exist, but to be only imperfectly apprehensible because of basically flawed human intellectual mechanisms and the fundamentally intractable nature of phenomena (Lincoln & Guba, 1994).
Dissemination	The transfer of knowledge with and across settings, with the expectation that the knowledge will be ‘used’ conceptually or instrumentally (Hutchinson & Huberman, 1993).
Embedded Units of Analysis	Includes multiple units of analysis; looking for consistent patterns of evidence across units but within a case (Yin, 1994).
Evidence-Based Practice (EBP)	A problem-solving approach to the delivery of care that integrates the best evidence from well-designed studies, a clinician’s expertise, and patient preferences and values (Sackett & Rosenberg, 1995).
Family-Centered Approach	An approach to care in which parents have final control over decision making, parents are treated respectfully and supportively, and parents are provided with all the relevant information to make decisions (King et al., 1999).
Gross Motor Function Classification System (GMFCS)	A standardized system to classify gross motor function of children with cerebral palsy between the ages of 1 and 12 years old, based on the observation of the child’s self-initiated movement and need for assistive technology (Palisano et al., 1997).
Health Information Management	A complex process that involves the interplay of beliefs and behaviours related to accessing and interpreting information as well as making decisions and taking action based on information (Gallo, Knafl & Angst, 2009).
Health Literacy	An individual’s ability to read, understand, and use health information to make appropriate health care decisions that affect their health outcomes (Bennett, Robbins & Haeker, 2003, and Weiss, Hart, McGee, & D’Estelle, 1992).

Knowledge Broker	Someone who is capable of bringing researchers and decision makers together, facilitating their interaction so that they are able to better understand each others' goals and professional culture, influence each other's work, forge new partnerships, and use research-based evidence (Canadian Health Services Research Foundation, 2003).
Knowledge Translation	The exchange, synthesis and ethically-sound application of knowledge – within a complex system of interactions among researchers and users - to improve the health of Canadians, provide more effective health services and products and strengthen the health care system (Canadian Institute of Health Research, 2009).
Knowledge-to-action (KTA)	The KTA framework is a conceptual framework based on a concept analysis of 31 planned action theories that was developed to help make sense of knowledge translation (Graham & Tetroe, 2010)
Objectivist Epistemology	Objectivity is a regulatory ideal, and extra emphasis is placed on external guardians of objectivity such as critical traditions (Do findings fit with previous knowledge?) and critical community (professional peer reviews) (Lincoln & Guba, 1994)
Paradigm	The basic belief system or worldview that guides the researcher (Lincoln & Guba, 1994).
Post Positivist	A particular paradigm which aims to do inquiry in more natural settings to solicit emic viewpoints to assist in determining the meanings that people ascribe to their actions (Lincoln & Guba, 1994).
Single Case Design	As opposed to multiple case; represents one topic of the empirical study (Yin, 1994).
Social Cognitive Theory	The theory that an individual's behaviour is influenced by behavioural, cognitive and environmental factors (Bandura, 1986).
Tacit Knowledge	Personal, practical and difficult-to-write-down knowledge. It is context specific, deeply rooted in action and captured in the term "know-how" (Ambrosini & Bowman, 2001).

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Dear Stephanie, First, please accept my apologies for the delay in replying. I have been doing a good deal of traveling lately.

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Best regards, Curt Olson

Curtis Olson, PhD
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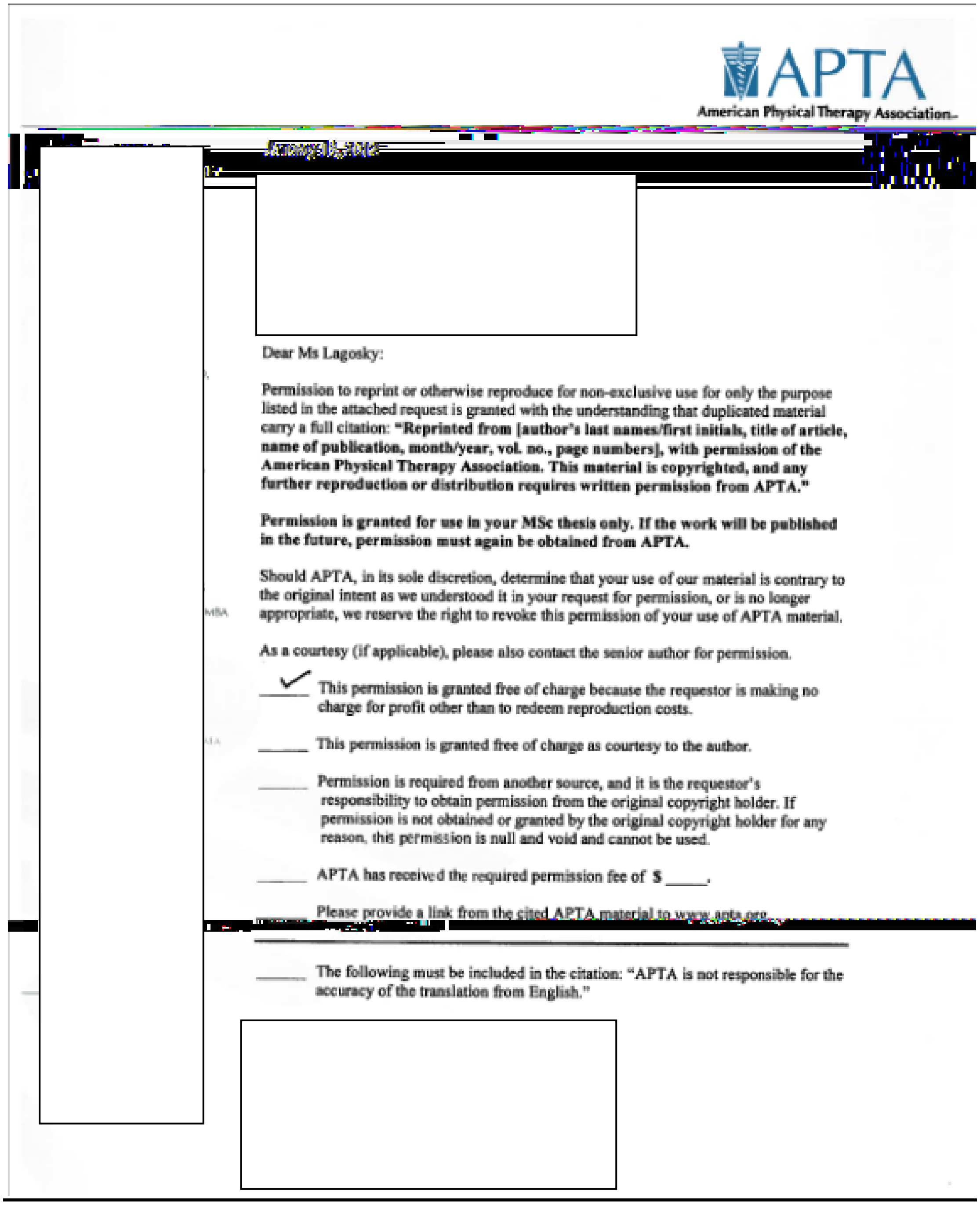

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January 13, 2012

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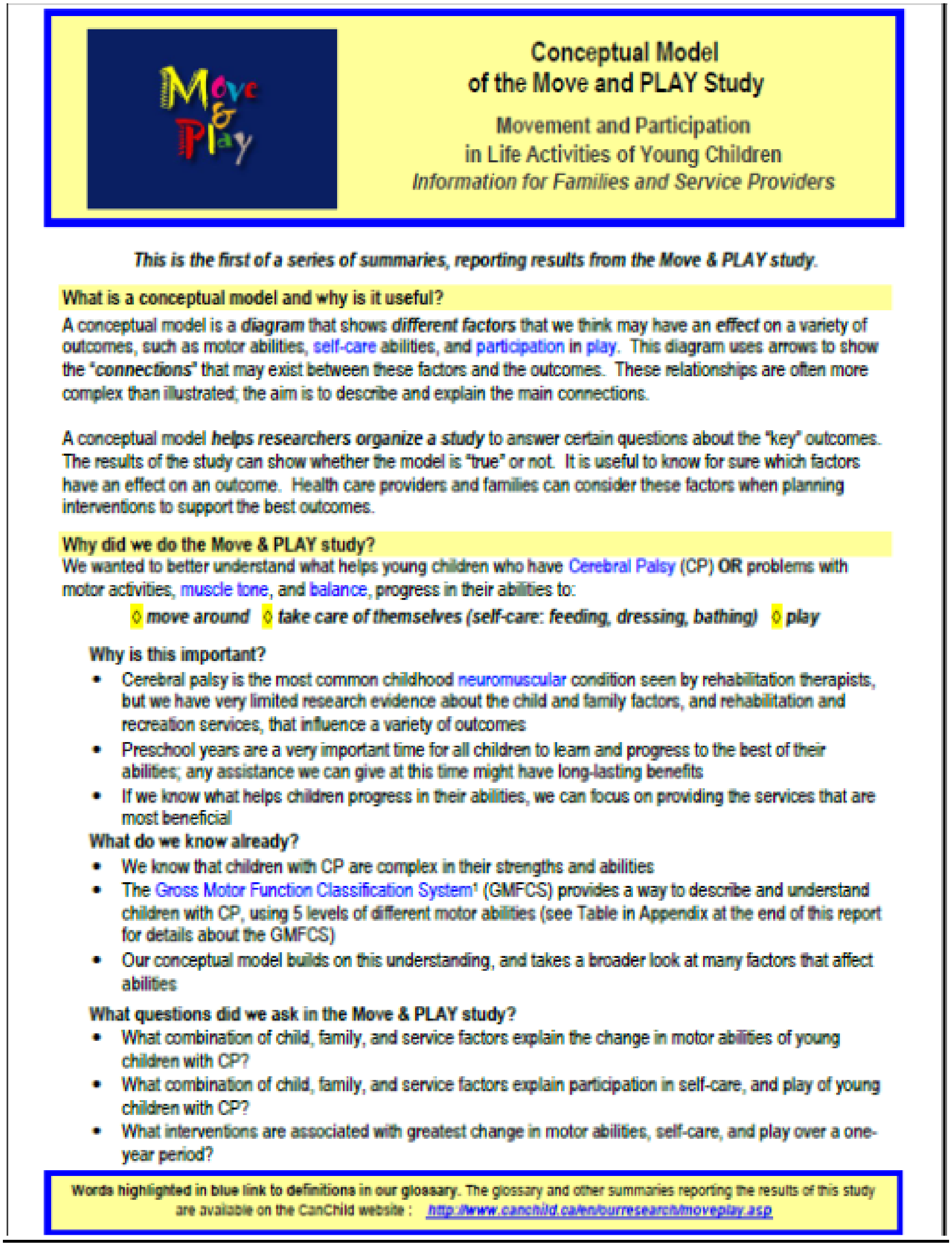
Appendix C: Examples of Move & PLAY Dissemination Pieces



Conceptual Model
of the Move and PLAY Study

Movement and Participation
in Life Activities of Young Children
Information for Families and Service Providers

This is the first of a series of summaries, reporting results from the Move & PLAY study.

What is a conceptual model and why is it useful?

A conceptual model is a ***diagram*** that shows ***different factors*** that we think may have an ***effect*** on a variety of outcomes, such as motor abilities, self-care abilities, and participation in play. This diagram uses arrows to show the "***connections***" that may exist between these factors and the outcomes. These relationships are often more complex than illustrated; the aim is to describe and explain the main connections.

A conceptual model ***helps researchers organize a study*** to answer certain questions about the "key" outcomes. The results of the study can show whether the model is "true" or not. It is useful to know for sure which factors have an effect on an outcome. Health care providers and families can consider these factors when planning interventions to support the best outcomes.

Why did we do the Move & PLAY study?

We wanted to better understand what helps young children who have Cerebral Palsy (CP) **OR** problems with motor activities, muscle tone, and balance, progress in their abilities to:

◊ *move around* ◊ *take care of themselves (self-care: feeding, dressing, bathing)* ◊ *play*

Why is this important?

- Cerebral palsy is the most common childhood neuromuscular condition seen by rehabilitation therapists, but we have very limited research evidence about the child and family factors, and rehabilitation and recreation services, that influence a variety of outcomes
- Preschool years are a very important time for all children to learn and progress to the best of their abilities; any assistance we can give at this time might have long-lasting benefits
- If we know what helps children progress in their abilities, we can focus on providing the services that are most beneficial

What do we know already?

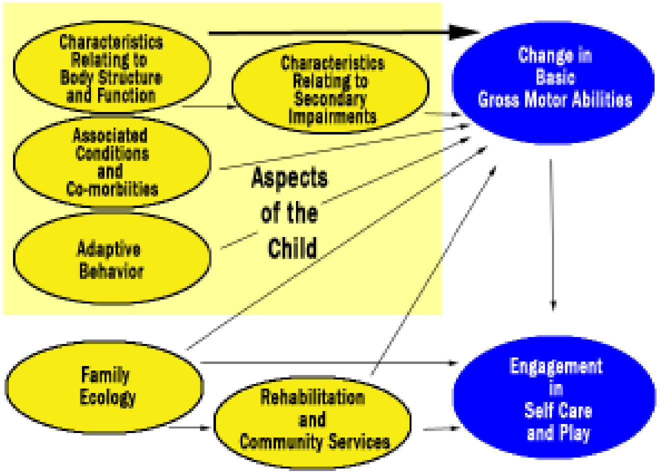
- We know that children with CP are complex in their strengths and abilities
- The Gross Motor Function Classification System[1] (GMFCS) provides a way to describe and understand children with CP, using 5 levels of different motor abilities (see Table in Appendix at the end of this report for details about the GMFCS)
- Our conceptual model builds on this understanding, and takes a broader look at many factors that affect abilities

What questions did we ask in the Move & PLAY study?

- What combination of child, family, and service factors explain the change in motor abilities of young children with CP?
- What combination of child, family, and service factors explain participation in self-care, and play of young children with CP?
- What interventions are associated with greatest change in motor abilities, self-care, and play over a one-year period?

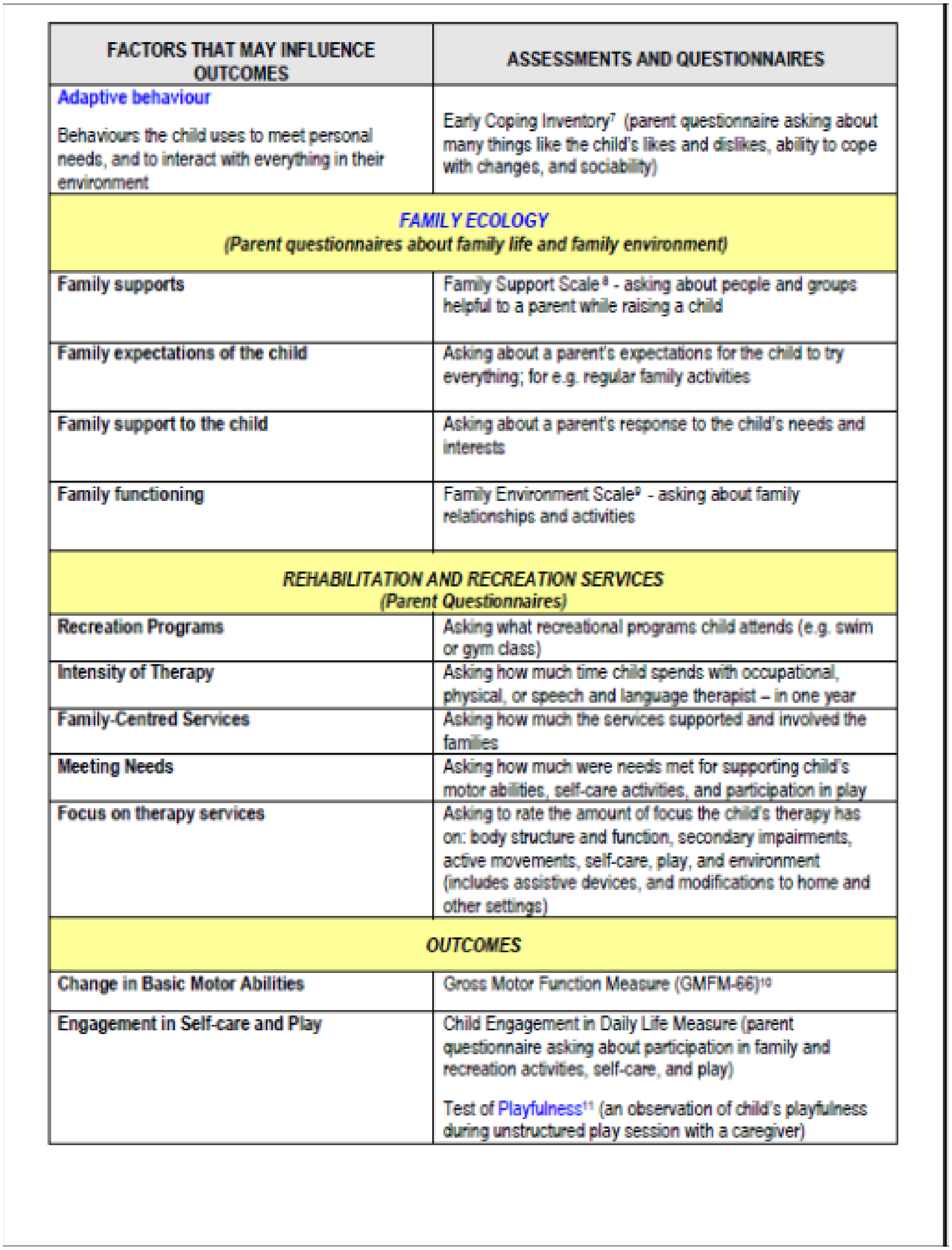
Words highlighted in blue link to definitions in our glossary. The glossary and other summaries reporting the results of this study are available on the CanChild website : http://www.canchild.ca/en/ourresearch/moveplay.asp

Move & PLAY study: Conceptual Model
showing many 'factors' that affect the 'outcomes'
yellow circles are the "factors' - blue circles are the 'outcomes'
(see the following table for explanation of the terms on the model)

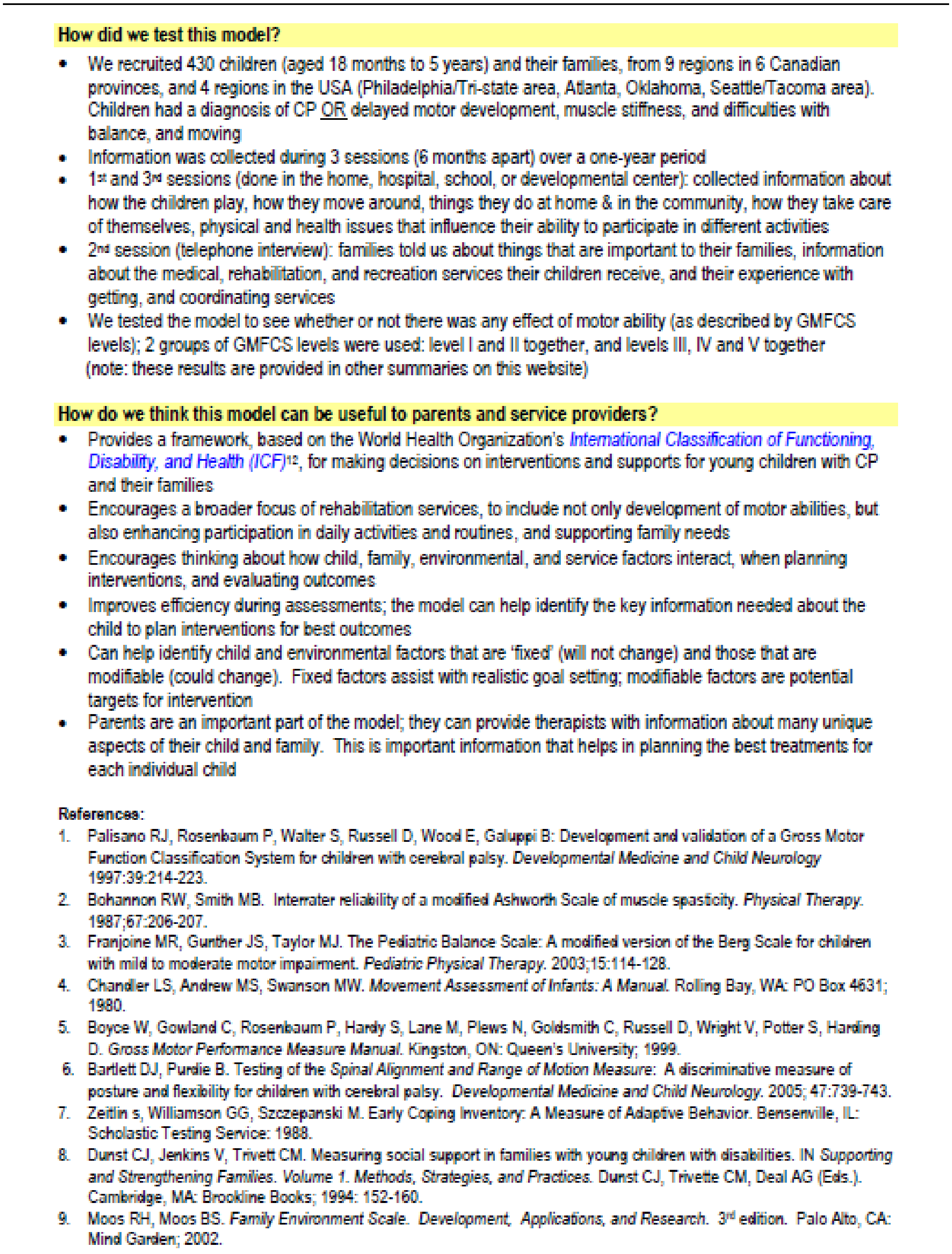


What information did we collect about these factors and outcomes?
This table shows all the assessments that were done by study therapists, and questionnaires done by parents. We collected detailed information about the many factors seen in the conceptual model. All these factors may have an effect on the outcomes. Outcomes are the children's motor abilities, and participation in self-care and play activities. Information about the reliability and validity of the measures developed for the study are provided in a supplementary file. (link)

FACTORS THAT MAY INFLUENCE OUTCOMES	ASSESSMENTS AND QUESTIONNAIRES
ASPECTS OF THE CHILD	
Body Structure and Function: (see primary impairments) Problems with body structure and function that have been present since the onset of CP	Spasticity: Modified Ashworth Scale (MAS)^2 Balance: Pediatric Balance Scale (PBS)^3 Movement Assessment of Infants (MAI)^4 Quality of movement: Gross Motor Performance Measure (GMPM) ^{5} Distribution of involvement: (the area of the body affected)
Secondary impairments: These happen over time - as a result of the original problems with body structure and function	Range of motion: Spinal Alignment and Range of Motion Measure (SAROMM)^6 Muscle strength: (functional assessment of muscle groups) Endurance: (parent rated intensity, frequency and duration of activity)
Associated conditions and Co-morbidities: These are chronic health conditions	Impact of chronic health conditions (parents provided information)



FACTORS THAT MAY INFLUENCE OUTCOMES	ASSESSMENTS AND QUESTIONNAIRES
Adaptive behaviour Behaviours the child uses to meet personal needs, and to interact with everything in their environment	Early Coping Inventory[7] (parent questionnaire asking about many things like the child's likes and dislikes, ability to cope with changes, and sociability)
FAMILY ECOLOGY *(Parent questionnaires about family life and family environment)*	
Family supports	Family Support Scale[8] - asking about people and groups helpful to a parent while raising a child
Family expectations of the child	Asking about a parent's expectations for the child to try everything; for e.g. regular family activities
Family support to the child	Asking about a parent's response to the child's needs and interests
Family functioning	Family Environment Scale[9] - asking about family relationships and activities
REHABILITATION AND RECREATION SERVICES *(Parent Questionnaires)*	
Recreation Programs	Asking what recreational programs child attends (e.g. swim or gym class)
Intensity of Therapy	Asking how much time child spends with occupational, physical, or speech and language therapist – in one year
Family-Centred Services	Asking how much the services supported and involved the families
Meeting Needs	Asking how much were needs met for supporting child's motor abilities, self-care activities, and participation in play
Focus on therapy services	Asking to rate the amount of focus the child's therapy has on: body structure and function, secondary impairments, active movements, self-care, play, and environment (includes assistive devices, and modifications to home and other settings)
OUTCOMES	
Change in Basic Motor Abilities	Gross Motor Function Measure (GMFM-66)[10]
Engagement in Self-care and Play	Child Engagement in Daily Life Measure (parent questionnaire asking about participation in family and recreation activities, self-care, and play) Test of Playfulness[11] (an observation of child's playfulness during unstructured play session with a caregiver)



How did we test this model?

- We recruited 430 children (aged 18 months to 5 years) and their families, from 9 regions in 6 Canadian provinces, and 4 regions in the USA (Philadelphia/Tri-state area, Atlanta, Oklahoma, Seattle/Tacoma area). Children had a diagnosis of CP OR delayed motor development, muscle stiffness, and difficulties with balance, and moving
- Information was collected during 3 sessions (6 months apart) over a one-year period
- 1st and 3rd sessions (done in the home, hospital, school, or developmental center): collected information about how the children play, how they move around, things they do at home & in the community, how they take care of themselves, physical and health issues that influence their ability to participate in different activities
- 2nd session (telephone interview): families told us about things that are important to their families, information about the medical, rehabilitation, and recreation services their children receive, and their experience with getting, and coordinating services
- We tested the model to see whether or not there was any effect of motor ability (as described by GMFCS levels); 2 groups of GMFCS levels were used: level I and II together, and levels III, IV and V together (note: these results are provided in other summaries on this website)

How do we think this model can be useful to parents and service providers?

- Provides a framework, based on the World Health Organization's *International Classification of Functioning, Disability, and Health (ICF)*[12], for making decisions on interventions and supports for young children with CP and their families
- Encourages a broader focus of rehabilitation services, to include not only development of motor abilities, but also enhancing participation in daily activities and routines, and supporting family needs
- Encourages thinking about how child, family, environmental, and service factors interact, when planning interventions, and evaluating outcomes
- Improves efficiency during assessments; the model can help identify the key information needed about the child to plan interventions for best outcomes
- Can help identify child and environmental factors that are 'fixed' (will not change) and those that are modifiable (could change). Fixed factors assist with realistic goal setting; modifiable factors are potential targets for intervention
- Parents are an important part of the model; they can provide therapists with information about many unique aspects of their child and family. This is important information that helps in planning the best treatments for each individual child

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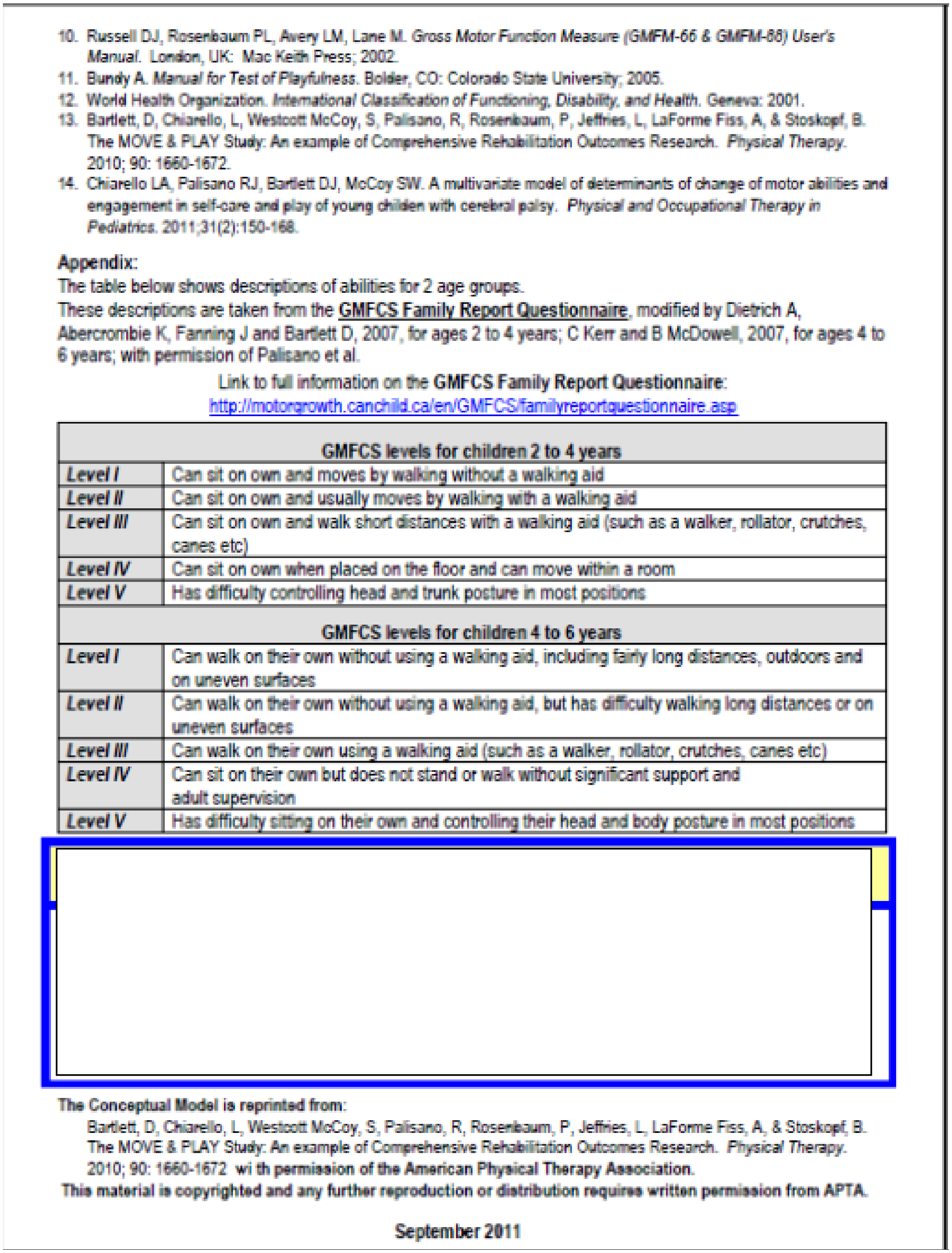

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14. Chiarello LA, Palisano RJ, Bartlett DJ, McCoy SW. A multivariate model of determinants of change of motor abilities and engagement in self-care and play of young childen with cerebral palsy. *Physical and Occupational Therapy in Pediatrics.* 2011;31(2):150-168.

Appendix:

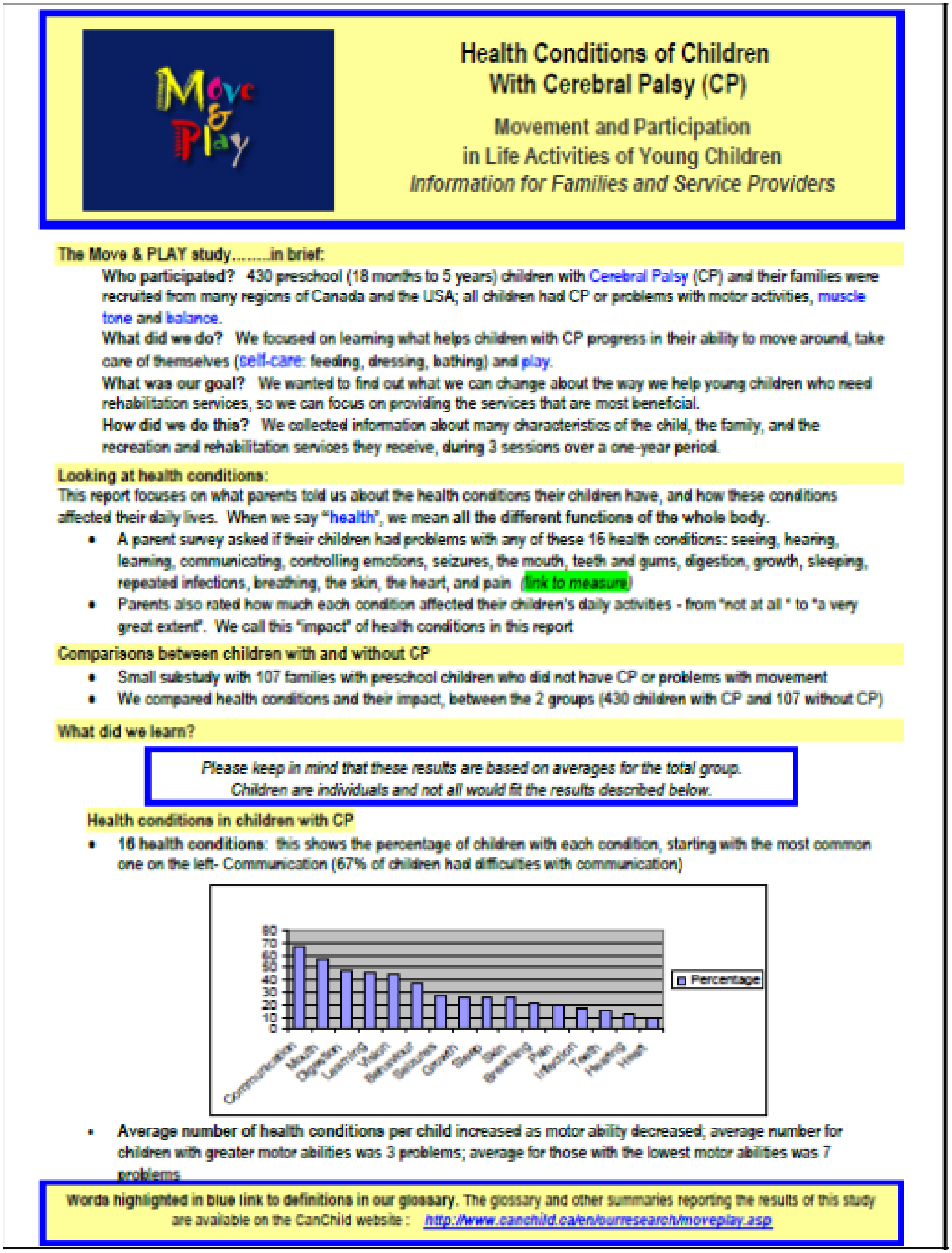
The table below shows descriptions of abilities for 2 age groups.
These descriptions are taken from the **GMFCS Family Report Questionnaire**, modified by Dietrich A, Abercrombie K, Fanning J and Bartlett D, 2007, for ages 2 to 4 years; C Kerr and B McDowell, 2007, for ages 4 to 6 years; with permission of Palisano et al.

Link to full information on the **GMFCS Family Report Questionnaire**:
http://motorgrowth.canchild.ca/en/GMFCS/familyreportquestionnaire.asp

GMFCS levels for children 2 to 4 years	
Level I	Can sit on own and moves by walking without a walking aid
Level II	Can sit on own and usually moves by walking with a walking aid
Level III	Can sit on own and walk short distances with a walking aid (such as a walker, rollator, crutches, canes etc)
Level IV	Can sit on own when placed on the floor and can move within a room
Level V	Has difficulty controlling head and trunk posture in most positions
GMFCS levels for children 4 to 6 years	
Level I	Can walk on their own without using a walking aid, including fairly long distances, outdoors and on uneven surfaces
Level II	Can walk on their own without using a walking aid, but has difficulty walking long distances or on uneven surfaces
Level III	Can walk on their own using a walking aid (such as a walker, rollator, crutches, canes etc)
Level IV	Can sit on their own but does not stand or walk without significant support and adult supervision
Level V	Has difficulty sitting on their own and controlling their head and body posture in most positions

The Conceptual Model is reprinted from:
Bartlett, D, Chiarello, L, Westcott McCoy, S, Palisano, R, Rosenbaum, P, Jeffries, L, LaForme Fiss, A, & Stoskopf, B. The MOVE & PLAY Study: An example of Comprehensive Rehabilitation Outcomes Research. *Physical Therapy.* 2010; 90: 1660-1672 **with permission of the American Physical Therapy Association.**

September 2011



Health Conditions of Children With Cerebral Palsy (CP)

Movement and Participation in Life Activities of Young Children

Information for Families and Service Providers

The Move & PLAY study……..in brief:

Who participated? 430 preschool (18 months to 5 years) children with Cerebral Palsy (CP) and their families were recruited from many regions of Canada and the USA; all children had CP or problems with motor activities, muscle tone and balance.

What did we do? We focused on learning what helps children with CP progress in their ability to move around, take care of themselves (self-care: feeding, dressing, bathing) and play.

What was our goal? We wanted to find out what we can change about the way we help young children who need rehabilitation services, so we can focus on providing the services that are most beneficial.

How did we do this? We collected information about many characteristics of the child, the family, and the recreation and rehabilitation services they receive, during 3 sessions over a one-year period.

Looking at health conditions:

This report focuses on what parents told us about the health conditions their children have, and how these conditions affected their daily lives. When we say "health", we mean all the different functions of the whole body.

- A parent survey asked if their children had problems with any of these 16 health conditions: seeing, hearing, learning, communicating, controlling emotions, seizures, the mouth, teeth and gums, digestion, growth, sleeping, repeated infections, breathing, the skin, the heart, and pain (link to measure)
- Parents also rated how much each condition affected their children's daily activities - from "not at all" to "a very great extent". We call this "impact" of health conditions in this report

Comparisons between children with and without CP

- Small substudy with 107 families with preschool children who did not have CP or problems with movement
- We compared health conditions and their impact, between the 2 groups (430 children with CP and 107 without CP)

What did we learn?

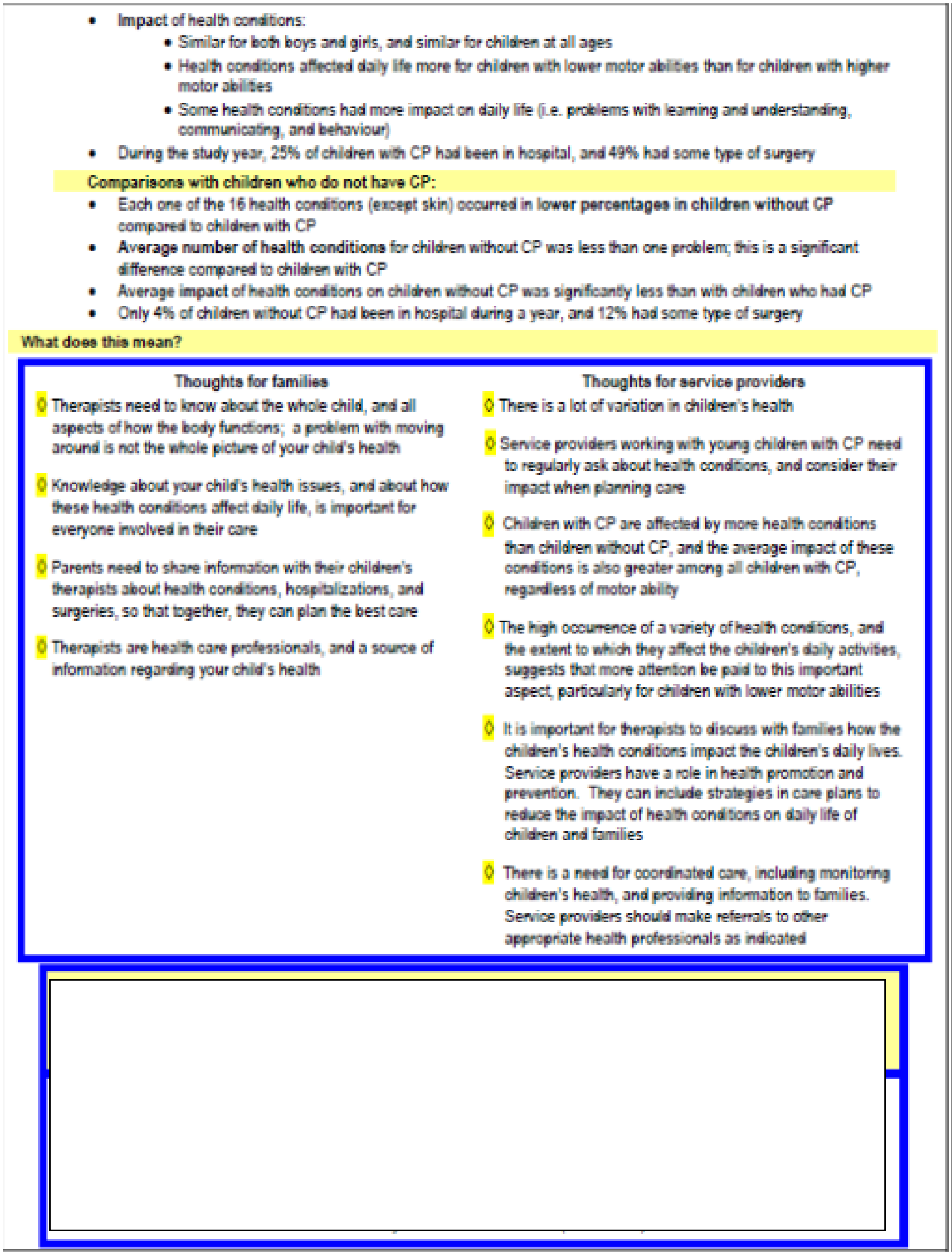
Please keep in mind that these results are based on averages for the total group. Children are individuals and not all would fit the results described below.

Health conditions in children with CP

- **16 health conditions**: this shows the percentage of children with each condition, starting with the most common one on the left- Communication (67% of children had difficulties with communication)

- Average number of health conditions per child increased as motor ability decreased; average number for children with greater motor abilities was 3 problems; average for those with the lowest motor abilities was 7 problems

Words highlighted in blue link to definitions in our glossary. The glossary and other summaries reporting the results of this study are available on the CanChild website : http://www.canchild.ca/en/ourresearch/moveplay.asp



- Impact of health conditions:
    - Similar for both boys and girls, and similar for children at all ages
    - Health conditions affected daily life more for children with lower motor abilities than for children with higher motor abilities
    - Some health conditions had more impact on daily life (i.e. problems with learning and understanding, communicating, and behaviour)
- During the study year, 25% of children with CP had been in hospital, and 49% had some type of surgery

Comparisons with children who do not have CP:

- Each one of the 16 health conditions (except skin) occurred in **lower percentages in children without CP** compared to children with CP
- **Average number of health conditions** for children without CP was less than one problem; this is a significant difference compared to children with CP
- Average **impact** of health conditions on children without CP was significantly less than with children who had CP
- Only 4% of children without CP had been in hospital during a year, and 12% had some type of surgery

What does this mean?

Thoughts for families

◊ Therapists need to know about the whole child, and all aspects of how the body functions; a problem with moving around is not the whole picture of your child's health

◊ Knowledge about your child's health issues, and about how these health conditions affect daily life, is important for everyone involved in their care

◊ Parents need to share information with their children's therapists about health conditions, hospitalizations, and surgeries, so that together, they can plan the best care

◊ Therapists are health care professionals, and a source of information regarding your child's health

Thoughts for service providers

◊ There is a lot of variation in children's health

◊ Service providers working with young children with CP need to regularly ask about health conditions, and consider their impact when planning care

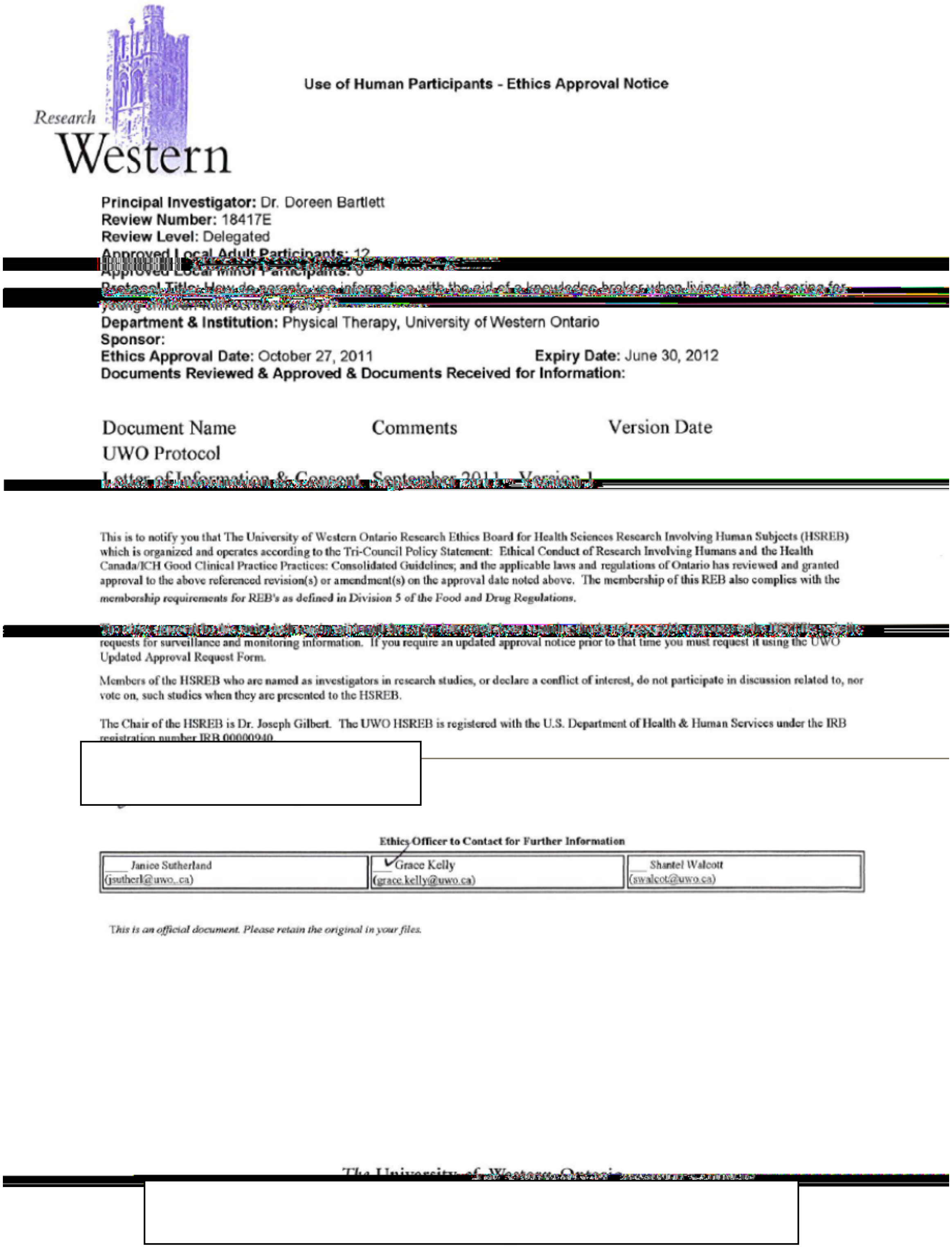
◊ Children with CP are affected by more health conditions than children without CP, and the average impact of these conditions is also greater among all children with CP, regardless of motor ability

◊ The high occurrence of a variety of health conditions, and the extent to which they affect the children's daily activities, suggests that more attention be paid to this important aspect, particularly for children with lower motor abilities

◊ It is important for therapists to discuss with families how the children's health conditions impact the children's daily lives. Service providers have a role in health promotion and prevention. They can include strategies in care plans to reduce the impact of health conditions on daily life of children and families

◊ There is a need for coordinated care, including monitoring children's health, and providing information to families. Service providers should make referrals to other appropriate health professionals as indicated

Appendix D: Ethics Approval from The University of Western Ontario



Research Western

Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Doreen Bartlett
Review Number: 18417E
Review Level: Delegated
[redacted]
[redacted]
Department & Institution: Physical Therapy, University of Western Ontario
Sponsor:
Ethics Approval Date: October 27, 2011 **Expiry Date:** June 30, 2012
Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
UWO Protocol		

[redacted]

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the *membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.*

[redacted] requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The UWO HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

[redacted]

Ethics Officer to Contact for Further Information

___ Janice Sutherland (jsutherl@uwo..ca)	✓ Grace Kelly (grace.kelly@uwo.ca)	___ Shantel Walcott (swalcot@uwo.ca)

This is an official document. Please retain the original in your files.

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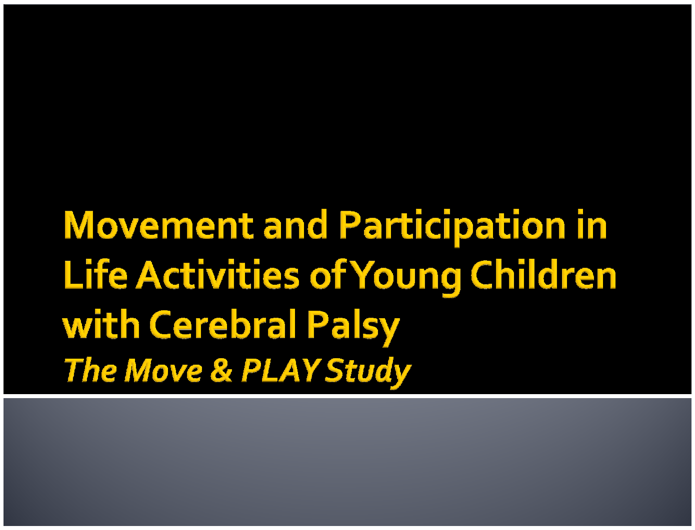
Appendix E: Researcher Interview Guide

How do parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy?

Researcher Interview Guide

1) Can you help me understand your involvement in the Move & PLAY study (prompt: how did you initially become involved? What, if anything, has changed over time? Are you still currently involved?)
2) What was the motivation to create research summaries from the research conducted through the Move & PLAY study? (prompt: How did this decision come about?)
3) What were the anticipated outcomes you were hoping the summaries might have, once they were completed? (prompt: How did you envision people would access them? How did you envision parents might use them?
4) Was there any planning for the evaluation of this process?
5) Can you tell me how parents of children with CP were involved in the creation and revision of these summaries?
6) Can you tell me how [the centre] was involved throughout the process of the Move & PLAY study? (prompt: from its inception until the summaries were completed)
7) Why was [the centre] chosen as a venue to promote the Move & PLAY study summaries to interested parents and therapists? (prompt: would any other venue have sufficed?)

Appendix F: Workshop Powerpoint Slides



Movement and Participation in Life Activities of Young Children with Cerebral Palsy

The Move & PLAY Study

Investigators and Funders

- Investigators
  - Doreen Bartlett, PT, PhD, University of Western Ontario
  - Lisa Chiarello, PT, PhD, PCS, Drexel University
  - Robert Palisano, PT, PhD, Drexel University
  - Peter Rosenbaum, MD,FRCP(C), McMaster University, CanChild Centre for Childhood Disability Research
  - Sally Westcott McCoy, PT, PhD, University of Washington
  - Lynn Jeffries, PT, PhD, PCS, Langston University
  - Alyssa LaForme Fiss, PT, PhD, PCS, Assistant Professor, Department of Physical Therapy, Mercer University, Regional Coordinator, Atlanta region
  - Barbara Stoskopf, RN, MHSc, McMaster University, CanChild Centre for Childhood Disability Research, Project Coordinator
  - Audrey Wood, PT, MS, Drexel University, Regional Coordinator, Greater Philadelphia region
  - Allison Yocum, PT, DSc, PCS, University of Washington, Regional Coordinator, Greater Seattle-Tacoma region
  - Barbara Sieck Taylor, USA, Parent consultant
  - Tina Hjorngaard, Canada, Parent consultant
  - Piotr Wilk, Statistician
- Funders
  - The Canadian Institutes of Health Research, MOP - 81107 (2006-2009)
  - U.S. Department of Education, National Institute of Disability and Rehabilitation Research, H133G060254 (2006-2009)

Workshop Co-ordinators

- Stephanie Lagosky, *MSc,*
  The University of Western Ontario
- Doreen Bartlett, *PT, PhD,*
  The University of Western Ontario

Why did we do the Move & PLAY study?

- We wanted to better understand what helps young children who have cerebral palsy or problems with motor activities, muscle tone, and balance, progress in their abilities to:
  - Move around
  - Take care of themselves (self-care)
  - Play

Why is this important?

- Cerebral palsy is the most common childhood neuromuscular condition seen by rehabilitation therapists, but we have very limited research evidence about the child and family factors, and rehabilitation and recreation services that influence a variety of outcomes
- Preschool years are a very important time for all children to learn and progress to the best of their abilities
- If we know what helps children progress in their abilities, we can focus on providing services that are most beneficial

What do we know already?

- We know that children with CP are complex in their strengths and abilities
- The Gross Motor Function Classification System (GMFCS) provides a way to describe and understand children with CP, using 5 levels of motor abilities

The GMFCS

GMFCS levels for children 2 to 4 years	
Level I	Can sit on own and moves by walking without a walking aid
Level II	Can sit on own and usually moves by walking with a walking aid
Level III	Can sit on own and walk short distances with a walking aid (such as a walker, rollator, crutches, canes etc)
Level IV	Can sit on own when placed on the floor and can move within a room
Level V	Has difficulty controlling head and trunk posture in most positions
GMFCS levels for children 4 to 6 years	
Level I	Can walk on their own without using a walking aid, including fairly long distances, outdoors and on uneven surfaces
Level II	Can walk on their own without using a walking aid, but has difficulty walking long distances or on uneven surfaces
Level III	Can walk on their own using a walking aid (such as a walker, rollator, crutches, canes etc)
Level IV	Can sit on their own but does not stand or walk without significant support and adult supervision
Level V	Has difficulty sitting on their own and controlling their head and body posture in most positions

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What questions did we ask in the Move & PLAY study?

- What combination of child, family and service factors explain the change in motor abilities of young children with CP?
- What combination of child, family and service factors explain participation in self-care and play of young children with CP?
- What interventions are associated with the greatest change in motor abilities, self-care and play over a one year period?

What were the results?

- We organized the answers to these questions in 12 different categories, each complete with a information booklet about the results, and what they can mean to you
- These summaries are meant to be viewed by both parents and service providers, so you could engage in a conversation about a particular result with your child's therapist
- Each summary has links to a glossary for some of our more uncommon words, as well as links to the measures that we used to come up with our results

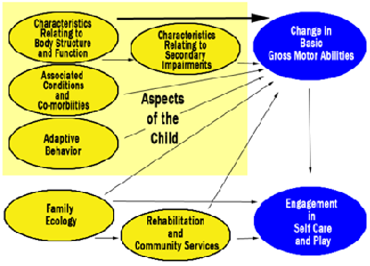
What are the 12 Summaries?

- The 12 summaries are titled:
  - Conceptual Model of the Move & PLAY Study
  - Health Conditions of Young Children with CP
  - Distribution of Involvement, Balance, Quality of Movement, and Spasticity (Primary Impairments)
  - Muscle Strength, Range of Motion, and Endurance (Secondary Impairments)
  - Gross Motor Function Measure (GMFM) New, Shortened Versions
  - Children's Participation in Self-Care and Ease of Caregiving for Parents
  - Children's Participation in Family Activities and Play
  - Family Life
  - Recreation and Rehabilitation Services
  - Motor and Self-Care Abilities
  - Participation and Playfulness
  - A closer look at Recreation and Rehabilitation Services

URL To Access Summaries

http://canchild.ca/en/ourresearch/move_play_materials.asp

The Conceptual Model of the Move & PLAY Study



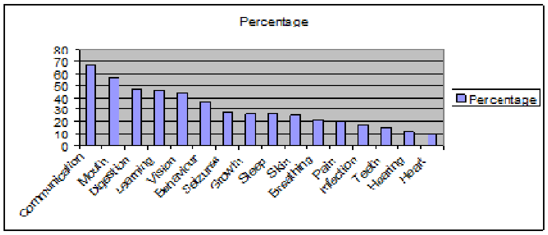
How Was This Model Tested?

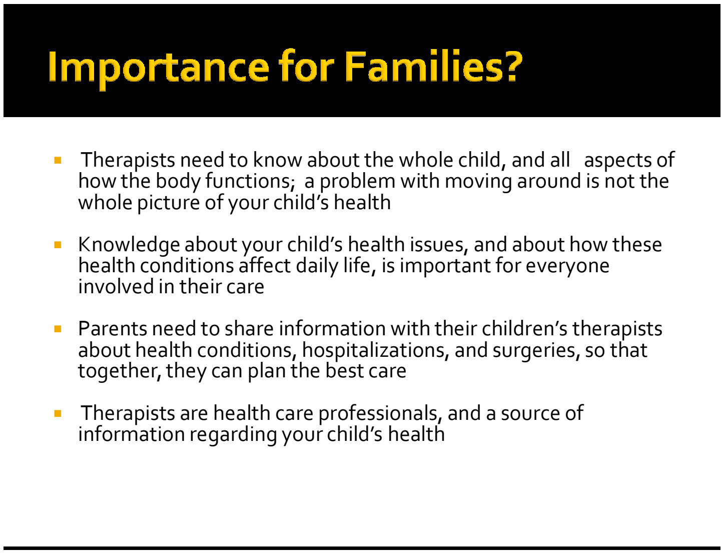
- 430 preschool (age 18 months to 5 years) children with Cerebral Palsy (CP) and their families were recruited from many regions of Canada and the USA; all children had CP or problems with motor activities, muscle tone and balance
- Information was collected during 3 sessions (6 months apart) over a one-year period
- 1st and 3rd sessions: collected information about how the children play, how they move around, things they do at home & in the community, how they take care of themselves, physical and health issues that influence their ability to participate in different activities
- 2nd session: families told us about things that are important to their families, information about the medical, rehabilitation, and recreation services their children receive, and their experience with getting, and coordinating services

Importance for Families?

- Encourages a broader focus of rehabilitation services
- Encourages thinking about how child, family, environmental, and service factors interact, when planning interventions, and evaluating outcomes
- Improves efficiency during assessments
- Can help identify child and environmental factors that are ‘fixed’ (will not change) and those that are modifiable (could change)
- Parents are an important part of the model; they can provide therapists with information about many unique aspects of their child and family

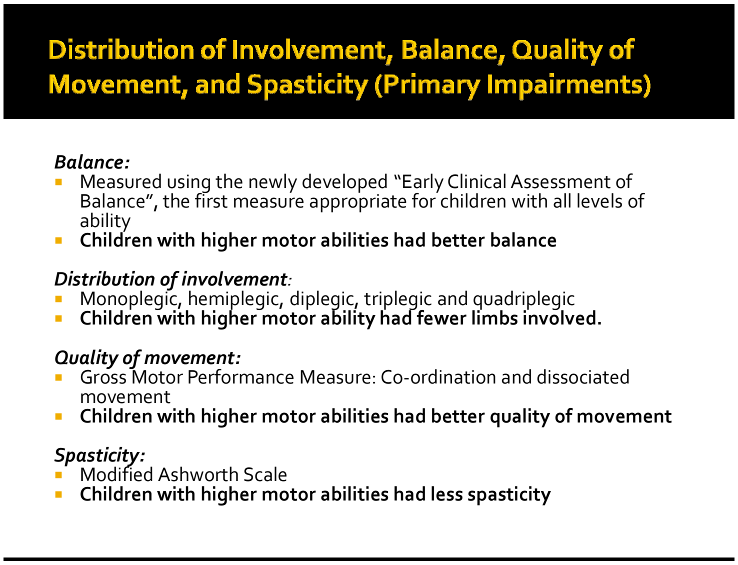
Health Conditions of Children with CP





Importance for Families?

- Therapists need to know about the whole child, and all aspects of how the body functions; a problem with moving around is not the whole picture of your child's health
- Knowledge about your child's health issues, and about how these health conditions affect daily life, is important for everyone involved in their care
- Parents need to share information with their children's therapists about health conditions, hospitalizations, and surgeries, so that together, they can plan the best care
- Therapists are health care professionals, and a source of information regarding your child's health



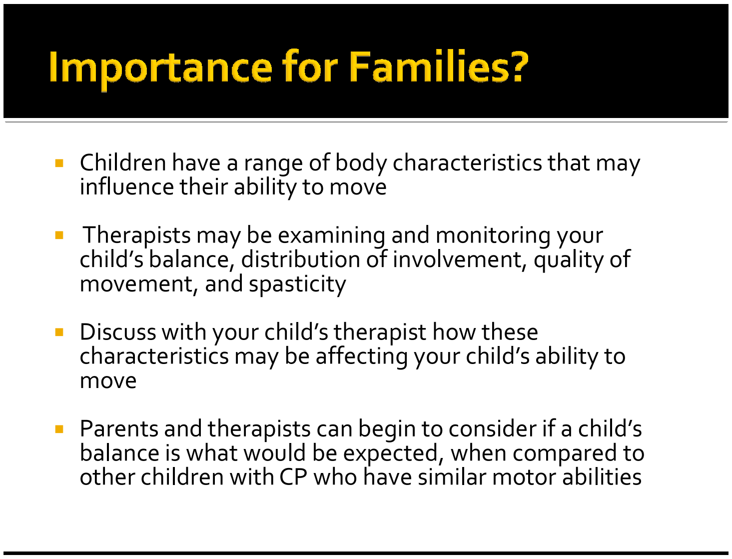
Distribution of Involvement, Balance, Quality of Movement, and Spasticity (Primary Impairments)

Balance:
- Measured using the newly developed "Early Clinical Assessment of Balance", the first measure appropriate for children with all levels of ability
- **Children with higher motor abilities had better balance**

Distribution of involvement:
- Monoplegic, hemiplegic, diplegic, triplegic and quadriplegic
- **Children with higher motor ability had fewer limbs involved.**

Quality of movement:
- Gross Motor Performance Measure: Co-ordination and dissociated movement
- **Children with higher motor abilities had better quality of movement**

Spasticity:
- Modified Ashworth Scale
- **Children with higher motor abilities had less spasticity**



Importance for Families?

- Children have a range of body characteristics that may influence their ability to move
- Therapists may be examining and monitoring your child's balance, distribution of involvement, quality of movement, and spasticity
- Discuss with your child's therapist how these characteristics may be affecting your child's ability to move
- Parents and therapists can begin to consider if a child's balance is what would be expected, when compared to other children with CP who have similar motor abilities

Muscle Strength, Range of Motion, and Endurance (Secondary Impairments)

Muscle strength:

- GMFCS level had a significant effect: **Children with higher motor abilities had more strength**.

Range of motion*:*

- Older children had more limitations in range of motion than younger children
- GMFCS level had a significant effect: **Children with higher motor abilities had more flexibility**

Endurance:

- GMFCS level had a significant effect: **Children with higher motor abilities had higher levels of endurance**

Secondary impairments**:**

- Muscle strength was shown to have the greatest contribution to secondary impairments, followed by (in order of importance) range of motion and endurance
- Higher motor function was shown to be associated with: more strength, more flexibility, and higher endurance

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Importance for Families?

- An important focus on prevention is to promote movement and activity, preventing tightness in joints for overall health and fitness
- Parents can observe their children's endurance for moving around and expending energy, and share this information with their therapists
- Being stronger, more flexible, and having more endurance all contribute to better motor abilities and life-long health

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Gross Motor Function Measure (GMFM)

- **GMFM-66** is widely used in clinical practice and research by therapists
- It measures change over time and/or as a result of treatment
- In the full version, there are 66 items and it takes about 45 to 60 minutes to assess a child (time varies according to each child's abilities)
- An important purpose of the Move & PLAY study was to **reduce the "burden" of time** needed to accurately assess children's motor abilities; this efficiency is beneficial to children, parents, and therapists
- The Move & PLAY team developed a new, even shorter method of using the GMFM: the **GMFM-66-B&C**

Importance for Families?

- A very accurate assessment of gross motor abilities is obtained with the GMFM-66-B&C and it takes less time
- Discuss with your therapist if the shorter version of the test is suitable for assessing and documenting your child's motor function
- Using a shorter motor assessment will provide your therapist with more time to assess other aspects of your child and family that are important to you

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Children's Participation in Self-Care and Ease of Caregiving for Parents

- Participation in self-care is one of the **primary activities** of young children
- Self-care is a **foundation to daily life**; a top priority of parents; and it encourages self-reliance in children

Self-care Abilities

- Older children were more advanced in their self-care abilities, however children with greater motor ability challenges (GMFCS level V) did not show higher scores with older ages
- GMFCS level had a significant effect: **children with higher motor abilities were more independent in self-care abilities**

Ease of caregiving for parents:

- Caregiving was easiest for parents of children with higher levels of motor ability (GMFCS Level I), and **most difficult for parents of children with lower levels of motor ability** (Level V). This was true for all ages

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Importance for Families?

- Therapists need to know about your child's usual participation in self-care activities; this information is very useful when planning care that will be most helpful to your child
- Parents of children with limited motor ability need to know that children may need support and adaptations to the environment to participate in self-care
- Parents need to base their expectations of self-care abilities on their children's age and motor function abilities
- Talk to your therapist about any challenges you have when helping your child with daily activities

Children's Participation in Family Activities and Play

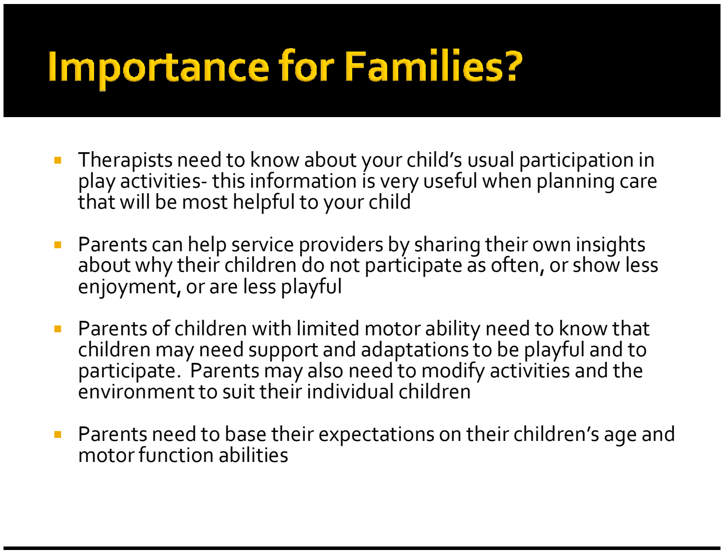
- Participation in play is the **primary activity** of young children
- **Play helps children learn new things** and give them a feeling of accomplishment

Participation and enjoyment in family activities and play:

- For all children, the following comparisons of activities were significant:
  - Played indoors more often than played outdoors
  - Played with adults more often than played with children
  - Participated in quiet recreation more often than active physical recreation
- GMFCS level had a significant effect on participation: children with **higher motor abilities participated more.** All children, regardless of motor abilities, showed a **high level of enjoyment** as they participated in activities

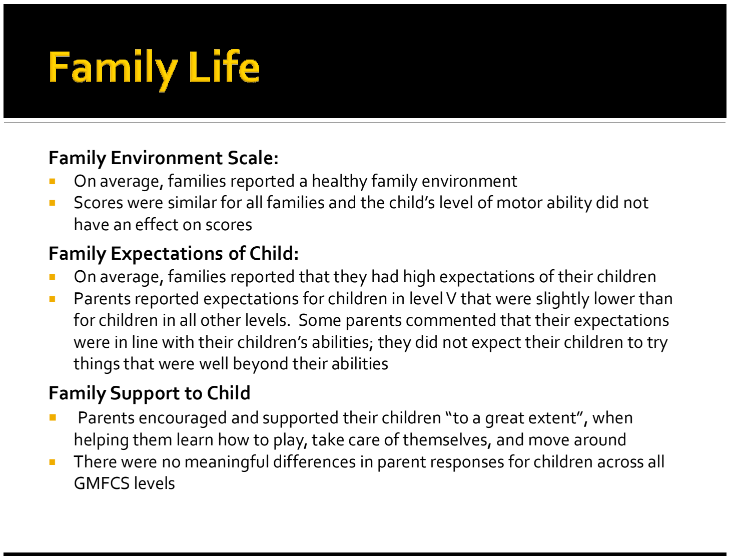
Test of Playfulness:

- Age differences: older children showed higher levels of playfulness than younger children. Some aspects of playfulness, such as humour, develop as children get older
- GMFCS level had a significant effect: in general, children with the **highest level of motor ability showed higher playfulness** than all the others



Importance for Families?

- Therapists need to know about your child's usual participation in play activities- this information is very useful when planning care that will be most helpful to your child
- Parents can help service providers by sharing their own insights about why their children do not participate as often, or show less enjoyment, or are less playful
- Parents of children with limited motor ability need to know that children may need support and adaptations to be playful and to participate. Parents may also need to modify activities and the environment to suit their individual children
- Parents need to base their expectations on their children's age and motor function abilities



Family Life

Family Environment Scale:

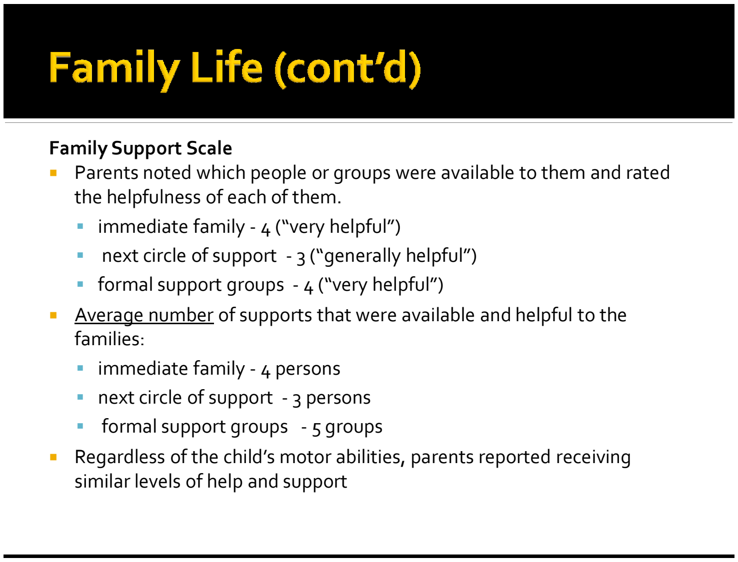
- On average, families reported a healthy family environment
- Scores were similar for all families and the child's level of motor ability did not have an effect on scores

Family Expectations of Child:

- On average, families reported that they had high expectations of their children
- Parents reported expectations for children in level V that were slightly lower than for children in all other levels. Some parents commented that their expectations were in line with their children's abilities; they did not expect their children to try things that were well beyond their abilities

Family Support to Child

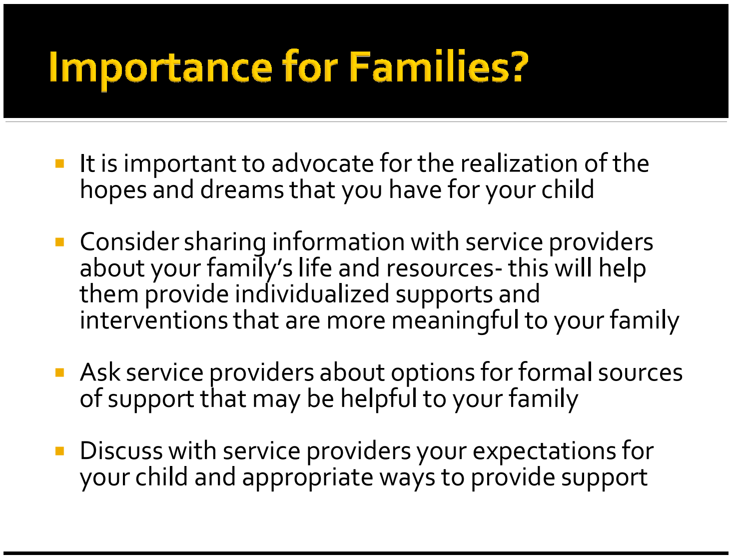
- Parents encouraged and supported their children "to a great extent", when helping them learn how to play, take care of themselves, and move around
- There were no meaningful differences in parent responses for children across all GMFCS levels



Family Life (cont'd)

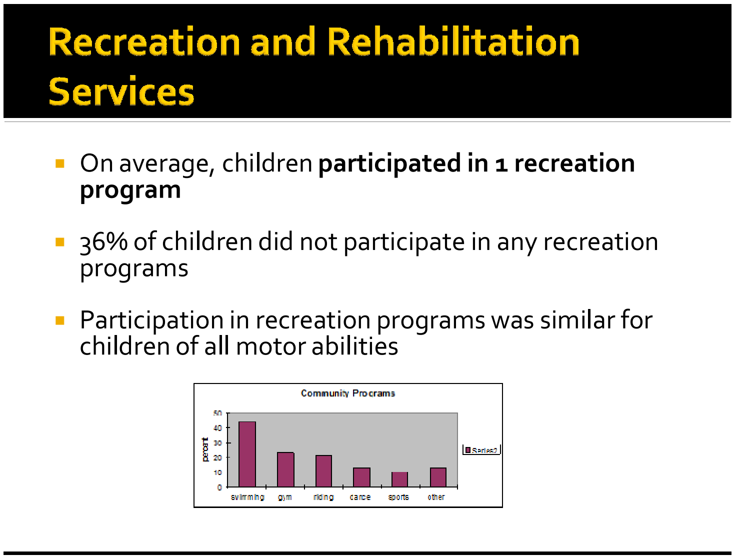
Family Support Scale

- Parents noted which people or groups were available to them and rated the helpfulness of each of them.
  - immediate family - 4 ("very helpful")
  - next circle of support - 3 ("generally helpful")
  - formal support groups - 4 ("very helpful")
- Average number of supports that were available and helpful to the families:
  - immediate family - 4 persons
  - next circle of support - 3 persons
  - formal support groups - 5 groups
- Regardless of the child's motor abilities, parents reported receiving similar levels of help and support



Importance for Families?

- It is important to advocate for the realization of the hopes and dreams that you have for your child
- Consider sharing information with service providers about your family's life and resources- this will help them provide individualized supports and interventions that are more meaningful to your family
- Ask service providers about options for formal sources of support that may be helpful to your family
- Discuss with service providers your expectations for your child and appropriate ways to provide support



Recreation and Rehabilitation Services

- On average, children **participated in 1 recreation program**
- 36% of children did not participate in any recreation programs
- Participation in recreation programs was similar for children of all motor abilities

Recreation and Rehabilitation Services (cont'd)

- Age of the child made no difference in the amount of therapy received
- Parents were asked to rate how well the services they received met the needs of their children in supporting development of motor abilities, self care abilities, and participation in play
    - Parents said that needs were met "to a great extent"

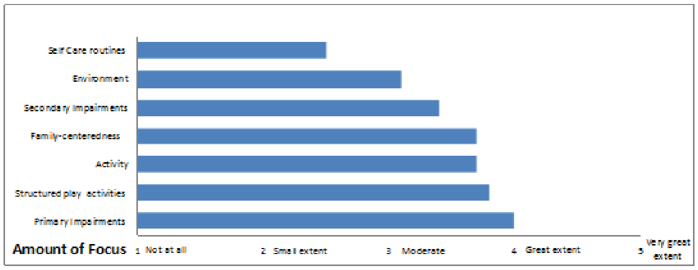
Physical Therapy (PT) services:
- **94%** of children received PT
- GMFCS level had a significant effect: children with **higher motor abilities (level I) had statistically significant less PT time** than all others

Occupational Therapy (OT) services:
- **85%** of children received OT
- GMFCS level had a significant effect: children with **higher motor ability received less hours of OT**

Speech Therapy services:
- **74%** of children received speech therapy
- GMFCS level had a significant effect: children with **higher motor abilities (level I) had significantly less speech therapy** than those children in level V

Recreation and Rehabilitation Services (cont'd)

- Parents of older children reported a greater focus of therapy on self-care routines and secondary impairments



Importance for Families?

- Partner with service providers to advocate for recreation programs in your community
- Parents who want recreational programs for their children can ask their therapist about options in their community and help to locate and connect with programs
- Parents should expect that team members will communicate with them and with other service providers about the services the family receives
- Parents should expect to receive services that meet their children's needs in supporting development of motor and self care abilities, and play
- Parents are encouraged to discuss with therapists the focus of therapy services, to make sure that services are meeting their priorities for their children

Motor and Self-Care Abilities: Factors Contributing to Motor Ability

Children in GMFCS levels I and II:
- The **factors related to motor abilities**, in order of importance, were:
  - Primary impairments had a strong relationship
  - Secondary impairments had a modest relationship
  - Participation in recreation programs had a small relationship
  - Health conditions, adaptive behaviour, and family ecology **were not related to** motor abilities in this group of children

Children in GMFCS levels III, IV, and V:
- The **factors that were related to motor abilities**, in order of importance were:
  - Primary impairments had a strong relationship
  - Secondary impairments had a modest relationship
  - Adaptive behaviour had a modest relationship
  - Health conditions, family ecology, and services **were not directly related to** motor abilities in this group of children

Comparisons of results between groups of children
- The Conceptual Model of child, family, and service factors provided greater explanation of factors related to motor abilities for children in GMFCS levels III, IV & V than for those in GMFCS levels I & II
- Adaptive behavior was related to motor abilities for children in GMFCS levels III, IV, and V, but not for children in levels I and II

Motor and Self-Care Abilities: Factors Contributing to Self-Care Ability

Children in GMFCS levels I and II:
- **Factors that were associated with self-care abilities**, in order of importance were:
  - **Gross motor ability** had a modest relationship
  - **Health conditions** had a modest relationship
  - **Adaptive behaviour** had a modest relationship
  - **Extent services met children's needs** had a small relationship
  - Primary impairments and family ecology **were not related** to self-care abilities

Children in GMFCS levels III, IV, and V:
- **Factors that were associated with self-care abilities**, in order of importance were:
  - **Gross motor ability** had a modest relationship
  - **Primary impairments** had a modest relationship
  - **Health conditions** had a small relationship
  - **Adaptive behaviour** had a small relationship
  - **Family ecology** had a small relationship
  - **Family-centredness of services** had a small relationship

Comparisons of results between groups of children
- The Conceptual Model of child, family, and service factors provided greater explanation of factors related to self-care abilities for children in GMFCS levels III, IV & V than for those in GMFCS levels I & II
- The influence of primary impairments was greater for children in GMFCS levels III, IV & V, whereas the influence of health conditions was greater for children in GMFCS levels I & II. The influence of parents' perceptions that services were meeting the child's needs was greater for children in GMFCS I & II

Importance for Families?

- Regarding Motor Abilities:
  - Ask your therapist about activities to improve balance and prevent secondary impairments with the goal of improving motor abilities
  - For parents of children with greater motor challenges (GMFCS Levels III, IV & V), encourage and support your child's self-awareness, adaptability, motivation, and interactions with people in a variety of situations. These adaptive behaviors help to optimize motor abilities
- Regarding Self-Care Abilities:
  - For all children with CP, motor function has a major impact on self-care ability; discuss with your therapist how best to use motor function to support emerging self-care abilities
  - Discuss what aspects of your child may facilitate or limit self-care abilities and collaborate with your therapist to tailor support for your child. Expect therapist to meet your needs in supporting your child's self-care abilities
  - Discuss with your health care team how best to monitor and support your child's overall health and well-being to optimize their self-care abilities
  - Supporting adaptive behavior from an early age, by encouraging motivation, persistence, problem-solving, and helping your child learn about him or herself promotes self-care abilities
  - For children with greater motor challenges, activities to improve balance promote higher self-care ability

Participation and Playfulness: Factors Contributing to Participation

Children in GMFCS levels I and II:

- The **factors related to participation**, in order of importance were:
  - ***Adaptive behavior*** had a modest relationship
  - ***Family ecology*** had a modest relationship
  - ***Number of recreation programs*** had a small relationship
  - Motor ability was **not related to** participation

Children in GMFCS levels III, IV, and V

- The **factors related to participation**, in order of importance were:
  - ***Adaptive behavior*** had a modest relationship
  - ***Family ecology*** had a modest relationship
  - ***Number of recreation programs*** had a modest relationship
  - ***Motor ability*** had a small relationship

Comparisons of results between groups of children

- Even though the small influence of motor abilities was only significant for children in GMFCS levels III, IV & V, none of the relationships were statistically different between the two groups of children

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Participation and Playfulness: Factors Contributing to Playfulness

Children in GMFCS levels I and II

- The **factors that were related to playfulness**, in order of importance were:
  - ***Health conditions*** had a modest relationship
  - ***Motor ability*** had a modest relationship
  - Adaptive behavior, family ecology, and services were **not related** to playfulness

Children in GMFCS levels III, IV, and V

- The **factors that were related to playfulness**, in order of importance were:
  - **Adaptive behavior** had a modest relationship
  - **Motor ability** had a modest relationship
  - **Services being family-centred** had a modest relationship
  - Health conditions and family ecology were **not related** to playfulness

Comparisons of results between groups of children:

- The Conceptual Model of child, family, and service factors was twice as strong in explaining playfulness in children in GMFCS levels III, IV & V, than for children in GMFCS levels I & II; however none of the relationships were significantly different between these two groups

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Importance for Families?

- For Participation:
  - Families are encouraged to support their child's self-awareness, flexibility, motivation, and interactions with people in a variety of situations. These adaptive behaviours, as well as strengths of your family, enhance your child's participation in a range of life activities
  - Families can ask therapists to assist them in accessing and collaborating with recreation programs to promote children's participation
  - If your child has greater motor challenges, ask your therapist how participation can be improved by a focus on practice of activities that consider your child's physical impairments
- For Playfulness:
  - Families can ask therapists the best ways to help their child move during play so that their child can have fun and be playful
  - If your child is in GMFCS level I or II, discuss with your health care team how best to monitor and support your child's overall health to optimize their ability to be playful
  - If your child is in GMFCS level III, IV or V, families are encouraged to support their child's adaptive behaviours to optimize their ability to be playful

Impressions?

- The 12 summaries are titled:
  - Conceptual Model of the Move & PLAY Study
  - Health Conditions of Young Children with CP
  - Distribution of Involvement, Balance, Quality of Movement, and Spasticity (Primary Impairments)
  - Muscle Strength, Range of Motion, and Endurance (Secondary Impairments)
  - Gross Motor Function Measure (GMFM) New, Shortened Versions
  - Children's Participation in Self-Care and Ease of Caregiving for Parents
  - Children's Participation in Family Activities and Play
  - Family Life
  - Recreation and Rehabilitation Services
  - Motor and Self-Care Abilities
  - Participation and Playfulness
  - A closer look at Recreation and Rehabilitation Services

Contact Information

Doreen Bartlett: [redacted]

Stephanie Lagos:

What's next?

- We want to see if these summaries are actually of use to YOU when living with and caring for your young children with cerebral palsy
- We want to know if using health information would be easier if you had access to someone called a Knowledge Broker who would help you access, understand and use this kind of material
- If you are interested, please see Stephanie,

Appendix G: Supports and Barriers Questionnaire

Supports and Barriers Questionnaire

The purpose of this questionnaire is to find out what you perceive to be the possible supports and barriers to implementing research and health information, such as those developed by The Move and Play Study at your organization. We will be using the information you provide in this questionnaire to help tailor our knowledge broker workshop, as well as the workshops between yourself and parents of young children with cerebral palsy.

The questionnaire is divided into sections that inquire about possible supports and barriers related to:

- *Your organizational structure*
- *Your organizational resources*
- *The therapists at your organization*
- *The families at your organization*

In each section, there is both a rating scale and an area for you to comment further on the supports, barriers, and any strategy you can suggest to overcome the identified barriers.

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1) Possible supports or barriers related to your *organizational structure*.

Please list below any aspects of your *organizational structure* that you believe may affect the use of dissemination materials at your organization.

Examples of such factors include: decision-making processes and procedures in your organization; extent to which decision-making processes are formalized through procedures; formal reinforcement by management to integrate dissemination materials into organizational policies; organizational size (number of employees); staff turnover; and logistical procedures related to the use of motor measures.

Supports:

Barriers:

Possible Strategies to overcome identified barriers:

Overall, to what extent do you feel your *organizational structure* is a support or a barrier to the use of dissemination materials at your organization?

Barrier -5	-4	-3	-2	-1	0	1	2	3	4	Support 5

2) Possible supports or barriers related to your *organizational resources*.

Please list below any factors related to your *organizational resources* that you believe may affect the use of dissemination materials at your organization.

Examples of such factors include: financial resources made available for the use of dissemination materials; reimbursement for health care professionals to facilitate extra efforts in using or applying dissemination materials; availability of staff responsible for coordination, implementation in the organization/department; available expertise in relation to seeking out and applying health information from dissemination materials.

Supports:

Barriers:

Possible Strategies to overcome identified barriers:

Overall, to what extent do you feel your *organizational resources* is a support or a barrier to the use of dissemination materials at your organization?

Barrier -5	-4	-3	-2	-1	0	1	2	3	4	Support 5

3) Possible supports and barriers related to the ***<u>health professionals at your organization.</u>***

Please list below any factors related to the *<u>health professionals at your organization</u>* that you believe may affect the use of dissemination materials at your organization.

Examples of such factors include: support from colleagues, supervisors, and the organization; extent to which colleagues use dissemination materials (modeling); extent to which health professionals have the knowledge, skills, and confidence needed to use the materials; the extent to which health professionals expect that the families will cooperate and be satisfied with the use of dissemination materials for their children; extent to which use of dissemination materials add to work-related stress or are contrary to the goals of the health professionals.

Supports:

Barriers:

Possible Strategies to overcome identified barriers:

Overall, to what extent do you feel that the *<u>health care professionals at your organization</u>* are a support or a barrier to the use of dissemination materials at your organization?

Barrier -5	-4	-3	-2	-1	0	1	2	3	4	Support 5

4) Possible supports or barriers related to the ***<u>parents and families</u>*** at your organization.

Please list below any factors related to the *<u>parents and families</u>* at your organization that you believe may affect the use of dissemination materials at your organization.

Examples of such factors include: the willingness of families to cooperate with the use of dissemination materials; the extent to which families are aware of the benefits of using dissemination materials to aid decisions; the extent to which families are confident regarding the therapist's expertise finding and using dissemination materials.

Supports:

Barriers:

Possible Strategies to overcome identified barriers:

Overall, to what extent do you feel that the *parents or families* at your organization are a support or a barrier to the use of dissemination materials at your organization?

Barrier -5	-4	-3	-2	-1	0	1	2	3	4	Support 5

Thank-you for filling out this questionnaire. Your answers will be kept anonymous and confidential. If you have any questions about this questionnaire, or any aspect of the research project, please contact Stephanie Lagosky at [redacted]

Appendix H: Knowledge Broker Weekly Log Sheet

How do parents use information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy?

Knowledge Broker Weekly Log Sheet

We are interested in knowing what you do in your role as a knowledge broker. Please complete this log on a weekly basis. Whenever you spend time on your KB role, please document it on this chart, indicating the amount of time you spent handling the inquiry. This information will help us to understand the contacts you had, the strategies you used, and the time you spent on this role. Thank you!

Date (DD/MM/YYYY)	**Type of Contact and Time Spent (minutes)**				
	Individual Parent	**Group of Parents**	**Administrator Or Program Manager**	**Research Team**	**Other (please indicate)**
Example: 15/08/2010	10 min			5 min	

Comments: (Include here who initiated the contact, the reason for the contact, the type of issue or topic of discussion [e.g. problem solving, teaching, responding to request], the plan decided upon/next steps, lessons learned, any resources used, and so on).

Appendix I: Knowledge Broker Interview Guide

How do parents use information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy?

Knowledge Broker Interview Questions

1) In what ways, if any, do you think it could have been beneficial for you to participate in a knowledge translation strategy using a KB? (Probe for whether there were any benefits that the KB could not expect and for whether there could have been an impact of their role at their center/program beyond facilitating the awareness, knowledge, and appropriate use of the Move & PLAY materials in practice).

2) Do you think that having a KB might be an effective strategy to help move research into practice more generally? Why or why not?

3) What factors do you feel would have been key to the success or lack of success of using this knowledge translation strategy at your site?

4) Were there any challenges (e.g. time, money, comfort with role, resources) that arose at your site related to the knowledge translation strategy using a KB?

5) How did you feel you were perceived in your role as KB by parents and other colleagues?

6) If you were to give advice to others wanting to start a KB role, what would be the 3 most important considerations?

7) Was there organizational support (e.g. release time for you or other staff, financial support such as funds to purchase additional resources) for this project beyond the time given to your center for your role (2 hours per week)?

8) Do you see the role of the KB continuing at your center for learning and promoting other evidence-based materials? Why or why not?

9) Would you consider being a KB at your center for other evidence-based materials? Why or why not?

10) Were there costs associated with the KB role beyond the study? Please describe.

Appendix J: Letter of Information and Consent

How do parents use information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy?

[redacted]

Letter of Information (September 2011)

What is this letter for?

As a parent who's young child with cerebral palsy (CP) receives services through Thames Valley Children's Centre (TVCC), you are being invited to participate in a research study examining how parents use health information with the aid of a knowledge broker (KB) when living with and caring for young children with cerebral palsy. The KB in this study is a staff member of TVCC, and may already be known to you. This letter contains information to help you decide whether or not to participate in this research study. It is important for you to understand why the study is being conducted and what it will involve. Please take the time to read this carefully and feel free to ask questions if anything is unclear or there are words or phrases you do not understand.

What exactly is this research about?

This research aims to understand, with the aid of a knowledge broker (KB), how you use knowledge and dissemination materials (such as those developed from the Move & PLAY study – a study about Movement and Participation in Life Activities) when living with and caring for your young child with CP. In your situation at TVCC, a KB is someone who helps parents access research information. We have engaged one KB from TVCC; her name is Wendy Worsfold and she is the Manager of the Resource Center. She has worked alongside the research team to conduct an introductory workshop to introduce dissemination materials from the Move & PLAY study to you. Dissemination materials are summaries of research that are meant to inform you of what a certain research study has found. However, our research will not be limited to the use of Move & PLAY materials, as we are interested in all types of knowledge use. This means we also want to know about other kinds of information (other than research) that you use when you make decisions about the health care that your child receives.

Who are we asking to participate in this study?

We are looking to sample 12 parents of young children with cerebral palsy. To be able to participate in this study, we ask that you have at least one child with cerebral palsy under seven years of age. Your child must have a primary diagnosis of cerebral palsy, which can range between levels I and V of the Gross Motor Function Classification System. You must have attended the introductory workshop and obtain services for your child through the Thames Valley Children's Centre. You need to be able to speak and understand English, and you must be over the age of 18.

What will your role be in this research?

At the beginning of this research, we will be collecting some information about you, your child, and your family. This is to help us understand the context in which you carry out your daily life. You will also be asked to answer a one-page questionnaire that will allow us to find out what GMFCS level your child is in. After we receive this information, you will have access to a KB over the course of three months, which is the duration of this phase of the study. You can access the KB however you like- ask her to find you certain kinds of information (perhaps on a certain topic), have her help you understand a research article you are reading, ask her for help finding other kinds of similar resources that you have found helpful in the past, and so on. Your contact with the KB is controlled entirely by you. This means that you can decide if you wish to talk with her at the same time each week, if you communicate by phone, email or in person at TVCC, or if you spend some weeks not using her services at all.

After three months, you will be asked to participate in one of two focus groups with the other parents who have participated so we can try to understand your experiences working with the KB. An example of a question that we would ask is: *how do you think your access to or use of research material has changed over the past three months?* The focus group, which will be held at TVCC at a time convenient to you, will be a maximum of 90 minutes long, and we will be recording your answers on an audio-tape. Depending on what you have said during the focus group, we may ask you to participate in an in-depth interview. This will allow us to find out a little more about your experience, in a one-on-one interview. This will be approximately 60 minutes long, will also be recorded, and will be conducted at a location convenient to you. An example of a question we would ask at this interview is: *what kinds of information did you use before this experience?*

After we have collected your answers through the focus group and interviews, we will begin to analyze what has been said. We will type out the audiotaped data, and then we will begin to organize what you have said by themes. It is possible that we need a bit more information on a certain theme we are developing, in which case we may need to have an additional interview with you. Before we finalize any of this research, we will go over our themes with you, to see if we have interpreted what you have told us correctly. Eventually, we hope to come to a set of core themes that describe what was said during the interviews and focus groups. This will help us create a model of how parents (such as yourself) use health information when living with and caring for their young children with cerebral palsy. This model will be an important addition to the field of knowledge translation and childhood rehabilitation, as it has implications for the facilitation of knowledge use in the everyday lives of families with children who have a disability.

Where will this research take place?

The focus groups will take place at TVCC; the interview will be held at a location convenient to you. How and where you spend your time with the knowledge broker is up to you.

Are there any risks or harms with participating in this research?

During the focus groups, you will be asked questions in a group atmosphere. It is possible that your answers are sensitive in nature, and you may feel uncomfortable sharing them with the group. However, it is up to you what you wish to contribute to this focus group, and you can choose not to answer questions.

Are there any benefits in participating in this research?

There are no direct benefits in participating in this research. However, the information that we receive from you in this study could benefit future families with children who have cerebral palsy.

Can I withdraw from this study?

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your future care at TVCC. [redacted]. Please note that your withdrawal in this research may not necessarily mean withdrawal of any data compiled up until that point.

Will my information be kept confidential and anonymous?

Yes. Parents will be asked to keep the content presented and discussed in the focus groups confidential. Recorded data will be destroyed after transcription to avoid potential voice identification. The transcript will be coded using unique numeric identifiers, and the master list will be held in a separate secure cabinet from the data. All sheets that are filled out by hand from participants will be re-typed to avoid hand-writing recognition, and IDs will be assigned to each form. Only Stephanie Lagosky and Doreen Bartlett will have access to information. If we find information we are required by law to disclose, we cannot guarantee confidentiality.

Will I be compensated (financially) for participating in this study?

We will be giving you $25 to help offset the costs of childcare, parking, and transportation for the focus groups and interviews.

What happens if this research gets published?

If the results of the study are published, your name will not be used. If you would like to receive a copy of the overall results of this study please email your name and address to [redacted]

Who should I contact if I have any questions?

Any questions about study participation may be directed to [redacted]

If you have any questions about your rights as a research participant or the conduct of the study, you may contact [redacted]

You do not waive any legal rights by signing this consent form.

This letter is for you to keep.

Consent Form (September 2011)

How do parents use information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy?

[redacted]

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Name of legal guardian (please print): ____

Signature: ____

Date: ____

Name of witness (please print): ____

Signature: ____

Date: ____

Name of Investigator (please print): ____

Signature: ____

Date: ____

Appendix K: Demographic Questionnaire for Parents

ID _______

Questionnaire For Parents

Thank-you for taking the time to fill out this questionnaire! There are three short sections to this form, asking questions about you, your child, and your family. If you do not feel comfortable answering some of the questions, feel free to leave them blank. For each question, please circle the answer that best applies, or fill in the blank space given.

First, we would like to find out more about you:

1) What is your age? ________

2) What is your gender?

Male Female

3) What is your current marital status?

Married

Never Married

Separated

Divorced

Widowed

Other (please specify): __________________________

4) What is your relationship to your child?

Mother	Father
Adoptive Mother	Adoptive Father
Stepmother	Stepfather
Foster Mother	Foster Father
Grandmother	Grandfather

Other (please specify): ________________________

5) What was the highest level of education you have attained?

Less than high school

High School Diploma

Community College

Technical Degree

University Bachelors Degree

University Masters Degree

University PhD or higher

Other (please specify): ___________________________

6) What is your current employment status?

Full Time

Part Time

Not Currently Employed

Other (please specify): __________________________

7) To what extent are you currently using research information on a regular basis:

1 2 3 4 5 6 7

|__________|__________|__________|__________|__________|__________|

Not at all Occasionally Very Often

Next, we would like to ask you some questions about your child.

8) What is your child's date of birth?

_______ _______ __________

Day Month Year

9) What is your child's primary diagnosis (by this, we mean what has the doctor told you is the main problem)?

Write your answer here: ____

10) At what age was your child diagnosed?

Age: ______

Finally, we would like to ask you questions about your family.

11) Please write down the initials and age of your spouse/partner, your other children, and other relatives like grandparents or aunts, uncles, and cousins who live with you. We also want to know about people who are not relatives, but who live with you. Please use initials, not names. You don't need to write anything here about yourself or your child.

For example:

BG 12 years old

SG 75 years old

_______ _____________

_______ _____________

_______ _____________

_______ _____________

_______ _____________

_______ _____________

_______ _____________

_______ _____________

Thank-you for filling out this questionnaire. Your answers will be kept anonymous and confidential. If you have any questions about this questionnaire, or any aspect of the research project, please contact Stephanie Lagosky at [redacted]

Appendix L: GMFCS Questionnaire for Parents

GMFCS Family Report Questionnaire:

Children Aged 2 to 4 Years

Please read the following and mark **only one box** beside the description that best represents your child's movement abilities.

My child…

☐ **Has difficulty controlling head and trunk posture in most positions**
and uses specially adapted seating to sit comfortably
and has to be lifted by another person to move about

☐ **Can sit on own when placed on the floor and can move within a room**
and uses hands for support to maintain sitting balance
and usually uses adaptive equipment for sitting and standing
and moved by rolling, creeping on stomach or crawling

☐ **Can sit on own and walk short distances with a walking aid** (such as a walker, rollator, crutches, canes, etc.)
and may need help from an adult for steering and turning when walking with an aid
and usually sits on floor in a "W-sitting" position and may need help from an adult to get into sitting
and may pull to stand and cruise short distances
and prefers to move by creeping and crawling

☐ **Can sit on own and usually moved by walking with a walking aid**
and may have difficulty with sitting balance when using both hands to play
and can get in and out of sitting positions on own
and can pull to stand and cruise holding onto furniture
and can crawl, but prefers to move by walking

☐ **Can sit on own and moved by walking without a walking aid**
and is able to balance in sitting when using both hands to play
and can move in and out of sitting and standing positions without help from an adult
and prefers to move by walking

Distributed by *CanChild* Centre for Childhood Disability Research, McMaster University
GMFCS modified with permission from Palisano et al. (1997) Developmental Medicine and Child Neurology, 39, 214-223.

GMFCS Family Report Questionnaire:

Children Aged 4 to 6 Years

Please read the following and mark **only one box** beside the description that best represents your child's movement abilities.

My child…

☐ **Has difficulty sitting on their own and controlling their head and body posture in most positions**
and has difficulty achieving any voluntary control of movement
and needs a specially-adated supportive chair to sit comfortably
and has to be lifted or hoisted by another person to move

☐ **Can sit on their own but does not stand or walk without significant support and adult supervision**
and may need extra body / trunk support to improve arm and hand function
and usually needs adult assistance to get in and out of a chair
and may achieve self-mobility using a powered wheelchair or is transported in the community

---

☐ **Can walk on their own using a walking aid** (such as a walker, rollator, crutches, canes, etc.)
and can usually get in and out of a chair without adult assistance
and may use a wheelchair when travelling long distances or outside
and finds it difficult to climb stairs or walk on an uneven surface without considerable help

---

☐ **Can walk on their own without using a walking aid, but has difficulty walking long distances or on uneven surfaces**
and can sit in a normal adult chair and use both hands freely
and can move from the floor to standing without adult assistance
and needs to hold the handrail when going up or down stairs
and is not yet able to run and jump

☐ **Can walk on their own without using a walking aid, including fairly long distances, outdoors and on uneven surfaces**
and can move from the floor or a chair to standing without using their hands for support
and can go up and down stairs without needing to hold the handrail
and is beginning to run and jump

Distributed by *CanChild* Centre for Childhood Disability Research, McMaster University
GMFCS modified with permission from Palisano et al. (1997) Developmental Medicine and Child Neurology, 39, 214-223.

Appendix M: Parent Interview Guide

How do parents use information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy?

Interview Guide for Parents

Over the past one to two months, you have had access to both a series of research summaries and a knowledge broker to help you find and use health information. I am interested in knowing a bit about how you used information before this whole research experience.

1) What information did you use before this experience? How did you become aware of this information? What were the things that made it easy or difficult for you to use information prior to this experience? *[Prompt: what information did you value, where did you access the information, what kind (oral or written) etc.]*

Now I would like you to help me understand how you currently use health information (specifically).

In particular, I would like to understand how you use health information in regards to your child.

2) Think of a situation where you had to make a decision that would change the direction of care you provided at home, at school, or within the social life of your child. What health information was helpful to you in making a decision or considering options about the direction of care? *[Prompt: Did this information change how you interacted with your child? What was the nature of this health information re: written brochure, article, information on web, shared from another source? How (if at all) did the health information combine with other sources of information to help you make a new direction in how you cared for your child/client at home at school or in the community or in the health care or rehabilitation system?]*

DEPENDING ON ABOVE ANSWER (SATISFIED OR UNSATISFIED), ASK THE OPPOSITE:

   a) Can you tell me about an example of a certain experience that helped you choose or make a decision you were satisfied with?
   b) Can you tell me about a situation where information you used did not lead to the outcome you wanted in the care of your child? *[Prompt: What was it that happened or led to you needing the information, who was involved and why you felt that the information did not help you achieve the outcome you were looking for? What would you do differently in considering the way you used information in this later situation?]*

3) Can you give me an example of a situation where you were unsure or uncomfortable with the health information you were considering, that was a situation where you did not necessarily believe the information would be helpful? What did you do along the way to sort out how to use it, and what steps (if at all) did you actually take to use the information?
4) How (if at all) does the way that others use health information influence the way you think about or use information in caring for your child? *[Prompt: Can you give me an example of situation where you considered how others viewed information? Does anyone else involved in your child's care (i.e. family, friends OR other health service providers) use health information? In what ways does this influence the way you made decisions about your child's care?]*
5) How do you decide what information is relevant to use when you need to make a challenging decision about the care of your child? How (if at all) do you use this information in context with what you already know? What if anything helps you sort out what information you use and what information you do not use? Can you give an example? *[Prompt: do you discuss it with others, or think about it for a period of time, what do you consider valuable about the information you use]*?
6) Can you give me an example of a situation where you have become more confident in making plans and making a decision about using information over time, to point that you do not think about it, you just know?
7) Given that in some instances a change in one thing may affect others, how do you go about sorting out what to do and how go about making changes in the care of your child? What do you do? How are decisions made?

8) In this study, we provided access to a KB, but I understand that you did not interact with this person.
    a) Is there anything that we could have done to facilitate this interaction?
    b) What else could we have provided that would have been of use to you in accessing and understanding information?
9) How if at all do you feel your approach to make decisions and considering health information has changed due to this experience?
    a) In what way do you feel that using research materials, such as those materials from the Move and Play study, impacted the way you view various rehabilitation and health options? *[Prompt: What is it about these materials that have helped you consider options? How do you use these materials to add to or compliment other things that you know?]*
    b) In what way do you think your usage of research materials will increase or stay the same?
    c) In what way do you think your approach to sharing information with your health service provider has changed? *[Prompt: For instance if you found new information from a different source such as the internet or a friend would you bring it forward?]*
    d) In what way do you think the health information you have learned will have other benefits in the daily care of your child (i.e. just increase of knowledge)?
10) Knowing that new parents will face new information and may struggle with how to use it, what advice would you give them about how to consider and think about health information before they make plans to use it?
11) Knowing that you were going to do this interview today, was there anything you were thinking of discussing regarding the use of information that we haven't talked about yet?

Thank you for sharing your experiences with us.

Appendix N: Resource Centre Co-ordinator Duties

Manage Written Information

- Information requests for staff, clients and community partners
- Find reliable (external and internal) information sources and use good judgement to decide the span of the topic (including pros/cons or positive/negative aspects)
- Journals
  - Place renewal orders and track receipt of issues
  - Notify staff of receipt of issues
  - Supply articles as requested and track requests
- Develop and Maintain Bulletin boards
  - Education for Staff
  - What's up in our community for clients and families
  - Equipment for sale
- Develop and Maintain Information files
  - Service Groups, Diagnosis, Etc.
- Information Kits - Develop and maintain as need arises

Develop & Manage Electronic Information System

- Play an integral part of website meetings
- Responsible for content sections "Resource Centre" and "Books & Resources for Loan"
- Train Website Champions
- Answer e-mail enquiries on behalf of the centre and forward to the appropriate person
- Maintain a list of websites that contain valuable and dependable information for our staff, clients, and community partners
- Develop and maintain DVD and video libraries

Coordinate Information

- Maintain contact with all agencies or groups that might offer information, workshops, services, etc. of interest to our clients, staff or community partners.
- Participate in the development of workshops as appropriate
- Use a variety of methods including electronic, written, posted and presented to provide information to our clients, staff and community partners
- Liaise with clients, staff and community partners to stay informed of their information needs

VITA

Name:

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Post-Secondary Education and Degrees:

The University of Western Ontario
London, Ontario, Canada
2006-2010 B.H.Sc. (Hons. Spec.)

The University of Western Ontario
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2010-2012 M.Sc.

Related Work Experience:

Research Assistant to Dr. Doreen Bartlett
The Move & PLAY Study
The University of Western Ontario
2010-2011

Teaching Assistant to Dr. Jessica Polzer
Social Determinants of Health
The University of Western Ontario
2011

Teaching Assistant to Dr. Phillip Doyle
Health Related Quality of Life
The University of Western Ontario
2011

Research Assistant to Dr. Anita Kothari
Knowledge to action processes in SHRTN collaborative communities of practice
The University of Western Ontario
2011-2012

Awards Received:

Principal's Award for High Academic Average
St. Joseph's College School, Toronto, Ontario
June 2006

School Pin Award for Extra-Curricular Involvement
St. Joseph's College School, Toronto, Ontario
June 2006

Dean's Honour List
The University of Western Ontario, London, Ontario
2009-2010

Presentations:

Lagosky, S., Bartlett, D. & Shaw, L.
How do parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy?
Poster presentation
The Faculty of Health Science Research Day
London, Ontario: March 2011, March 2012

Lagosky, S., Bartlett, D. & Shaw, L.
How do parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy?
Oral presentation
Health Professional Education Seminar Series
London, Ontario: April 2011

Lagosky, S., Bartlett, D. & Shaw, L.
How do parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy?
Poster Presentation
NeuroDevNet Cell-to-Person Symposium
Toronto, Ontario: May 2011

Lagosky, S., Bartlett, D. & Shaw, L.
How do parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy?
Oral Presentation
Centre for Education, Research and Innovation Symposium
October 2011

Coulson, S., Kothari, A., Conklin, J., Stolee, P.
& Lagosky, S.
Knowledge to action processes in SHRTN collaborative communities of practice: Year One
Poster Presentation
ARGC/FHS Conference
London, Ontario: February 2012

Coulson, S., Kothari, A., Conklin, J., Stolee, P.
& Lagosky, S.
Knowledge to action processes in SHRTN collaborative communities of practice: Year One
Poster Presentation
Faculty of Health Science Research Day
London, Ontario: March 2012