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How Do Individuals with Cerebral Palsy and their Families Prefer to Receive and Use Evidence-Based Information to Individualize Services to Optimize Outcomes?

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Graduate Program in Health and Rehabilitation Sciences
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Abstract

The main objectives of this study were to: (1) describe the format in which children with cerebral palsy (CP) and their parents prefer to receive information pertaining to development; (2) understand how children with CP and their parents intend to use this information; and (3) gain insight on how children with CP wish to be represented in the information in terms of being both comprehensive and respectful. Ten children with CP and their parent(s) or guardian(s) participated. Semi-structured interviews were conducted and analyzed using constant comparative analysis. Eight themes were created related to the type and format of information preferred by children with CP and their parents. The results of this study provide a next step for disseminating the individualized information obtained in the OnTrack study, as well as for narrowing the gaps that currently exist in the literature related to information preferences of children with CP and their families.

Keywords

Cerebral palsy, individualized information, information preferences, information format, evidence-based information, individualized services, family-centered care

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List of Abbreviations

CCAC	Community Care Access Centre
CFCS	Communication Function Classification System
CP	Cerebral Palsy
GMFCS	Gross Motor Function Classification System
GMFM	Gross Motor Function Measure
MACS	Manual Ability Classification System
Move & PLAY	Movement and Participation in Life Activities of Young Children with Cerebral Palsy
OnTrack	On Track: Monitoring Development of Children with Cerebral Palsy or Gross Motor Delay
QD	Qualitative Design
RAC	Research Advisory Committee
TVCC	Thames Valley Children's Centre

Chapter 1: Introduction

If a researcher wishes to make an impact, it is important that her or his findings are taken up in the relevant field of practice. Recently, the healthcare research community has gradually begun to see evidence as a necessary tool in narrowing the gaps that exist between what is currently known and what is currently done (Bhattacharyya, Reeves, & Zwarenstein, 2009). One step toward bridging the gap between evidence and practice in the healthcare field is by creating collaborative partnerships among researchers, healthcare practitioners, and patient/client-participants. It is clear that research findings should be actively disseminated to healthcare practitioners, but how often do researchers take particular care to disseminate findings in a way that is *useful* to research participants and healthcare consumers? The purpose of this research project was to explore this potential connection. Specifically, this research explores how children with cerebral palsy and their parents or legal guardians (hereafter collectively referred to as “parents”) involved in an international multi-site study wish to receive and use relevant, evidence-based information related to the research findings.

Before reviewing what is currently known about how children with cerebral palsy and their parents prefer to receive and use evidence-based information, the health condition of cerebral palsy is defined and its heterogeneous nature is described. Evidence-based and evidence-informed practice are defined and the context of this research is described. Finally, the next step of knowledge translation is outlined and a rationale for conducting this research is subsequently provided. This chapter ends with a description of the study objectives.

1.1 Cerebral Palsy

The most commonly used definition of cerebral palsy (CP) is that conceptualized by Rosenbaum, Paneth, Leviton, Goldstein, and Bax (2007), which states:

Cerebral palsy describes 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. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems. (p. 9)

Although this definition is extensive, its components can be explored further to provide a more comprehensive understanding. When referring to CP as a “group of permanent disorders”, the authors are referring to the heterogeneity in impairment severity and etiology. The authors used the terminology “attributed to” to signify that, despite increasing neurobiological understandings allowing clearer structural-functional correlations, the actual causal pathways of many cases of CP are still unknown. Furthermore, “non-progressive disturbances” means that the disruption to typical brain structure and function that led to CP is no longer active. Although developmental processes may change due to CP over time, the disorder itself does not progress. Finally, the last sentence of the definition is meant to outline the range of impairments and comorbidities that accompany the motor disorders of CP.

Prior to the development of the Gross Motor Function Classification System (GMFCS) by Palisano and colleagues (1997), the terms used to describe a child’s CP-related abilities were neither consistently used nor clearly defined (Rosenbaum, Palisano,

Bartlett, Galuppi, & Russell, 2008). In an attempt to provide a more meaningful measure, the GMFCS was designed as a valid and reliable tool to classify motor function in children with CP. The GMFCS consists of five levels of functioning, denoted by roman numerals, wherein gross motor abilities decrease as GMFCS level increases. Level I is used to classify children with CP who can walk, run, jump, and perform other gross motor abilities without assistance but who have limited speed, balance, and coordination. Children in Level II are less able to run and jump and have difficulty walking for longer distances or on uneven terrain without some assistance. In Level III, children walk with an assistive device and often use a wheelchair to travel for long distances. A child in Level IV may walk short distances with physical support and will use manual or powered assistive devices for all other mobility. Finally, children in Level V require a wheelchair for mobility and often require head and trunk support along with assistance in limb control (Palisano et al., 1997).

Following the creation of the GMFCS, two additional systems were developed to provide further functional classifications related to children with CP. Each system is similar to the GMFCS in that it includes five levels of increasing relative severity of CP. First, the Manual Ability Classification System (MACS) was designed by Eliasson et al. (2006) to provide classifications for children with CP based on their abilities to handle objects in daily activities. Second, the Communication Function Classification System (CFCS) was created by Hidecker et al. (2011) to fill the gap in classification of functional communication in everyday life situations. For more information on the levels of classification of each of the three systems, including a more detailed explanation of the levels in MACS and CFCS, please see *Appendix A*.

Use of the three classification systems for CP is especially important to understand the heterogeneous nature of CP. In recent work to better understand the inter-relationships of gross motor function, manual abilities, and communication functions, Dyszuk, Bartlett, Galuppi, and Gorter (2014) found the most prevalent combination of GMFCS, MACS, and CFCS levels to be I, I, I, respectively. This combination accounted for only eleven percent of possible identified combinations. The second and third most common were I, II, I, and II, II, I, accounting for an additional ten percent and six percent of combinations, respectively. Each of the remaining possible presentations of CP (i.e. the remaining 76 of 79 cells of 125 possible combinations) accounted for less than five percent of all cases. These statistics are key in presenting the numerous possible variations in which CP can present in an individual.

Considering this information, the three classification systems outlined above are important for describing the abilities of children with CP in broad brush strokes so that treatment and therapy plans can be individualized to provide optimal treatment. Further individualized decision-making is supported by detailed assessments of children's co-morbid health conditions and primary and secondary impairments (Jeevanantham & Bartlett, in press) in the context of status of motor function, self-care, and participation in recreation and leisure (Bartlett et al., 2012).

1.2 Evidence-Based Practice

As defined by Sackett, Straus, Richardson, Rosenberg, and Haynes (2000), evidence-based practice is the integration of the best research evidence available, along with the clinical expertise of the practitioner and the unique values of the patient to optimize outcomes and improve overall quality of life. Evidence-based practice can be

differentiated from evidence-informed practice, wherein the latter relies on the ability of practitioners to construct an informed decision instead of on choosing a predetermined decision (Nevo and Slonim-Nevo, 2011). There is some debate as to which of evidence-based or evidence-informed is better for healthcare practice; however, what can be taken from both concepts is the fact that practice should be correlated with existing evidence.

As stated in the previous section, CP is a heterogeneous condition. As such, people with CP require multiple interventions that are tailored to each individual's specific needs. Although practitioners have been described to rely on their experience, tacit knowledge, and 'mindlines' (Gabbay & le May, 2004; Kothari et al., 2012), there is still a need to refer to and rely on evidence when planning care for health users. This creates a challenge for therapists, as standardized and definitive evidence, specifically in the trusted form of randomized controlled trials (RCTs), is not often available, or appropriate, for conditions with such variation in presentation as CP (Bartlett et al., 2010). Furthermore, evidence-based guidelines are frequently applied poorly to complex conditions with multiple comorbidities (Greenhalgh, Howick, & Maskrey, 2014). The work conducted in both the Move & PLAY and OnTrack studies aims to assist therapists in this respect by gathering evidence and disseminating findings in a way that is particularly useful for planning individualized services. These projects are described next.

1.3 Move & PLAY and OnTrack Studies

A study called Movement and Participation in Life Activities of Young Children with Cerebral Palsy (Move & PLAY) was conducted by Bartlett et al. (2012) with 430 children from both Canada and the United States between 18 months and 4.5 years of age. The study's goal was to understand the determinants that support the development of

motor abilities, self-care, participation, and play of young children with CP. Specifically, the determinants were considered in relation to child, family, and service delivery factors. Data were collected over the course of one year with three separate collection points. Based on the findings of the Move & PLAY study, a better understanding of the factors associated with outcomes important to the two functionally distinct groups of children with CP (i.e. GMFCS levels I and II, and GMFCS levels II, IV, and V) and their families has been provided.

As a follow-up to the Move & PLAY study, the On Track study: Monitoring Development of Children with Cerebral Palsy or Gross Motor Delay (Bartlett et al., 2013) was developed to incorporate the use of the MACS and CFCS in addition to the GMFCS to assist with individualized interpretations. This study involved a total of 708 children with CP and their families from Canada and the United States, some of whom were recruited through their involvement in the preceding Move & PLAY study. The children with CP ranged from 18 months to 10 years of age at study entry and they spanned all levels of the GMFCS. Over a period of two years, the children involved in the study were observed on five separate occasions, each time being assessed by both their parents and a trained therapist assessor. Methods used to develop the Ontario Motor Growth Curves (Rosenbaum et al., 2002) and the reference percentile curves for the Gross Motor Function Measure (Hanna, Bartlett, Rivard, & Russell, 2008) have been replicated on the various determinants and outcomes of the Move & PLAY study. Specifically, the objectives of the OnTrack study were to describe changes in: (1) primary and secondary impairments (balance, range of motion limitations, strength, and endurance); (2) impact of health conditions; and (3) participation in self-care and in

recreation and leisure activities. As a result of this data collection, the goal was to create: (1) longitudinal growth curves to understand average trajectories of functional subgroups of children with cerebral palsy; and (2) reference percentiles to determine if children with cerebral palsy are doing ‘as expected’, ‘more than expected’, or ‘less than expected’ on all determinants and outcomes. Interpretation using the reference percentiles enables greater understanding of individual children’s attributes than can be attained using the GMFCS, MACS, and CFCS information alone.

1.4 Next Steps – Knowledge Translation

Again, researchers have an important role in bridging the gap that exists between evidence and practice. One way that this can be addressed is through efforts of knowledge translation. According to the Canadian Institute of Health Research (2015), knowledge translation is: “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products, and strengthen the healthcare system”. In simpler terms, knowledge translation is a complex process in which people with various roles and perspectives work together to ensure that knowledge becomes incorporated into practice.

Thus, the next step of the Move & PLAY and OnTrack studies is to facilitate the translation of findings from knowledge into practice. Bartlett and her colleagues have recognized this need and have taken steps to ensure that this idea becomes a reality. One of the steps for promoting the uptake of the Move & PLAY and OnTrack findings into practice is the research I completed under the supervision of Dr. Bartlett. In summary, I conducted interviews to better understand how we can communicate individualized

information most effectively to children with CP and their families to optimize care. To begin this work, I conducted a detailed literature review to ascertain what is already known on this topic. To set the stage for the literature review, the study objectives are stated next.

1.5 Study Objectives

As part of consideration of knowledge translation activities, investigators of the Move & PLAY and OnTrack studies wished to better understand how to communicate individualized information to children with CP and their families. To accomplish this goal, there were three specific objectives of this research: (1) to describe the format in which children with CP and their parents prefer to receive individualized, evidence-based information from the Move & PLAY and OnTrack studies about their children's development; (2) to understand how children with CP and their parents intend to use individualized evidence-based information pertaining to their development; and (3) to gain insight on how children with CP wish to be represented in the individualized information presented to them in terms of being both comprehensive and respectful.

Chapter 2: Literature Review

2.1 Search Strategy

The scope of this research is wide-reaching in the sense that it has the potential to be categorized under a range of subject types. For example, a paper focusing on how parents of children with disabilities prefer to receive information could fall under the subject of “Family Medicine”, “Health and Rehabilitation Sciences”, “Paediatrics”, or “Nursing”. Therefore, a variety of databases were included in the literature search in an effort to identify all important publications. The 11 databases searched were as follows: The Allied and Complementary Medicine Database (AMED), CINAHL, EMBASE, Family and Society Studies Worldwide, MEDLINE, ProQuest Nursing and Allied Health Source, PsycINFO, PubMed, Scopus, SocIndex, and Web of Science.

This literature search took place in two separate phases. Phase One of the search took place in January of 2016 and focused specifically on exploring the relevant literature that exists related to parents and families. Phase Two of the search took place in April of 2016 and focused on the information that exists relative to children. Although the literature search was conducted in two phases, both searches followed the same procedure.

Both searches included all relevant articles from each databases’ inception. The terms used in the search were derived directly from the research objectives, by considering what word(s) might be used to explore the ideas of the objectives. When relevant articles were found, any new terms related to the objectives were added to the list of terms and searched separately. A secondary method of searching involved citation tracking and reference list scanning. Different authors often used interchangeable

terminology to address similar, relevant topics, so this method was quite useful. A full list of the search terms and database results for both phases of the literature search can be found in Table 2-1 and Table 2-2 below.

Table 2-1. Phase one of literature search: search terms and databases.

Search Terms		Databases										
1. family AND research AND “receive information”		1. AMED										
2. parents AND “receive information”		2. CINAHL										
3. “informing parents”		3. EMBASE										
4. “information needs” AND parents AND how		4. Family/Society Studies										
5. “prefer to receive” AND parents AND information		5. MEDLINE										
6. “mode of delivery” AND parents AND information		6. ProQuest Nursing/Allied										
7. “communication tool” AND parents		7. PsycINFO										
8. “communication preference” AND parents		8. PubMed										
		9. Scopus										
		10. SocIndex										
		11. Web of Science										
Search Terms	Databases											
	1	2	3	4	5	6	7	8	9	10	11	
1	3	31	40	17	78	16	28	0	50	17	23	
2	4	22	92	43	56	27	42	0	80	24	60	
3	1	79	111	53	90	33	90	93	118	21	86	
4	10	108	64	27	43	16	34	0	237	9	57	
5	0	3	11	4	5	2	6	0	8	3	5	
6	0	0	25	10	12	6	5	23	27	0	19	
7	0	8	30	7	21	13	19	21	57	3	17	
8	0	20	1	0	0	0	3	0	16	0	0	
Total	36	271	374	161	305	113	227	137	593	77	267	
Total number of articles before inclusion and exclusion: 2561												

Table 2-2. Phase two of literature search: search terms and databases.

Search Terms		Databases										
1. child/children/youth AND research AND “receive information		1. AMED										
2. “informing child”/ “informing children”/ “informing youth”		2. CINAHL										
3. “information needs” AND child/children/youth AND how		3. EMBASE										
4. “prefer to receive” AND child/children/youth AND information		4. Family/Society Studies										
5. “mode of delivery” AND child/children/youth AND information		5. MEDLINE										
6. “communication tool” AND child/children/youth		6. ProQuest Nursing/Allied										
7. “communication preference” AND child/children/youth		7. PsycINFO										
		8. PubMed										
		9. Scopus										
		10. SocIndex										
		11. Web of Science										
Search Terms	Databases											
	1	2	3	4	5	6	7	8	9	10	11	
1	0	42	37	14	50	9	35	0	43	17	29	
2	0	358	45	20	33	16	37	0	49	19	35	
3	0	238	95	31	72	22	63	0	553	21	81	
4	0	5	15	1	9	2	7	0	11	1	8	
5	0	26	162	24	92	26	22	130	118	9	0	
6	2	93	84	15	63	18	43	53	184	14	59	
7	0	33	4	1	2	1	7	3	28	0	1	
Total	2	795	442	106	321	94	214	186	986	213	213	
Total number of articles before inclusion and exclusion: 3440												

I speculated in advance of the literature search that my topic would have few relevant papers, therefore I did not want to place many restrictions on the search results. The only limitation placed on the search was for articles to be available in English. Once non-English papers and duplicates were removed, I screened the search results based on titles and, when titles were unclear, based on abstracts. This initial screening provided a

total of 39 papers in Phase One and 40 papers in Phase Two that were potentially relevant to my research question.

Secondary screening involved reading these 79 articles to determine their relevance, with the articles from Phase One reviewed in January and the articles in Phase Two reviewed in April. Many papers focused on how to inform parents of critical medical diagnoses of their children, which is not the specific “how” that is the focus of this research. Furthermore, most papers related to children focused on revealing a difficult diagnosis or on obtaining informed consent. A flow chart of the screening and exclusion process for both phases of the literature search can be found in Figure 2-1 below. Following the secondary screening, a total of 15 articles remained in Phase One and six in Phase Two as relevant to my research question.

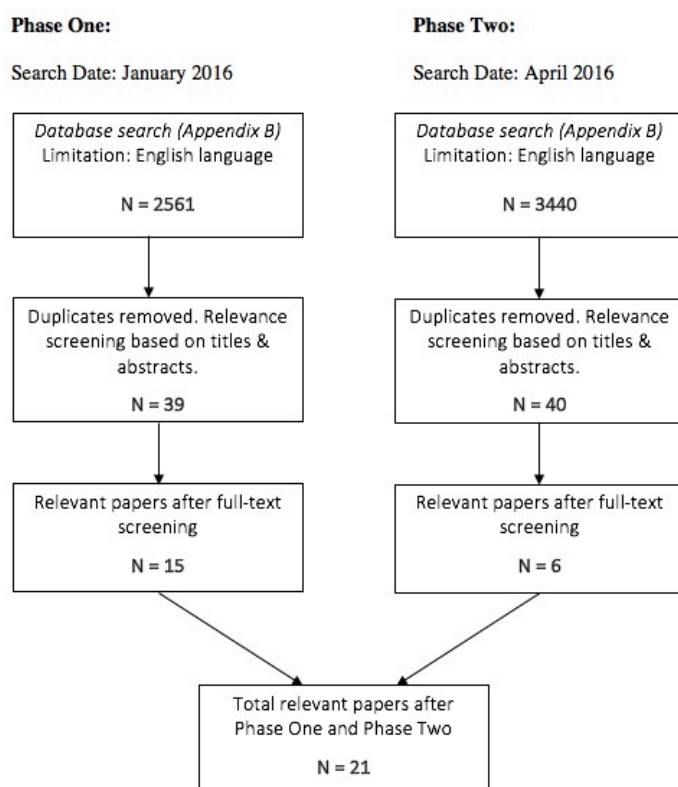


Figure 2-1. Screening and exclusion process for literature search.

2.2 Results

Five major themes emerged from the literature: *why* parents need information, information source preferences, information format preferences, barriers to obtaining information, and information preferences pertaining to children. Taken together, the five themes provide an overview of the currently available information that is relevant to understanding how children with CP and their parents prefer to receive information.

2.2.1 Theme One: Why Parents Need Information

Generally speaking, people tend to make better decisions when they have more information. According to the literature, this is also true for parents – specifically, for parents who have children with a disability. Children with CP require a significant amount of support from their parents (Higginson & Matthewson, 2014). According to two studies, this support is most advantageous when parents have access to relevant information (Higginson & Matthewson, 2014; Al-Daihani & Al-Ateeqi, 2015). Furthermore, parents need access to this information as early on in their children’s lives as possible to ensure that they can successfully meet their children’s needs and provide them with the opportunity to live fulfilling lives (Al-Daihani & Al-Ateeqi, 2015). In addition to facilitating parents to provide the best support for their children, having access to information has been shown to be a positive coping strategy for families of children with a disability (Davies & Hall, 2005). It can help foster beneficial feelings of control and self-efficacy among families who are experiencing a significant level of stress (Mitchell & Sloper, 2002). Moreover, the information acts as an empowering tool in the efforts of parents to support their children (Mitchell & Sloper, 2002; Sciberras, Iyer, Efron, & Green, 2010).

Furthermore, the literature has indicated that parents are not just interested in having general information about their children's disability. Two articles discussed families' interest in having access to research directly pertinent to their children's individual progress. In research done by King, Wright, and Russell (2011), therapists discussed how they had, in the past, been told that parents and families had no desire to be informed of measurements pertaining to their children's specific development – they just wanted therapists to treat their children. However, the same therapists went on to explain that families found measures (i.e. the Gross Motor Function Measure, GMFM) to provide useful information once they understood the role of measurements in the whole intervention process (King et al., 2011). Providing parents with research information about their children has been found to empower families by removing uncertainties about the intervention process to more fully understand the benefits to their children's needs (Cox, Fernandez, Chambers, Bandstra, & Parker, 2011; King et al., 2011).

Overall, the literature discussed in this theme signifies that there is sufficient research to rationalize *why* parents need information; the next step is to understand *how* to effectively provide information to parents in a way that suits each family's individualized learning needs. Multiple authors discussed the variation in families' information needs (Nightingale, Friedl, & Swallow, 2015; Sciberras et al., 2010). Additionally, Mitchell and Sloper (2002) directly addressed the gap in research pertaining to *how* families want to receive information. This helps to situate my research, building on what we know about *why* parents need information, towards filling the current gap in understanding *how* families prefer to receive information.

2.2.2 Theme Two: Information Source Preferences

Information can be presented via a range of sources. Given the variation in families' information needs, it makes sense that a variety of sources have been presented as options for providing families with information. A recent study by Al-Daihani and Al-Ateeqi (2015) used surveys to investigate information source preferences among parents in Kuwait who have children with special needs. According to their findings, the top source of information ranked by parents was information via doctors or physicians. Similar research done in North America provides support for these findings, showing that parents prefer to receive information first from practitioners followed by a written version of the spoken information for future re-reading (Davies & Hall, 2005; Higginson & Matthewson, 2014; Mitchell & Sloper, 2002; Sciberras et al., 2010; Pain, 1998). Another source in the literature that involves a hard-copy is information via mail. A study done by Cox and colleagues (2011) used a questionnaire to assess parents' appraisals of receiving mailed results of their children's scores on standardized psychological assessments. The parents involved found the use of a mailed letter to be satisfactory so long as resources existed to seek further information (Cox et al., 2011).

In contrast to hard copies, multiple studies investigated the use of electronic information materials available through use of the Internet (Boudewyns et al., 2015; Goldman & Macpherson, 2006; Mulligan, Steel, MacCulloch, & Nicholas, 2010; Sciberras et al., 2010). These results are discussed next in chronological order, as it is important to appreciate each study's findings in light of the continual progression of Internet use. First was a study by Goldman and Macpherson (2006), which found that 87% of the parents involved in the research project had access to the Internet and were

interested in receiving emails with information about their child. One study from 2010 explored the benefits of both hard copy and electronic copy, but concluded that parents generally prefer receiving relevant information in hard copy format (Mulligan et al., 2010). Finally, the most recent study examined patients' comprehension of the same information being presented via different sources and concluded that patients comprehended the printed version of the material better than the electronic version (Boudewyns et al., 2015). Evidently, the trend in the literature shows that parents prefer to receive information as a written hard-copy when compared to an online electronic copy.

2.2.3 Theme Three: Information Formatting Preferences

The literature provided helpful information regarding four different aspects of formatting preferences. The first aspect deals with the *layout and design* of the information being presented. As part of a list of good practice for providing patients with written information, Mitchell and Sloper (2002) included two evidence-based suggestions related to design and layout. Firstly, the front page or cover page of the information being provided should have an interesting and attractive design (Mitchell & Sloper, 2002). Secondly, the information should be easy to navigate, perhaps via colour-coding or simple reference systems (Mitchell & Sloper, 2002). Later research by Mulligan and colleagues (2010) provides further support for the use of an attractive design and a table of contents. They also suggested that a flowchart design could be used to help parents make decisions that are influenced by the information being presented, specifically when choosing support services for their children (Mulligan et al., 2010). Furthermore, research by Boudewyns et al. (2015) concluded that information is easier to navigate and better

retained by readers when it is sectioned into categories with obvious borders, less clutter, and more white space.

A similar aspect of formatting preferences is *content*: the actual information that is included in the resource. Multiple articles discussed the helpfulness of including real comments and quotes from other parents by making the information more realistic and relatable (Mitchell & Sloper, 2002; Mulligan et al., 2010; Young, Jones, Starmer, & Sutherland, 2005). However, it was noted that the appropriate amount of “parent tips” to include is not easily deduced (Young et al., 2005). Two articles touched on the importance of supplementing general information with appropriate local, region-specific information (Mulligan et al., 2010; Pain, 1998). Research by Young and colleagues (2005) explained that parents require unbiased information about all available options, followed by a discussion of the pros and cons of each to facilitate decision-making. Parents reading the information should be able to understand the information in terms of what it means for their individual circumstances (Young et al., 2005). Finally, it is important for people creating the content to understand who the users will be – the information should be tailored such that it is inclusive of and accessible to individuals of all cultural, socioeconomic, and demographic backgrounds (Hummelinck & Pollock, 2006; Mulligan et al., 2010).

Part of parents being able to understand the content of the information is based on the content being written in the appropriate *language*. In order to accommodate all parents’ varying levels of comprehension and information needs, it is important that the content is written in simple and explicit language (Boudewyns et al., 2015). One research study showed that information presented at the sixth-grade reading level was more

successfully retained than information presented at the eighth-grade reading level, despite the country's average reading level being estimated at eighth-grade (Boudewyns et al., 2015). Similarly, parents and anyone who is not a healthcare professional may be confused by "medical jargon", so it is best to keep the information in lay terms (Hummelinck & Pollock, 2006; Mitchell & Sloper, 2002; Mulligan et al., 2010). If including medical jargon is inevitable, Mitchell and Sloper (2002) suggested including clear definitions that are easy to find within the content. Aside from the type of language used, the tone is also of importance. Multiple studies concluded that parents preferred the presentation of accurate information in a tone that promoted hopefulness and encouraged parents to seek more support if necessary (Mitchell & Sloper, 2002; Mulligan et al., 2010).

The last aspect covered in the literature in relation to formatting preferences is the desired *length and comprehensiveness* of information. It is important to provide information that is comprehensive of the subject (Michell & Sloper, 2002); however, it is important to keep in mind that people can be confused when presented with large amounts of information in one sitting (Hummelinck & Pollock, 2006). There is support for creating information sources that are shorter in length, with a focus more on the specific content that the parents find important (Boudewyns et al., 2015). Additionally, a study that examined patients' comprehension of three different versions of the same information found that patients were better at comprehending shorter, more focused resources because they were easier and less burdensome to read (Boudewyns et al., 2015).

2.2.4 Theme Four: Barriers to Obtaining Information

Three barriers were discussed in the literature that are relevant to the understanding of how families of children with disabilities prefer to receive information. Research done in Kuwait to understand the information needs of parents with children with disabilities revealed a significant barrier: a lack of resources in the official language of Arabic (Al-Daihani & Al-Ateeqi, 2015). It may not be the case that there is a lack of information sources in the official languages of Canada and the United States, but the language barrier encountered in the study by Al-Daihani and Al-Ateeqi is a reminder that people should have access to information in the language with which they are most comfortable. Another barrier discussed was the overuse of “medical jargon”, which caused parents to feel confused by the information (Hummelinck & Pollock, 2006; Mitchell & Sloper, 2002; Mulligan et al., 2010). Finally, parents were often intimidated by information when there were barriers that prevented them from asking questions or discussing concerns (Hummelinck & Pollock, 2006; Nightingale et al., 2015).

2.2.5 Theme Five: Information Pertaining to Children

While it is important to understand the health information seeking behaviours of researchers and healthcare providers, it has become apparent that the study of such behaviour includes negligible information on healthcare consumers (Okoniewski, Lee, Rodriguez, Schnall, & Low, 2014). Furthermore, there is a specific lack of information pertaining to the type and quality of information available to adolescents with chronic conditions (Grootens-Wiegers, deVries, & van den Broek, 2015; Okoniewski et al., 2014). This is problematic for multiple reasons, including the simple fact that children do have a desire for more information about their condition, even from a young age

(Szybowska, Hewson, Antle, & Babul-Hirji, 2007). Furthermore, this information is important for self-management as children with chronic health conditions transition to adolescence and adulthood.

Although there is a lack of literature relevant to children's information preferences, the information that does exist is valuable. In terms of language used in health information directed at children, it is important that the information is written in plain, explicit terms in an active voice (Grootens-Wiegers et al., 2015; Tait, Voepel-Lewis, Zikmund-Fisher, & Fagerlin, 2010). Additionally, the information should not be overly complex, and anything not at the appropriate reading level for the individual child should be explained as clearly as possible (Tait, Voepel-Lewis, & Levine, 2015; Tait et al., 2010). Sometimes it is necessary to use medical terminology or other words that cannot be made simpler. A systemic review by Grootens-Wiegers et al. (2015) found that children may still understand the meaning of the implied concept despite not being able to explicitly define the term used.

According to Szybowska et al. (2007), children and adolescents primarily seek and receive health information from their parents. It is important to know this source preference so that efforts can be made to provide parents with as much evidence-based information as possible to narrow the gaps between what health information exists and what they and their children know (Szybowska et al., 2007). Multiple studies have shown that this is not always the case, as there is evidence of discrepancies between what adolescents know, what their parents understand, and what information exists (Szybowska et al., 2007; Tait et al., 2015). In addition, it has become common for children to use the Internet to answer their health-related questions, which raises concern

over the quality of the answers (Skinner, Biscope, Poland, & Goldberg, 2003). This fact raises the importance of providing children and parents with access to relevant health information so that they are not relying on potentially questionable sources.

In terms of children's information format preferences, there are multiple studies that provide evidence for the use of interactive presentations that make use of colours, pictures, graphs, and other visual information (Grootens-Wiegers et al., 2015; Tait et al., 2015; Tait et al., 2010). The benefits of these formats in comparison to standard text format include: the use of emotional factors instead of cognitive factors for understanding the information (Grootens-Wiegers et al., 2015; Tait et al., 2010); the promotion of active learning (Tait et al., 2015); and the ability to keep the attention of children (Tait et al., 2010). In their study to examine how children understand informed consent documents in randomized controlled trials, Tait et al. (2015) used a theory called "pictorial superior effect" to describe the tendency for children to find pictorially represented information easier to understand than text-based information.

Finally, children experience barriers in seeking health information that differ from the previously explained barriers faced by parents. Four barriers were described in the literature: (1) the child does not want to share personal information with her or his healthcare provider; (2) the child and the healthcare provider do not communicate effectively; (3) the presence of the parent discourages the child from asking questions or sharing information; and (4) the child does not have the opportunity to ask questions to check her or his understanding of information presented (Grootens-Wiegers et al., 2015; Skinner et al., 2003; Szybowska et al., 2007). Overall, more studies need to consider the

specific health information needs of children so that more conclusive findings can guide the related information delivery.

2.3 Summary and Conclusion

As a result of a search inclusive of 11 separate databases, five major themes emerged from a combined total of 21 relevant articles. These five themes provided a background of what is currently known about how children with disabilities, their families, and people in general prefer to receive health information. First, parents of children with disabilities need information to provide support to their children, to cope with the stress that may accompany raising children with disabilities, and to empower families by increasing overall understanding. In terms of sources of information, parents preferred to receive information verbally from physicians accompanied by a hard-copy re-iteration, as well as access to further resources. Interestingly, electronic sources were not considered ideal. Moreover, preferences for information format covered layout and design, content, language, and length and comprehensiveness. Parents and children encounter separate barriers when seeking information. Finally, children like information in plain language in an interactive, pictorial format.

Although the articles from the literature review provided helpful information on information preferences, the results illuminated a threefold gap in knowledge. First of all, none of the articles were directly related to *how* children with disabilities and their parents prefer to receive evidence-based information that is individualized to their children's development. Additionally, there was no research pertaining to the information preferences of parents who have children with CP. Finally, there were no articles detailing the information preferences of children with CP. Clearly, there are gaps in

knowledge that require further research. Through this work focusing on understanding how children with CP and their parents prefer to receive and use individualized evidence-based information, my research will add to the literature and assist in closing these gaps.

Chapter 3: Methods

3.1 About the Researcher

3.1.1 Contextual Influences

To situate myself in the context of this research, I believe it is important to acknowledge aspects of my life experiences that impacted my analytic processes. As explained in the *Reflexivity* section, this information is relevant as it provides background on life experiences relevant to how I inevitably approached and interpreted this research.

First and foremost, I am a student at Western University conducting research under the supervision of Doreen Bartlett, a researcher in the Rehabilitation Sciences Field of the Health and Rehabilitation Sciences Graduate Program. Her previous work, outlined in the *Background* section, has had an impact in her field and is the foundation upon which my research project originated. Dr. Bartlett is understandably determined to see her work translated into useful information for the children and families from whom it was derived. Although my research has been my own project, it is important to note the influence that Dr. Bartlett's previous research and future goals have had on my work.

Unlike Dr. Bartlett and a considerable number of other researchers in her field, I do not have experience as a professional therapist (i.e. physical therapist or occupational therapist). I have stepped into the role of a researcher from a purely educational background, having received a Bachelor of Health Sciences (Honours) from Western University in 2015. As a researcher with this type of background, it is understandable that I brought different perspectives and interpretations to the information than someone with different previous life experiences.

Although I do not have experience as a therapist, I do have significant experience with CP. More specifically, I grew up and had the privilege of being friends with a girl who has CP. It is my extensive life experience with her that sparked my interest to pursue a Masters degree with a supervisor who specialized in children with CP. It is important to include this relationship in my efforts to be reflexive as my time spent with her constantly influenced my thoughts and opinions of information as it was presented. Moreover, her GMFCS, MACS, and CFCS levels are all at level IV or V, in my opinion. This means that my experience with children with CP is restricted in terms of understanding the heterogeneity of the condition. In other words, I grew up without the understanding that CP had presentations other than that of a child with severe gross motor mobility, communication, and manual ability restrictions. Overall, my friendship with this girl has been a major influence in my research.

3.1.2 Pragmatism

Before beginning a qualitative study, researchers should situate themselves relative to their basic beliefs about the nature of truth and reality so that their findings can be appraised and analyzed appropriately. These basic beliefs can be referred to as a *paradigm* and it is through an intentional questioning of one's paradigm that one can gain a deeper understanding of the ontological, epistemological, and methodological assumptions on which the paradigm is based (Guba & Lincoln, 1994). Overall, my beliefs situate me as an individual with a pragmatic approach to problem-solving.

Pragmatism, the philosophy of solving problems based on practicality rather than theory, is a useful paradigm for researchers conducting practical research (Creswell & Plano Clark, 2007). My paradigmatic beliefs align with the structure of my objectives in

relation to the knowledge translation goals of the OnTrack study: the OnTrack team wants to understand how children with CP and their families want to receive individualized assessment information, so my method is, simply, to ask. This direct link between the problem (not understanding how children with CP and their families want to receive and use information) and the solution (creating a research study to ask children with CP and their families how they want to receive and use information) is a pragmatic approach to creating evidence that is more effective in practice (Shaw, Connelly & Zecevic, 2010).

3.2 Qualitative Description

In an attempt to satisfy the three previously outlined objectives of this research project, I used a qualitative description (QD) approach. The main focus of QD, which is commonly used in qualitative, health-related studies, is to gain insight on the experiences of others regarding an area that is otherwise not fully understood (Kim, Sefcik & Bradway, 2017). One way to differentiate QD studies from other qualitative research methods (e.g. grounded theory or ethnography) is its basis in naturalistic inquiry as opposed to a specific methodologic framework (Sandelowski, 2000). That being said, QD studies often ‘borrow’ techniques in varying, flexible degrees from other qualitative research methods (Sandelowski, 2000). For example, a QD study may use a version of constant comparative analysis, which is most frequently associated with grounded theory methods (Sandelowski, 2000). The goal of QD is not to produce a theory but rather to describe the data collected in a way that is useful and meaningful (Sandelowski, 2000).

Data collection in QD studies usually involves interviews of varying structure with groups or individuals (Sandelowski, 2000). Analysis is “data-derived” and is

intertwined with data collection such that analyzed data influences the collection of future data, and the collection of new data influences the analysis of previously-collected data (Sandelowski, 2000). This fusion of data collection and analysis is also seen in grounded theory's constant comparative analysis. For an illustrated version of the constant comparative analysis process, based on Charmaz (2014), please see *Appendix B*.

The ultimate goal of my research was to use what participants have to say to make a difference in their lives. The flexible foundations of QD allowed me to approach my research with this goal and to describe the data collected in a way that is useful for participants and for future researchers, therapists, and families. Additionally, this choice of method was conducive to working with participants to understand their experiences and produce information that reflects their subjective realities. Finally, the ability to incorporate constant comparative analysis made QD an ideal choice for designing a research study to help solve a problematic gap in the knowledge.

3.3 Reflexivity

As defined by Finlay (2002), reflexivity is self-awareness that involves the continual recognition of subjectivity as it pertains to the constructive process of conducting research. Engaging in reflexivity throughout one's research project can contribute to the integrity and trustworthiness of the process and findings by providing accountability for the knowledge created (Finlay, 2002). Being reflexive is not effortlessly achieved and the action has received criticism from both quantitative and qualitative researchers. Generally speaking, the dismissal of reflexivity from quantitative domains is largely related to the assertion that subjectivity has no legitimate purpose in research and only contributes to researcher bias (Finlay, 2002). These arguments are valid

if one aligns oneself with this paradigmatic view. Criticism from qualitative parties comes from the notion that being truly reflexive is beyond our capability – is it possible for a researcher to be self-aware to a point that is neither problematically self-conscious nor insufficiently deconstructed (Finlay, 2002)? Although these are reasonably founded criticisms, it can be argued that the cost of not being reflexive is higher than the benefit of avoiding the potential concerns (Finlay, 2002). It was my goal to be as reflexive as possible throughout the entire research process.

3.4 Proposed Sample

We aimed to recruit ten to 12 children with CP and their parents or legal guardians (again, hereafter collectively referred to as “parents”) as participants in this study. Children as young as seven were approached to participate. All participants were required to have conversational level English. Recruitment of children and their families was assisted by the local coordinator for the OnTrack study at the Thames Valley Children’s Centre (TVCC). Additional children and their parents were recruited outside of the OnTrack by the same coordinator who worked in the CP clinic at TVCC and was involved in the circle of care to attempt to ensure diversity of age, gender, and ethnicity. The telephone script that was used for recruitment can be found in *Appendix C*.

The sample of children with CP was aimed to be as representative as possible of all functional levels of the three classification systems: GMFCS, MACS, and CFCS. That being said, attempting to interview children with CP who are in levels IV or V of CFCS would have been difficult and could have been detrimental to the child, potentially causing unnecessary stress and confusion. For this reason, interviewing was restricted to

children with CP in CFCS levels I or II if the child or adolescent was to be interviewed alone, or levels I, II, or III if she or he was to be interviewed with the parent.

Finally, it was our goal to recruit children and parents as diverse as possible in relation to age (from seven to 21 years for the children), gender, and ethnicity. It is important to remember that a small group of children with CP and their families is not fully representative of all children with CP and their families due to the heterogeneity of CP and the diversity of families it impacts.

3.5 Data Collection

3.5.1 Demographic Questionnaire

A demographic questionnaire was administered to participants who were recruited from outside of OnTrack study, as OnTrack participants had previously filled out the same information. The purpose of having participants complete this questionnaire was to understand the demographic characteristics of the group of individuals involved in the study from which generalizability of the study results could be judged. The demographic questionnaire can be found in *Appendix D*.

3.5.2 Pre-Interview Questionnaire

The next step in the data collection process was to administer a pre-interview questionnaire to the recruited participants. A study by Sobo (2004) involved the creation and distribution of a questionnaire to gauge patient communication preferences to improve overall quality of care. The final product, a tool called the Patient/Parent Information and Involvement Assessment Tool (PIINT), included a two-part questionnaire with five multiple choice questions and a chart on which the parent could

mark their information preferences based on their answers (Sobo, 2004). Overall, the language used in the questions, the format of the questions, and the general nature of the questions were all reported by the parents involved to be valid and easy to complete (Sobo, 2004). The PIINT was useful in providing an exemplar for this study.

Questions four and five of the PIINT tool were the inspiration for including a pre-interview questionnaire in the methods of this research project. Additionally, based on the information gained in the literature review, the questionnaire used simple and explicit language written at the sixth-grade reading level and was easy to navigate with a lot of white space. Furthermore, the questionnaire was sent to recruited families by email. The goal of sending questionnaires to the families and children in *advance* of the interviews was to clarify baseline information preferences. This information was analyzed and used as a guide or a starting point for the interviews in the second part of data collection. The pre-interview questionnaire that was sent to participants can be found in *Appendix E*.

3.5.3 Semi-Structured Interviews

The next part of the data collection process was semi-structured interviews that were guided by the families' answers to the previously administered questionnaire. The purpose of these interviews was to gain a more in-depth understanding of how families of children with CP wish to receive evidence-based information. More specifically, the interviews were "intensive interviews", which went beyond simple conversations into in-depth explorations of the experiences of the interviewees (Charmaz, 2006). Using this method, the researcher takes on the role of the subjective outsider who is attempting to understand the topic through the participants' views. That being said, the interviews had structured prompts to encourage the participant to transform their tacit knowledge into

explicit knowledge. Although the researcher may be seen as the one in control of the interview, she or he must acknowledge and remember that the participant sharing their significant life experiences is the expert on the topic.

The interviewer must also remain aware of certain concerns about the relationship that they have with the participant (Charmaz, 2006; Carpenter & Hammel, 2000): what perceptions does the participant hold of the power or status of the researcher? Does the participant feel like her or his voice is powerful, or do they feel like an irrelevant token filling a quota? Are there cultural or racial differences between the researcher and participant that may intimidate the participant? How does the gender of the participant affect their perception and subsequent action in interviews? These and many other questions are very important for the researcher to acknowledge and address before, throughout, and after the interviews.

In terms of conducting the interviews, a researcher should create a few open-ended questions that will ideally lead to detailed discussion (Charmaz, 2006). The broader the question, the more likely it is for participants to elaborate in a way that is not preconceived by the researcher. In her book, Charmaz (2006) provides a list of sample questions. She suggests creating as few questions as possible. It is also recommended that novice interviewers, such as myself, should use an interview guide to keep the process focused (Charmaz, 2006). Furthermore, it is suggested that interviewers encourage participants by acknowledging their responses with a neutral comment that stimulates further reflection – the goal is to explore the topic, not to interrogate the participant (Charmaz, 2006). If the interviewer wishes to hear more on a specific topic, she or he can shift the conversation back to an earlier comment or respectfully request that the

participant re-explore an earlier comment. A list of the possible questions used to guide the interviews can be found in *Appendix F*.

The interviews were audio-taped with the participants' consent so that I could pay full attention to the participant during the session and then revisit the interview later. The interviews were then transcribed from audio so that they could be analyzed. Furthermore, a second interview provided an opportunity to pilot test "mock-ups" of various formats suggested in the first interviews. Additionally, I memoed immediately following the interviews to keep a record of perceptions, dynamics, problems, or overall key messages as they developed (Carpenter & Hammell, 2000). The interviews were conducted with the goal of being sufficient for theory construction, not for population representativeness.

3.5.4 Member Reflections

When all the data were collected and analyzed, a summary table of the themes that evolved was created. In addition, mock-ups of children's actual assessment results from the OnTrack study were created for the eight participants who were recruited from this study based on the information preferences of children and their parents that arose in the interviews. The participants were contacted to review the summary table to ensure that the themes were meaningful and that they truthfully reflected their participation. Furthermore, the participants were asked to provide feedback on the mock-ups to understand if we accurately incorporated their preferences into our designs and, if not, how we could change the design to better reach this goal.

3.6 Data Analysis

3.6.1 Demographic Data Analysis

Once the demographic data were collected, they were tabled to describe the group of participants. Analysis of the demographic questionnaire provides the study with transparency as readers will be able to determine which demographics were represented and to what degree.

3.6.2 Pre-Interview Questionnaire Data Analysis

To analyze the data gathered from the pre-interview questionnaires, frequency counts of each answer were performed. The number of times that people selected each answer was reported to determine if there are any significant patterns in terms of which answers were most often chosen and which answers were least often chosen.

3.6.3 Constant Comparative Analysis

As is integral in QD studies, data collected from interviews were analyzed alongside the collection of new data from subsequent interviews. As soon as data were collected, the process of analyzing the data began and the process continued throughout the entire research process. Part of the process of constant comparative analysis was the process of coding. This process began with initial coding, which involved regrouping the collected interview data into labelled categories with similar meanings. This coding involved categorizing in such a way that each piece of coded data with the same label pertains to the respective topic of the data. Next, focused coding was the process of using the most frequent or significant codes from initial coding to refine the codes into coherent categories. This entire process was iterative in that it involved the constant comparison of

codes (Charmaz, 2014) to gain an understanding of how individuals with CP and their families prefer to receive and use evidence-based information to individualize services to optimize outcomes. For a visual representation of these steps, please see *Appendix B*.

3.6.4 Memoing

Memoing took place following each interview to elaborate on the data in relation to the experience. Some ideas to record were (Carpenter & Hammel, 2000): how did the environment, including the people present, impact the interview? Did any topics or key comments stand out? Were there any non-verbal responses? What was my overall impression of the interview? What can I improve on as an interviewer for the next interview? What might I want to ask if I interview them again? Memoing also occurred throughout the constant comparative analysis as a method of keeping track of my reflexivity while deriving themes from the coding.

3.6.5 Member Reflections

Part of conducting a credible study is ensuring that the interpretation of the data is consistent with what the participants intended to convey. While a term like *member checking* infers that one true reality exists, the term *member reflections* accommodates the paradigmatic belief that multiple subjective realities exist (Tracy, 2010). The reason for integrating the member reflections into the process is for the researcher to distill the findings in order to check that the interpretation rings true and is meaningful to participants (Tracy, 2010). Both the mock-ups and a summary of results was shared with participants, who were encouraged to share supportive comments or constructive criticisms.

3.6.6 De-briefing

My research team consisted of my supervisor (Dr. Doreen Bartlett) and my thesis advisor (Dr. Deb Lucy). Several meetings occurred with Dr. Bartlett to review interviews, debrief analyses and to ensure that my research was heading in the right direction. In addition, I debriefed basic results with participants involved in this research by means of a table of summarized results (Table 4.4-1). In addition to member reflection, this step was especially important to inform them that their participation in this study was followed up and translated into information that they can use.

3.7 Ethics

Prior to beginning data collection, a research proposal was submitted for approval by the Thames Valley Children's Centre (TVCC) Research Advisory Committee (RAC), as the study involved recruiting TVCC clients as research participants. This research proposal was also submitted to the Ethical Review Board at Western University in compliance with the requirement to obtain approval of studies involving human participants. Following approval from both TVCC RAC and the Ethical Review Board at Western University (*Appendix G*), potential participants were contacted by the local OnTrack coordinator at TVCC by phone. A sample of the phone script that was used for recruitment can be found in *Appendix C*. The individuals who chose to participate were sent a Letter of Information, with attached forms of Consent (for adults, one for parents and one for adults with CP aged 18-21 years) and Assent (for children aged seven to 18 years). A sample of this letter and the Consent and Assent forms can be found in *Appendix H*.

Chapter 4: Results

4.1 Participant Demographics

Ten families were recruited in total. Two additional families were initially contacted, showed interest in participating, and intended to set up times for an interview; however, both withdrew due to personal time constraints. All interviews were conducted as dyads (mother and child) or as triads (mother, father, and child). The children ranged in age from seven to 17 at the time of the interview. There were equal participants of boys and girls. The children covered four of the five possible GMFCS levels.

Table 4-1: Summary of child characteristics.

ID	Gender	Age	Ethnicity	GMFCS Level
1	Female	11	White	IV
2	Female	9	White	III
3	Male	13	White & South Asian	II
4	Male	17	White	IV
5	Female	9	White	I
6	Male	12	White	I
7	Female	11	White	I
8	Male	11	White	I
9	Male	10	White	III
10	Female	7	White	I

The parents ranged in age from 32 to 64 at the time of the interview. In Table 2, the second column shows that more mothers than fathers participated. It should be noted that the three entries with asterisks indicate that both parents participated equally in the interview despite the mother being the parent whose demographic data were recorded. The rest of the interviews were conducted with only one parent present.

Table 4-2: Summary of parent characteristics.

ID	Relationship to Child	Marital Status	Age	Education Level	Ethnicity	Household Income
1	Mother*	Married/living with partner	36	Masters degree	White	\$75,000 - \$89,999
2	Mother*	Married/living with partner	34	Community college diploma	White	\$90,000 +
3	Mother	Married/living with partner	33	Bachelors degree	South Asian	\$90,000 +
4	Mother	Married/living with partner	47	Community college diploma	White	N/A
5	Mother	Married/living with partner	32	Bachelors degree	White	\$90,000 +
6	Grandmother	Married/living with partner	59	Community college diploma	White	\$90,000 +
7	Mother*	Married/living with partner	41	Community college diploma	Other – mixed (black and white)	\$75,000 - \$89,999
8	Mother	Married/living with partner	48	High school or GED	White	\$45,000 - \$59,000
9	Mother	Married/living with partner	36	High school or GED	White	\$90,000 +
10	Grandmother	Divorced	64	Community college diploma	White	N/A

* = both parents present for interview

4.2 Pre-Interview Questionnaire Analysis

In this section, frequencies greater than ten per question indicate that multiple answers were selected by at least one parent. Frequencies less than ten per question indicate that at least one parent selected “other” and wrote their own answer to the question in the space provided.

The first question included on the Pre-Interview Questionnaire asked parents what the main reason was that they sought out information about CP. Most parents selected the answer that they wanted to learn more about CP as it directly relates to their individual

child. The rest said that they wanted to learn about CP in general terms. One parent selected both of these answers. None of the parents indicated that they did not seek out information about CP, and none of the parents opted for providing their own, different answer in the “other” option.

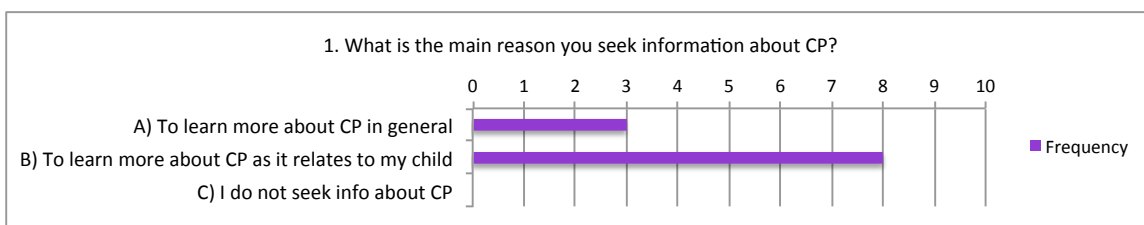


Figure 4-1: First question of pre-interview questionnaire.

The second question asked parents about what sources of information they use. The majority selected that they seek out information electronically, with the rest saying they seek out hard copies or verbal information.

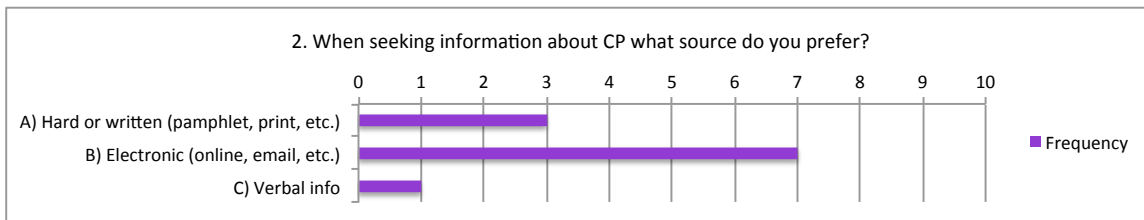


Figure 4-2: Second question of pre-interview questionnaire.

The third question pertained to CP-related content. The responses for this question were almost evenly distributed among the first three options. None of the parents selected the fourth option of “other” to provide their own response about what type of information they would prefer to receive.

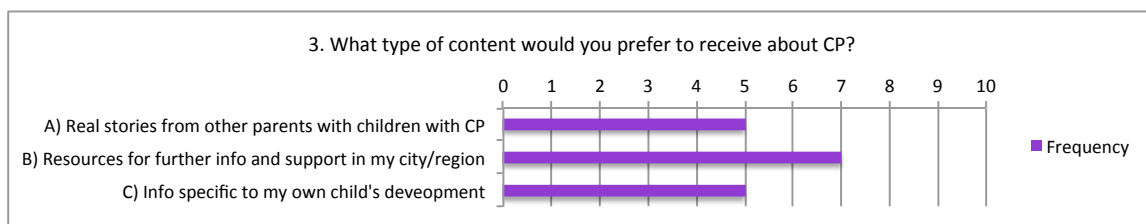


Figure 4-3: Third question of pre-interview questionnaire.

The fourth question asked parents about the amount of information they would like to receive about CP. Not surprisingly, none of the parents wanted to receive as little information as possible. Just over half of the parents responded that they would like as much information as possible, and some said that they would prefer in-depth information that didn't exceed more than two pages. One parent did select the "other" option, and wrote "information as sought out or updates to something new or educational".

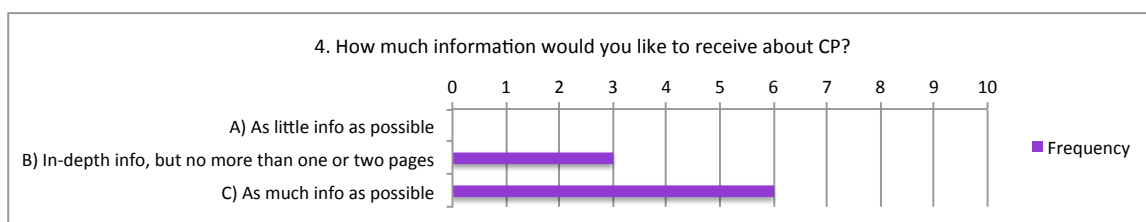


Figure 4-4: Fourth question of pre-interview questionnaire.

The final question of the questionnaire was an overall satisfaction question regarding parents' experiences with individualized information. None of the parents responded that they were completely unsatisfied with the information they have now. Most parents selected the response that indicated they were somewhat satisfied – they have some information, but not enough. One parent felt that she had the right amount of information. Three parents responded using the "other" option. The first response explained that the parent was satisfied with the information she currently has on CP, but noted that this is in large part due to her occupation that involves working with children

with developmental and mental health issues. She ended by saying that she is, however, “*always interested in more information*”. The second parent used the “other” option to explain how she learns about new information: “*If there is something new or educational and I was not seeking out the information I would not know it were available unless it was shared through peers, physicians, etc.*” Finally, the last parent to use the “other” option provided a very simple response: “*As much as we can get*”.

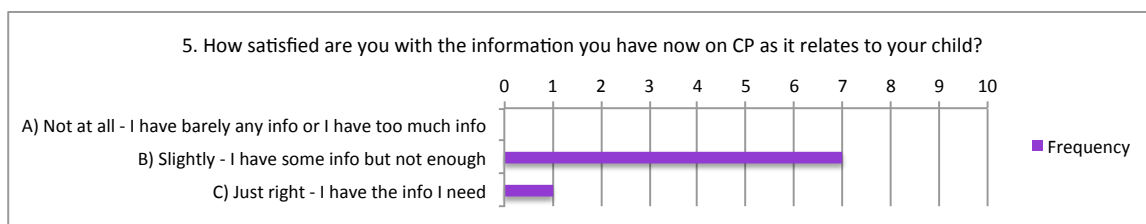


Figure 4-5: Fifth question of pre-interview questionnaire.

4.3 Memoing

Once my first interview was complete, data analysis commenced in the form of memoing. Because I traveled to participants throughout Southern Ontario, I used the time during my drives home to reflect on the interview and create “mental” memos. When I arrived home, I would use the questions included in section 3.7.4 as a loose guide to record any thoughts, ideas and/or observations that arose during the interview and my reflection. These memos were recorded by hand on the back of the hard copy of my interview guide. Transcriptions of a sampling of the memos can be found in *Appendix I*.

4.4 Coding and Themes

In the previous chapter, I explained the process of constant comparative analysis. Once I received the transcript of my first interview, this process began. As I read through the transcript, I began initial coding by using numbers to label sections of the transcript

that had similar topics. After reading each of the ten transcripts for the interviews I conducted, I had a total of 20 separate topics (*Appendix J*). Once I completed initial coding for all interviews, I undertook focused coding by organizing the topics into overarching categories called themes. Overall, eight themes became apparent; they are described next with selected accompanying quotes.

4.4.1 Theme One: Child Preferences for Information Format

During the interviews, I made a point of directly asking both the parents and the children about what type of format they prefer to receive information. I suggested that they think of any type of information that they have received, not just related to CP, and to tell me what it was about the format of that information that they found useful. There was a strong preference among children for information to include visual information in the form of pictures and/or charts. Using colours can be engaging, especially when there is a fair amount of text involved. Furthermore, children preferred point form if there was writing in the information. If there is too much writing, they lose interest and the message of the writing may be lost. Finally, the concept of receiving information verbally from therapists was raised. Although healthcare professionals may not be intending to exclude a child when focused on giving information to her or his parents, children expect to be told information directly in words that they can understand.

4.4.2 Theme Two: Parent Preferences for Information Format

Parents expressed a need for receiving information that was a combination of both text and visual information. This combination needs to be a balance, as too much text can be overwhelming. In contrast, not enough text can leave parents wondering if there is

more information that they should be seeking out. Generally speaking, parents said it was their experience that anything longer than one page was either overwhelming or redundant; therefore, limiting written communication to one page is recommended. Furthermore, point form information in straightforward terminology was encouraged, with accompanying graphs to elaborate on the information when applicable. For example, if a child completes a strength assessment with a therapist, parents want to receive the score, a concise summary of what that score means, and a visual representation of the score that can be understood at a glance.

Finally, parents stressed the importance for the information they receive to have a format that encourages two-way communication between themselves and the therapist(s). Suggestions included having a section on the information sheet that is designed for parents to provide comments on the information they have received.

Parent: "...it's that family-centered care, right? So they're collaborating...it allows them to participate and give information back. I like the idea of allowing the kids and the parents to provide their feedback about the outcomes as well as the goals, like a report card, I think it would be nice."

The idea of providing children and families with a "report card" format of information was apparent early on in data analysis. As constant comparative analysis is iterative in nature, this idea was presented to participants in future interviews and was very well received. Parents said they were familiar with the report card format as a result of receiving them from school over the years and supported keeping a similar format for receiving their children's assessment information. The idea of the "report card" will be explored more in the Discussion section.

4.4.3 Theme Three: Type of Information Children Want to Receive

Firstly, it is important to clarify that children do want to receive information. When asked if they ever receive any information about themselves, all children responded that they did not get anything meant specifically for them. A child's body language can be very indicative of her or his feelings – at this point in the interview, it was perceived that most children were somewhat disappointed by not receiving information, whether they verbally communicated it or simply shrugged their shoulders and lowered their heads. One young girl vocalized her feelings with a memorable quote:

Interviewer: *“So you’ve never gotten information just for you?”*

Child: *“No it’s always...it says my name on it, but it’s really just for my mom and dad.”*

Parent: *“[Laughs] That’s true, I’ve never thought about it ‘til right this minute, you’ve...there’s never been anything that’s for [child].”*

Child: *“It’s always...it has my name on it, but then it’s not really for me.”*

Interviewer: *“How would you feel about getting something addressed to you that was actually for you?”*

Child: *“I would like that.”*

Now that it has been established that children do want to receive information, it is important to determine what type of information they would like to receive. A common inclination among the children interviewed was to have access to stories about other children with CP who have grown up to become successful adults. One family told me about “Emily Included”, a nonfiction book about a woman with CP named Emily Eaton who fought to be included in the classroom at a time when children with CP were segregated (McDonnell, 2011). The family explained that this book was a great opportunity to learn about what people with CP can do. Unfortunately, the family also

said that stories with relatable role models like these are hard to come by. I shared this book title with the rest of the families I interviewed, and the enthusiasm expressed by both children and parents was notable.

4.4.4 Theme Four: Type of Information Parents Want to Receive

From the coding, it became apparent that there were four main areas of information that parents would like covered in relation to their children's CP. First, parents were very interested in having concrete information pertaining to their children's strengths and weaknesses. With this type of information, parents aimed to understand where improvements were possible and to therefore work with their children and their children's therapist(s) to create realistic goals. To help with goal setting and overall improvements, parents discussed the potential for therapists to accompany strength and weaknesses with a "now what?" component.

Parent: "So, you know, you could even accompany the results with... what do I do with this information? Like a quick fact sheet, right? Who can I share this with? What can I use it for? Suggestions or websites to visit based on this outcome, this outcome, this outcome. And you may want to put a qualifier in for the individuals who have been consistently falling below the norm of... because what did they do with that? What are some more new goals you can set for children who aren't going to ever achieve any of these things? There's got to be something, right?"

Furthermore, although parents recognized the necessity of addressing setbacks, there was a considerable discussion related to providing parents with more "can dos" and less "can not dos". This was especially relevant to children in higher GMFCS levels (i.e. greater functional limitations) – no matter where a child is at, there are always goals that can be created and achieved based on her or his strengths.

Second, parents often wanted to be able to place their children's developmental trajectory into a bigger picture. For some parents, this bigger picture includes a comparison to other children with similar CP diagnoses. Parents were quick to say that they understood the difficulty in gauging their child's development next to other children with CP due to the heterogeneity of the condition.

The third type of information that parents wanted to receive was how their children will look in the future. How will my child be three months from now? Six months? Where will we be at this time next year? Parents noted that they received a significant amount of this type of information when their children were young, prior to entering the school system; however, once they began school this type of information quickly diminished. One parent raised this concern and then commented on how she knew it was "wishful thinking" to get information on development "down the road". Parents want to make sure their children are heading in the right direction and having an idea of what that direction might look like would be helpful.

Parent: "Cause one of the things I am interested in, and I think [child]'s interested in too is looking to say well what is it going to look like when I'm 18? What is it going to look like when I'm 16? Because when...she was littler there was more, like, when she was first diagnosed there was more well she's level III, IV and so these are the expectations. But I think if you're getting older it's harder to kinda...now there is very little, like..."

Interviewer: "So...okay, so maybe some sort of developmental trajectory?"

Parent: "Yes. I found that very helpful when she was small just to kind of wrap my head around expectations...to what would be possible or not possible right? Knowing what's going on and what would be next, yeah."

The fourth type of information that parents wanted to receive was about resources available in their region. Resources mentioned ranged from opportunities for financial assistance to the various extra-curricular programs available in the family's area. With

today's heavy focus on electronic information, it was not surprising that many parents expressed an interest in having a list of websites that contained any type of resource related to CP. A common experience among parents was stumbling upon a resource while using the Internet and then being amazed that they had made it so far without knowing that that resource existed.

Parent 1: *"I was Googling something and it came up and I'm like oh there's an Ontario Federation of Cerebral Palsy? How did I not know about this?"*

Parent 2: *"Yeah. We didn't know anything about it, so we signed her up as a member, she's a lifelong member now. So now they're going to email us newsletters and information as it comes out."*

Parent 1: *"But I didn't even know there was a site. I was Googling something trying to find something out and sure enough I popped onto this and I'm like that's a thing? Wow."*

As a final point on this theme, it should be noted that parents commented that they often did not know what types of information actually existed prior to stumbling upon it. It is difficult for parents to know what type of information to ask for when they are unsure about what type of information is even available.

4.4.5 Theme Five: Other Families as an Information Source

Meeting and interacting with other parents of children with CP was a major theme in the interviews. Although some parents said they benefitted from hearing "feel good stories" about other families of children with CP, it was much more common that parents used other families' experiences as an actual source of information. In fact, multiple parents commented on the usefulness of hearing another family's experience regarding medical procedures when considering whether the procedure was a good idea.

Parent 1: *“So it's not from doctors that we heard it, but through a friend whose boy had it done and it was that family's story, meeting him, that said okay we want to do this. It wasn't, you know, the doctors telling us what was going to happen because we wanted the family aspect. Just to see, you know, what actually went on other than the doctors [saying] this is going to happen and it'll be eight weeks in [city] and... okay, well that's good to know, but you also want to know the emotional side, what the family went through, so sometimes the family stories are good too.”*

Parent 2: *“'Cause there's a lot more to life than just sitting in a doctor's office.”*

Parent 1: *“That was part of our decision, how's it going to affect the family? What's she going to go through emotionally and physically and how are we as a family going to handle this?”*

Parents often considered other parents to be the most honest source of information available, not just in medical situations like the one above, but in any situation. If parents sought an expert opinion, the best place to start was another parent. It is important to note that families from remote areas had less opportunity to meet with other parents who have a child with CP.

4.4.6 Theme Six: Not Receiving Enough Information

Generally speaking, parents of children with CP want more information than they currently have. As a result of not receiving a sufficient amount, parents resorted to seeking out their own information. The most common method for this was using the Internet. Interestingly, parents did not seem to consider the Internet as a “good” source so much as they considered it the “only” source. Parents discussed the cons of having the Internet as the only source, stating that it can increase stress by leading parents to incorrect assumptions or by overwhelming them with the task of distinguishing what is relevant. Another concern was the difficulty in finding information directly relevant to a

child who has multiple diagnoses, as is often the case with children with CP. One mother described her experience with this obstacle:

Parent: "If your child has autism, there's still maybe, like, different ways that it impacts them, but I feel like there's more concrete information about what autism looks like and how that may impact [the child], but because [child] has so many multiple diagnoses and things happening, it's hard to... like, is this related to the CP, is it related to sensory issues, is it related to cortical vision issues, is it... [Laughs]. It's difficult to find information because she has those multiple diagnosis, it's not just one."

4.4.7 Theme Seven: Being Inclusive and Respectful

The third objective of this research was to gain insight on how children with CP wish to be represented in the individualized information presented to them in terms of being both comprehensive and respectful. This objective arose in an effort to ensure that the resulting method of disseminating the information from the OnTrack study incorporated the views of children and youth with CP. Specifically, to ensure that the information was not in any way condescending, disrespectful, or exclusive. Questions alluding to this objective were included in the interview guide. In the interviews, the children and parents were eager to share stories about their experiences with therapists; while the questions related to the third objective were asked and answered, the theme that arose from coding revolves more around how children feel about their interactions with therapists than how they wish to be represented in individualized information.

Children were generally very happy with their interactions with their therapists. Some children expressed feeling nervous about having assessments done, but this anxiety appeared to originate from their desire to perform well and not from their fear or discomfort related to the therapist. Because of their ages, many children participated in therapy during school time and some mentioned that they would prefer not to be pulled

out of class for therapy so they did not miss any opportunities for learning or playing with their friends. One parent explained how happy she was with the school for creating therapy exercises that her child could do at the back of the class so that he could remain included in the classroom.

Most children interviewed were in elementary school and were therefore participating in therapy during school hours without their parents present. In this setting, it becomes particularly important for the therapist to interact with the child in a way that makes her or him feel comfortable. Most children said they weren't always told why an assessment was being done, but they all felt like they could ask their therapist a question if they had any. When parents are present and the therapist is sharing information about their children, parents expressed the need for therapists to be conscientious of how they proceed. Parents urged therapists to tell their children first – explain it to her or him as best they can.

Parent: *“Therapists need to be conscientious when they're sharing info in front of the kids. Because sometimes the kids only hear certain pieces and they [get] overwhelmed.”*

Child: *“Tell the kids first, before you even tell the parents.”*

Parent: *“Tell it in a frame that the kids understand too. At times too I would find that they would talk like he wasn't even there. It's like well ask him. The [facility] did excellent with the pre-surgery, we went with a person that was doing basically play therapy with him. And she [showed him] where the incision was going to be and all that kind of stuff.”*

Child: *“Oh yeah. Yeah. Basically show what was going to happen.”*

Parent: *“Cause that takes some of the scariness out of it too, right?”*

Another topic included under this theme was directly related to the proposed language used in the information packages created for disseminating the OnTrack study information. It was proposed that the information would include the phrases “developing

as expected”, “developing better than expected” and “developing more poorly than expected” to represent a child’s development. I asked the parents and children how they felt about this language. Most parents were fine with the wording, saying that it was straightforward and necessary to get the point across; however, they also recognized that other parents may be less accepting. The parents who were initially uncomfortable with the phrasing expressed concerns about the language sounding as though the child was failing. This language was changed to “doing as expected”, “doing more than expected” and “doing less than expected”. The families’ opinions on this language is described in Section 4.6.

4.4.8 Theme Eight: Sharing Information with School

Parents expressed significant interest in having information that they can share with others. A large part of this theme was the ability to help inform the child’s school about what supports may be required and what limitations may exist in order to empower the child in her or his school environment.

Parent: “Not so much for my family because I look after her most of the time. But school. School’s really, um, you know, the school tries to support me. This year has really been good. So, anything I can tell them helps them help her. It’s a big bonus. Or her extracurricular activities, same thing. You know, have to kind of inform them what she can do and what she can’t do. So that’s where I like to use it.”

Interviewer: “If it was for school then, do you think they would benefit from a one page thing or is it more of a verbal conversation you’d have to have?”

Parent: “Um well I think if they gave, if it was strictly on her, a page when she starts her classroom would be great. Cause I have to go in and inform them, right? Sometimes I don’t always remember what I should tell them, or, you know, what her limits are or you know, then you have to go back and they’re not aware. They’re aware but they forget. Or whatever, right?”

Parents explained that any information provided to schools should be very brief, kept to one page. The information needs to be very clear on what the child needs and what the child does not need in terms of support in everyday activities. If this is not explicitly outlined or communicated to the school personnel, parents said it was common for their children to receive either too much or not enough support due to misunderstanding.

4.4.9 Tabled Summary of Themes

Table 4.4-1 contains a summary of the themes discussed. This table was provided to participants for member reflections, described in sections 3.7.5 and 4.6.

Table 4-3: Summary of themes from data analysis.

Theme One	Child Preferences for Information Format	<ul style="list-style-type: none"> • Visual information (pictures, charts) • Use of colour • Point form/straightforward • When verbal, address child directly with appropriate language level
Theme Two	Parent Preferences for Information Format	<ul style="list-style-type: none"> • Combined text and visuals • Brief, point form when possible • Format that encourages two-way communication between family and therapist(s)
Theme Three	Type of Information Children Want to Receive	<ul style="list-style-type: none"> • Important: children want information • Specific visual information about themselves • Stories about other children/youth with CP
Theme Four	Type of Information Parents Want to Receive	<ul style="list-style-type: none"> • Child's strengths and weaknesses • Child's function in context of children with CP of similar level • Child's prognosis • Community resources
Theme Five	Other Families as an Information Source	<ul style="list-style-type: none"> • Valuing the lived experience of others/impact on both child and family • Going beyond medical information
Theme Six	Not Receiving Enough Information	<ul style="list-style-type: none"> • Dilemma of accessing and appraising information from internet
Theme Seven	Being Inclusive and Respectful	<ul style="list-style-type: none"> • Address children directly, not just parents • Use empowering language
Theme Eight	Sharing Information with School	<ul style="list-style-type: none"> • Brief and succinct information • One page • Clear on what child does/does not need

Note: CP = cerebral palsy.

4.5 Creation of Mock-Ups

Mock-ups of individualized information were created after data analysis revealed the important themes related to how children with CP and their parents prefer to receive and use information. The mock-ups were designed in collaboration with Barb Galuppi,

the project coordinator of the OnTrack study. Together, we generated three “levels” of information intended for a range of users to understand a child’s individual assessment information. Each of these levels were modeled in a similar “report card” format for consistency and ease of transitioning between levels. Examples of the three mock-ups can be found in *Appendix K*.

Mock-up 3, the most complex, provides families with a detailed account of the information collected in the OnTrack study. For each assessment, a family is given their child’s “most recent” score and their “past” score from roughly one year prior. These two scores are plotted on the accompanying graphs, created by the OnTrack team, that show the reference percentiles for each GMFCS level of children with CP. The plotted points are converted to percentiles and the difference between these percentiles is calculated as a plus/minus. Using the table beneath the graph, this plus/minus difference is shown to correspond with how the child is doing on a scale of “doing as expected”, “doing less than expected”, or “doing more than expected”. The child’s position on this scale is then entered onto mock-up 3, in the columns beside the child’s past and most recent scores. It is important to clarify that “how the child is doing” is relative to the predicted development of children in the same GMFCS level, based on the results of the OnTrack study.

Mock-up 1 and 2 are derived from the information in mock-up 3 and carry the same overall chart format. Mock-up 2 provides a family with their child’s most recent score on each assessment and the corresponding scale of how he or she is doing. Mock-up 1 is the simplest, designed for children, with just the title of the assessment, an image to represent the assessment, and a symbol to represent how the child is doing on the scale.

All of the mock-ups have a space designated for notes to encourage families to communicate with their therapist(s) to ask questions and plan realistic goals.

4.6 Member Reflections

The mock-ups and the tabled summary of themes were shared with parents via email, with the exception of one parent whose information was sent via regular mail as she was not comfortable with computers. I provided an explanation of each level of the mock-ups and told the families that I was eager to receive their feedback, either by email or phone. After sending a follow-up reminder email and allowing a two-week timeframe to review the mock-ups and summary, I received responses from three participants. I did not receive any responses pertaining directly to the tabled summary of themes.

The first parent to respond emailed that her child, who was sitting with the parent at the computer at the time, gave a “thumbs up” to mock-up one. The parent said it was “great to get more information” and that it was “good to see the improvement” in her child’s development. The second parent to respond also emailed, saying that “mock up number 3 appeals to me the most however I couldn’t figure out what the different colours on the graph represented”. She also said “mock up number 1 would be great for children that are interested in their progress”; however, she then said she would not likely share the mock-up with her child as he “doesn’t like to think of himself as disabled and would focus on the negative”.

The final parent to respond sent an email asking me to call her, as her feedback would be better understood if she could explain it over the phone. Overall, she liked getting information and felt like it was a positive experience. For mock-up one, she said she preferred the second version with the “thumbs up” emojis but her child preferred the

first version. They both preferred the “thinking” face that corresponds with “doing less than expected” in the first version because it represents a constructive response to the score rather than a negative response. The parent said “*doing less than expected might be reality for some families so it needs to be positive somehow*”. The parent could see the usefulness of mock-up two but said she preferred mock-up three instead, mainly because she wanted to see the current score compared to a past score instead of just on its own. Additionally, she preferred the section for “notes” on mock-up three, explaining that “*one big box for all notes is a better idea than having separate boxes for notes because it allows for more general comments and for different disciplines to comment together*”. She added that the title of the notes section on mock-up three, “Supporting Your Child’s Development” was positive and encouraging. Although she preferred mock-up three, she did not see much use, personally, for the attached percentile graphs because she could see it confusing many parents. Finally, she had two suggestions for improving the mock-ups. The first was to add the emojis from mock-up one to mock-up three, simply replacing the asterisk used in the chart that indicates how a child is doing. This way, the visual is carried through the levels. Secondly, she suggested keeping the child’s first scores available on the chart so that families can see the full range of their children’s progress over the years.

Although I only received responses from three participants, the overall view of the information was positive. There were few suggestions for change and none of them pertained to presenting the information in a different way than the report card format. The team of people involved in the OnTrack study, including therapists, parents of children with CP, youth with CP, researchers and others, gathered in June 2017 to share all related

research and wrap up the project. This provided a final opportunity to present this information and receive more feedback from a wide range of stakeholders. Overall, the team had a very positive reaction to the information presented. Parents and youth commented on the usefulness of the report cards, including the format, which was echoed by the therapists on the team. Therapists discussed the usefulness of having a package of individualized information that they can give to children with CP and their families – something they recognized is missing or not readily available in current practice. Furthermore, the youth and their parents discussed their contentment with mock-up one, especially regarding its design and use of visual information for children. Suggestions were provided for the assessments that are currently missing images in mock-up one, and the majority of the youth (and the rest of the OnTrack team) preferred Version One (emojis).

Chapter 5: Discussion

Overall, the results of this study provide information to begin filling in the gap that currently exists in the literature related to providing information to children with CP and their families. The Pre-Interview Questionnaire responses were a small-scale representation of the large-scale need for children and families to receive more individualized information from therapists and other healthcare providers. The lack of information is so significant that families are not sure what information actually exists and are therefore not sure what information they should be asking for. Furthermore, the interviews showed that children with CP do want to receive information about themselves and they explored the format and types of information that children preferred. The same topics were covered for parents, and it was evident that they would like to receive information that can be shared with others, including but not limited to family members, schools, and daycare centres. Parents revealed that a major source of current information is other families, but maintained throughout that the amount of information they are currently receiving is not enough.

In this chapter, I discuss the themes covered in the results in relation to the projected outcomes of the OnTrack study, including the potential benefits of formatting the information in a report card format as described in the previous chapter. Next, findings of the literature review are compared and contrasted to findings of this study. Topics related to the research question that arose beyond the themes are explored. Finally, limitations of the study are outlined and directions for future research are suggested.

5.1 Themes Related to the OnTrack and Move & PLAY Studies

Throughout the interviews, parents showed an interest in having a better understanding of how their children are doing compared to other children “like them”. In other words, parents wanted to know ‘how does my child compare to other children with a similar CP diagnosis’? Parents were quick to explain their understanding of the heterogeneity of CP and how this interest is therefore “wishful thinking” and very challenging to assuage. By gathering information on a large sample of children with CP, the OnTrack research team was able to create longitudinal growth curves to understand average trajectories of functional subgroups of children with CP and, from there, to develop reference percentiles to determine if children with CP are doing ‘as expected’, ‘more than expected’, or ‘less than expected’ (Bartlett et al., 2013). In other words, the OnTrack analysis provides parents with a way to compare their children’s development to others in the same GMFCS level as well as to interpret an individual child’s change over time. This work is modeled after the GMFM work on longitudinal growth curves (Rosenbaum et al., 2002) and reference percentile levels (Hanna et al., 2008).

Longitudinal motor growth curves in relation to CP are evidence-based estimates of an average child’s motor development based on her or his age and GMFCS level (Rosenbaum et al., 2002). By comparing an individual child’s motor progress to the longitudinal growth curve of children of similar age and severity of CP, families can better assess their child’s motor development and therefore have a better understanding of their child’s prognosis (Rosenbaum et al., 2002). This information also allows therapists who work with children with CP and their families to set appropriate goals (Rosenbaum et al., 2002). Therapists can also use longitudinal growth curves to tailor anticipatory

guidance that further ensures realistic developmental expectations (Edwards, 2016). Anticipatory guidance, a proactive method of providing children and families with information about potential future outcomes, can be an important component to a families' overall ability to empower their children and reduce anxieties that inevitably arise throughout their children's lives (Edwards, 2016). Both children and parents report increased satisfaction with their health-related experiences and readiness for the future when anticipatory guidance is provided (Edwards, 2016; Syverson et al., 2016). The information from the OnTrack study, when presented in a useable format, can assist children with CP and their parents in collaborating with their therapist(s) to make realistic plans for maintenance and/or improvement, as they will have more individualized information than could be attained by using the GMFCS, MACS, and CFCS alone.

In addition to having a better understanding of their children's relative development, many parents discussed their desire for more concrete information on their children's strengths and limitations. Notably, these parents also stated that they appreciate information that is strengths-based – they understood the need to be provided with declines or limitations, but they expressed a large interest in focusing on what their children can do well and how to maintain these abilities. This interest aligns with a strengths-based approach, a key component of family- and client-centered care (Allen & Petr, 1996). With this approach, the internal and external abilities inherent in each individual are sought out, understood, and employed in an effort to build upon existing strengths (Saleebey, 2010; Allen & Petr, 1996). The OnTrack reference percentiles that determine how a child is doing relative to other children in their GMFCS level provide parents with more accurate information on their children's strengths and limitations as

they develop over time. By being transparent in presenting a child's assessment results and her or his corresponding percentiles, children and their parents are also able to see where they are developing as expected, and where they are either above or below this middle ground. In turn, this allows families to pinpoint their children's strengths and work with their therapists to develop plans to maintain or continue to improve these areas.

In this thesis, I explained how the information from the reference percentiles generated in the OnTrack study can be provided to children with CP and their families in a range of levels of detail. The most detailed level contains a child's assessment scores with her or his corresponding reference percentiles graphed onto the reference percentiles for his or her GMFCS level. Derived from this information, the simplest level can be a visual representation or symbol of how a child is doing in each assessment without including any scores or other text. Providing children with this level of visual information can help meet their desire for receiving information about themselves in the format that they prefer. Furthermore, a middle level of information can provide a child's assessment scores and an indication of whether she or he is 'doing as expected', 'more than expected', or 'less than expected'. As was apparent from the interviews, many families have different information needs and preferences. This differentiation even existed within some families, as evidenced by one family in which the mother preferred detailed information on her child's assessment results whereas the father preferred a simple statement on how the child was doing overall. The OnTrack information can be provided in each of these levels to all families in a "package" so that each family and its members

can use the level of information that they prefer. This format is discussed further in the next section.

5.1.1 Report Cards

To provide assessment information to children with CP and their parents, it is necessary to first understand what format both parties would find most useful. The results of this study showed that families are interested in receiving information in a way that is similar to school report cards, in large part because this way of providing information is a format with which both children and their parents are familiar and comfortable. In order to provide families with this familiar format, we modelled our information after report cards by creating separate sections for each assessment, including a space to encourage two-way communication between families and their therapist(s), and formatting the results into an easy-to-read chart.

Aside from familiarity, another benefit of the report card style of information is that the format can be easily modified to provide different amounts of information for a range of audiences. This includes, but is not limited to, children with CP of different ages and with different levels of cognitive functioning, parents with varying information needs, siblings, members of a family outside of the immediate unit, schools, teachers, daycare centres, and coaches or leaders of extracurricular activities. As CP is such a heterogeneous condition, it is important for the aforementioned people to have accurate information on the abilities of each child with CP. Multiple parents in the interviews raised the importance of giving their children's schools the right information so that the appropriate amount of support can be provided. Although it is possible for the school to unknowingly not provide enough support, it is also possible for the school to go the other

direction and provide too much support. For example, a child in GMFCS level III uses assistive devices to walk and may choose to use a wheelchair to cover longer distances. If staff is not made aware of this, they may assume the child always needs a wheelchair ultimately, preventing the child from her or his muscles or causing autonomy concerns. Parents suggested having multiple copies to distribute to various staff members throughout the school. On reflection, the report card could also include the MACS and CFCS levels in addition to the GMFCS levels and results of individual measures.

Another benefit to the report card format is that they can easily be modified to provide different “levels” of information. These three levels, described in detail in Section 4.5, range from simple pictorial representations of how the child is doing to comprehensive assessment scores paired with graphed reference percentiles. The three levels were designed to suit a range of information needs and preferences for various people; however, they can also be used as a way to promote self-management in children with CP over time. By starting with receiving information at the simplest pictorial level, young children can be introduced to information about their development. As children develop into adolescents and teenagers, they can move onto the next levels of information. Their increased maturity and ability to contemplate the future will allow them to begin to participate in their own healthcare decisions (Sawyer & Aroni, 2005). Furthermore, the report card levels would promote shared management by fostering the systematic transition of leadership from the healthcare providers and parents to the maturing young adult (Gall, Kingsnorth & Healy, 2006). Children with CP can begin with using the simplest level of information to participate while they are receiving care, and gradually move to the next levels as they begin to manage their own care (Gall et al.,

2006). If children will not be fully managing their own care, the proposed levels would still provide them with the ability to participate in their care to a degree beyond that of the passive healthcare recipient.

Based on individual family members' goals and preferences, different information will be relevant for different families. For example, a child in GMFCS level V may be focused on improving participation in recreation and leisure whereas a child in GMFCS level I may be focused on increasing motor function. Furthermore, a child in GMFCS level III may be focused on participation in self-care. It is important for therapists to work collaboratively with families, just as it is important for therapists to work with parents and children to create realistic goals. Results from the Move & PLAY study provide therapists with foundational knowledge of determinants of outcomes of motor function, self-care, and participation. For the child in GMFCS level I, it will be important to consider how the child's primary impairments (especially postural stability), secondary impairments (strength, range of motion, and endurance) and participation in recreation and community programs either facilitate or hinder gross motor function (Bartlett et al., 2014a). For the child in GMFCS level III, knowledge of significant determinants of self-care, that is gross motor abilities, postural stability, the impact of health conditions, adaptive behaviour, and attributes of the family will need to be considered (Bartlett et al., 2014b). Similarly, interventions focusing on increasing participation in recreation and leisure activities for the child at GMFCS level V will be more successful if they focus on potential contributions of motor function, adaptive behaviour, and attributes of the family. (Chiarello et al., 2016). Therapists and other service providers involved in the

care of a child with CP must understand the family dynamic if they want to provide successful support for the child and his or her family (Bartlett et al., 2014a).

In the interviews, parents raised the importance of having the ability to have these discussions with therapists. One way to encourage this two-way communication is by having a section on an information sheet that is designated for parents and therapists to make notes. These “Notes” sections are a component of school report cards and were incorporated into the format of the mock-ups created for this thesis research. Ideally, this space will foster communication between families and their children’s service providers, enabling them to work together to provide appropriate support in all aspects of their children’s lives.

5.2 Connections to Literature Review

In conducting the literature review prior to collecting data, the main finding was that there is a large gap in the literature with respect to how children with CP and their families prefer to receive and use information. Notably, the studies included in the literature review were either not directly related to CP, not related to being given individualized assessment information, or both. That being said, some of the findings of this study can be directly compared or contrasted to what was found in the literature review.

5.2.1 Contrast: Internet Use

The most significant contrast involved how families use the Internet to seek out information. Interestingly, the literature review revealed that, overall, parents preferred not to use the Internet as a source of information when seeking out or receiving

information about their child (Boudewyns et al., 2015; Mulligan et al., 2010; Sciberras et al., 2010). Based on the responses to the second question of the Pre-Interview Questionnaire and the subsequent discussions in the interviews, parents showed a significant preference for using the Internet. I believe this difference stems from the fact that there was no literature available on this topic specifically related to children with CP and their families. Children with other diagnoses and their families may have various credible options for sufficient information outside of the Internet whereas children with CP and their families are left with few options. Therefore, while they may not necessarily trust or be satisfied with the Internet as a source of information, it is often the only source of information that they feel they have. The Internet can be a good source of information, and I believe children with CP and their parents should be encouraged to use it to seek out new resources. As therapists actively seek out their own information and often play the role of information provider to their clients (Lagosky, 2012), they and other service providers may be useful in guiding families to credible websites or in helping families appraise information that they have found themselves.

5.2.2 Compare: Formatting Information for Children

A similarity with the findings of the literature review involved how children prefer information to be formatted. Multiple studies in the literature review revealed that children prefer information that uses colours, pictures, and other visual information (Grootens-Wiegers et al., 2015; Tait et al., 2015; Tait et al., 2010), with one study showing that children find picture-based information easier to understand than text-based information (Tait et al., 2015). One benefit to using visual information with children is that it allows them to use emotional factors instead of cognitive factors to understand

what is being presented (Grootens-Wiegers et al., 2015; Tait et al., 2010). When creating mock-ups of the OnTrack information suitable for children with CP, a conscious decision was made to follow the literature and use visual information to represent how the children are “doing”. Specifically, “emojis” were used as they depict a facial expression that represents an emotional reaction to the child’s developmental progress: a thinking face for when children are ‘doing less than expected’, meant to encourage children and families to think about what can be done to improve this score for future assessments; a thumbs up for when children are ‘doing as expected’, meant to show children that they are doing well; and a double thumbs up for when children are ‘doing more than expected’, meant to show children they are doing even more than is expected and encourage their efforts. When asked for feedback on the mock-ups, the families who responded, including the children, expressed their preference for the “emojis”.

5.2.3 Compare: Parent Information Preferences

The literature revealed that parents prefer shorter amounts of information formatted into categories with obvious borders (Boudewyns et al., 2015) that includes information on region-specific resources (Mulligan et al., 2010; Pain, 1998). Parents reiterated these preferences throughout the interviews. When asked about formatting and length, parents were clear that information should not be any longer than it needed to be, preferably no more than one or two pages at most. Furthermore, they discussed their preferences for information to be sectioned into point-form or short, straightforward sections whenever possible. Finally, parents were adamant about needing access to resources that are available in their region and most of them commented that they still

know very little about what actually exists, despite their efforts to seek information on potential resources out. This is discussed more in Section 5.3.2.

The literature review also revealed that families want information directly pertinent to their children, as it can empower the family and help them more fully understand their children's needs (Cox et al., 2011; King et al., 2011). The responses to the first question of the Pre-Interview Questionnaire reflected this preference, with the majority of parents selecting that they seek out information about CP to learn more about CP as it relates to their child. When asked to expand on these responses in the interview, families discussed their need to better understand their children's specific circumstances so that they can do everything possible to empower their children now and throughout the rest of their lives.

5.3 Additional Themes

Many additional topics arose beyond the relevance to the OnTrack study and the earlier literature review that provide more insight into the information-related preferences of children with CP and their families. Parents raised the importance of connecting with other families of children with CP in order to learn from each other's experiences and to get a better understanding of community resources. Children expressed an interest in hearing stories about other children with CP who have succeeded. Finally, both children and their parents discussed the need for a balance in information such that it is respectful and inclusive while also being straightforward and accurate.

5.3.1 Need for Interaction with Other Families

One conversation that frequently occurred in the interviews was about the difficulty of finding resources when living in a more rural area. The resources sought ranged from extracurricular activities that would accommodate their children's needs to organizations that would provide financial support to families of children with disabilities. Some families explained that they learned about resources by specifically asking a therapist about a particular resource they had in mind. Unfortunately, without knowing what resources exist, many families in this study did not know what to ask for and therefore did not get access to a range of resources that they may find helpful. The resource that parents found most important was the lived experiences of other families.

In one interview, when discussing this difficulty, a father explained how the only reason his family had found out about a particular treatment was by crossing paths with a family of another child with a disability. Even though the other family's child did not have CP, they talked about their separate experiences and learned about new resources from each other. Similarly, one family (family A) explained how they benefited from interacting with another family of a child with CP (family B) because family B's child underwent a medical procedure that family A was considering for their child. This interaction was integral in determining whether or not family A would choose the medical procedure as it gave them the "family" perspective, beyond any description that the doctor could offer. Family A wanted to know how the medical procedure would effect the family, how the costs of living would be covered while they were caring for their recovering child, and what emotional or psychological impact(s) the medical procedure would have on their child. Although healthcare professionals do their best to

inform families, family A used this anecdote to demonstrate that there are some aspects that can only be understood from family to family.

Living in a more rural area significantly limits the opportunities for these important interactions, and, as many of the families involved in this study were from rural areas, this type of anecdote was not uncommon. This is a good rationale for providing families with Internet-based interaction opportunities so that parents can benefit from these shared experiences regardless of their geographic location. Russell et al. (2016) explored how using Facebook (a social media website) can play a helpful role in connecting parents of children with disabilities with each other and with researchers. In their evaluation, the researchers found that families were more often using the private Facebook group to connect with each other rather than with researchers; parents reported feeling a sense of belonging to this online community where their experiences were validated and their access to information and resources was guided by trustworthy peers (Russell et al., 2016). When researchers *were* involved in the Facebook group, it was often to link families to credible information sources (Russell et al., 2016). The success of this group should be seen as a positive outcome of using the Internet to connect families and can be used as a guide for future groups looking to create a similar online community.

5.3.2 Stories about Other Children with CP

Unsurprisingly, this study showed that children with CP do want to receive information about themselves. The types of information that children want was described in Section 4.4.3; however, one particular anecdote from the first interview became an interesting talking point in all of the remaining interviews. Towards the end of the first

interview, one of the parents told me about their experience with a book called *Emily Included* (McDonnell, 2011). They told me that the book was about a young woman with CP who fought to be included in the school system among non-disabled peers. This book provided this family, especially the child, with a positive and empowering story of a child with CP who became a successful young woman. They explained that it was rare to come across a book about a child with a disability, let alone one with CP, and how important it was for their child to see herself represented in such an encouraging and real way. I wrote down the title of the book and told the rest of the families that I interviewed about this resource. All of them seemed at least somewhat surprised that such a book existed, and they all asked for the book title again so that they could write it down and seek it out. Clearly, children with CP want to see themselves represented in society in positive ways – not an uncommon desire, I believe, for any children of any ability.

5.3.3 Being Respectful

Overall, children and their parents expressed positive experiences with their therapists. Families did, however, have some anecdotes that could provide therapists and other healthcare professionals with some suggestions for future interactions. For example, one parent explained that her child was frequently mistaken as nonverbal which she presumed was because of her child's physical limitations. One healthcare practitioner was going over options for a treatment and asked the mother what she thought. In response, she said to ask her son what he thought and about his priorities. The healthcare practitioner looked at her and said "*he's verbal?*" Stories like this reiterate the importance of treating children and young adults with CP with respect. Regardless of an individual's abilities or whether an adult or caregiver is in the room, it is important to ensure that

communication with the child is respectful. This includes sitting or standing as even with the child's height as possible, maintaining comfortable eye contact, using appropriate tone and language (not condescending), and explaining the purpose of the interaction (Guest, 2016). Healthcare practitioners should also be cognisant of their non-verbal communication, ensuring not to display body language that could be construed as being disinterested or bothered by questions (Guest, 2016). Communicating respectfully, both verbally and non-verbally, is a significant component to building a positive relationship between children with CP and their therapists.

5.4 Personal Reflections on Rigor

As stated in Section 3.4, I intended to be as reflexive as possible throughout this research process. My goal was to be thorough and accountable in my methods so that I could produce trustworthy results. This began with my interpretation of the first set of Pre-Interview Questionnaire responses. When I received the responses from the first participants, I thought about how they could guide the questions that I intended to ask in the interview. As more Pre-Interview Questionnaires and interviews were completed, I would inevitably think about the new responses in relation to the previous responses. What patterns were developing? Have all of the parents responded the same for this question so far? How does this parent's comment in "Other" relate to the experiences of that family? Is it possible that these "Other" responses pertain to other families as well? This subjectivity was integral in discovering and substantiating my themes.

Due to the nature of constant comparative analysis, I was also memoing while I was interpreting the Pre-Interview Questionnaire responses. A sampling of my memos can be found in *Appendix I*. Although all memos were essential, I found it particularly

valuable to record my perceptions of any non-verbal responses that occurred throughout the interviews. Non-verbal responses can be good indicators of thoughts or emotions and, if noted, can be a powerful form of communication. It may be quite obvious, but it is important to remember that recorders can only record vocalizations. If an interviewer does not create a memo about a non-verbal response, it may not be recalled when reading the transcribed interview. Jotting down non-verbal responses becomes even more important when interviewing children. Children can be quite expressive in their body language for a number of reasons, ranging from innate shyness to the mere fact that they simply have not yet learned how to effectively verbalize their thoughts. When interviewing a family, I took note of the child's non-verbal responses to the conversation, whether she or he was directly involved in a response or not. These memos became essential to data analysis over the course of data collection

Finally, reflexivity was a major component to the coding and creation of themes. Subjectivity is inevitable when analyzing interviews to discover topics with meaning. After all, if I did not perceive a section of an interview to be meaningful to the participant or myself while reading the transcript, I would not have coded the data and thus would not have used it in my analysis. Because I am neither an individual with CP nor a parent of a child with CP, I am not an expert in these experiences – the experts are the children and families I interviewed. This is a major reason as to why member reflections were conducted, so that my results could be shared with the families and they could decide if the results were meaningful. After sharing the results and the mock-ups with participants, and giving them a two-week timeframe to respond, I only received feedback from three families. Furthermore, I did not receive any responses pertaining directly to the tabled

summary of themes. Although receiving more responses from participants would have been ideal, an additional opportunity for feedback was during an OnTrack team meeting in June 2017. The parents and children present at the meeting was asked about the results of this work and encouraged to share any comments they have pertaining to its significance.

5.5 Limitations

Given the heterogeneity of the families of children with CP and of CP itself, a sample size of ten families was not intended to be fully representative of all families with children with CP. However, there were limitations related to participant demographics despite our efforts to be as diverse as possible in recruitment. Of the ten families involved in this study, nine of the children and eight of the parents identified their ethnicity as White. The parent participants in the interviews were primarily mothers, with only three fathers present in the ten interviews. Furthermore, the ten children involved only spanned GMFCS levels I to IV, including four children in GMFCS level I and no children in GMFCS level V. Although participants were recruited for this study, participation was completely voluntary. It is possible that parents and children who do not wish to partake in research hold different views regarding the research question. Finally, when looking for participant feedback on the results from this study, emailing the tabled summary of themes may have constrained opportunities for responses. Sending an email asking families for feedback on a table may be the most convenient method; however, scheduling a phone call or another in-person meeting may have been more effective.

5.6 Future Research

Much of this thesis addresses the need for children with CP and their parents to receive evidence-based information and how this information can be provided. Future research should explore how youth and young adults with CP prefer to receive information and what type of information they prefer, if any. This is especially relevant to people with CP who are self-managing, who live on their own or with anyone other than a caregiver. Furthermore, a goal of future research in this area should be to include a more diverse sample of participants and consider the impact of intersectionality of functional ability level and ethnicity on how individuals with CP and their families wish to use information. Given the preference for using the Internet to seek out information, future research could involve the creation of information that is intended to be distributed electronically, perhaps via email. This may make providing information easier for therapists and could be more convenient for families who use the Internet on a regular basis.

5.7 Conclusion

Although this research was initially conceived as a knowledge translation step for the results of the OnTrack study, a literature review revealed that information preferences of children with CP and their families had not been published. The results of this study can begin to narrow this gap by identifying what type of information children with CP and their parents prefer to receive, in which format they prefer to receive information, and how they intend to use information. This study found that children prefer visual information with minimal text, while parents prefer a combination of text and visuals

with point-form, straightforward text. Both suggest information should not exceed one page unless necessary.

A major point from this study is that children with CP do want to receive information about themselves and their assessments. Children also want to have access to stories about other people with CP. Parents are interested in their children's strengths and limitations for realistic goal planning, how they are developing relative to other children with similar CP diagnoses, and what their future prognosis entails. Succinct versions of this information pertaining to a child's abilities are useful for sharing with schools. Parents also value lived experiences of other families, especially when considering the potential non-medical impacts of treatment options. Most families use the Internet as a source of information and use this and other methods to learn about resources available in their region. Finally, any verbal communication involving a child, whether her or his parent(s) or guardian(s) are present or not, should address the child directly and be mindful of using empowering, strengths-based language.

In summary, the results of this study provide a next step for disseminating the evidence-based information obtained in the OnTrack and Move & PLAY studies, as well as for narrowing the gaps that currently exist in the literature related to the information preferences of children with CP and their families. These steps, in turn, are expected to contribute to better child and family outcomes over time.

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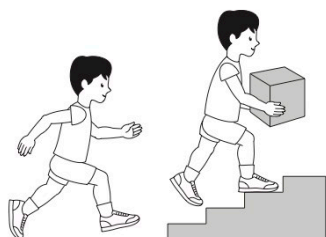
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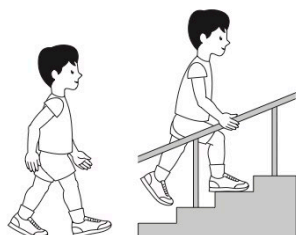
Appendices

Appendix A: Classification Systems



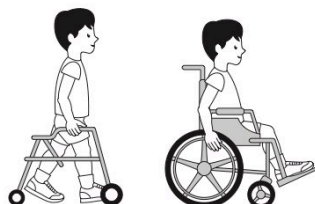
GMFCS Level I

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.



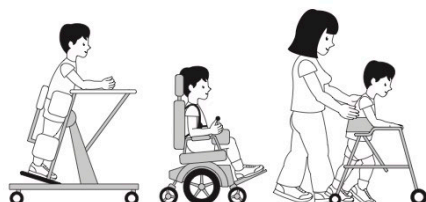
GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.



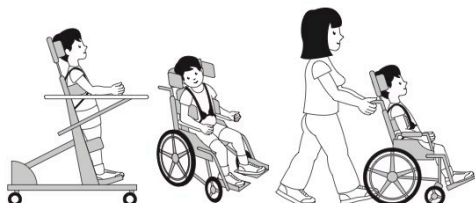
GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.



GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.



GMFCS Level V

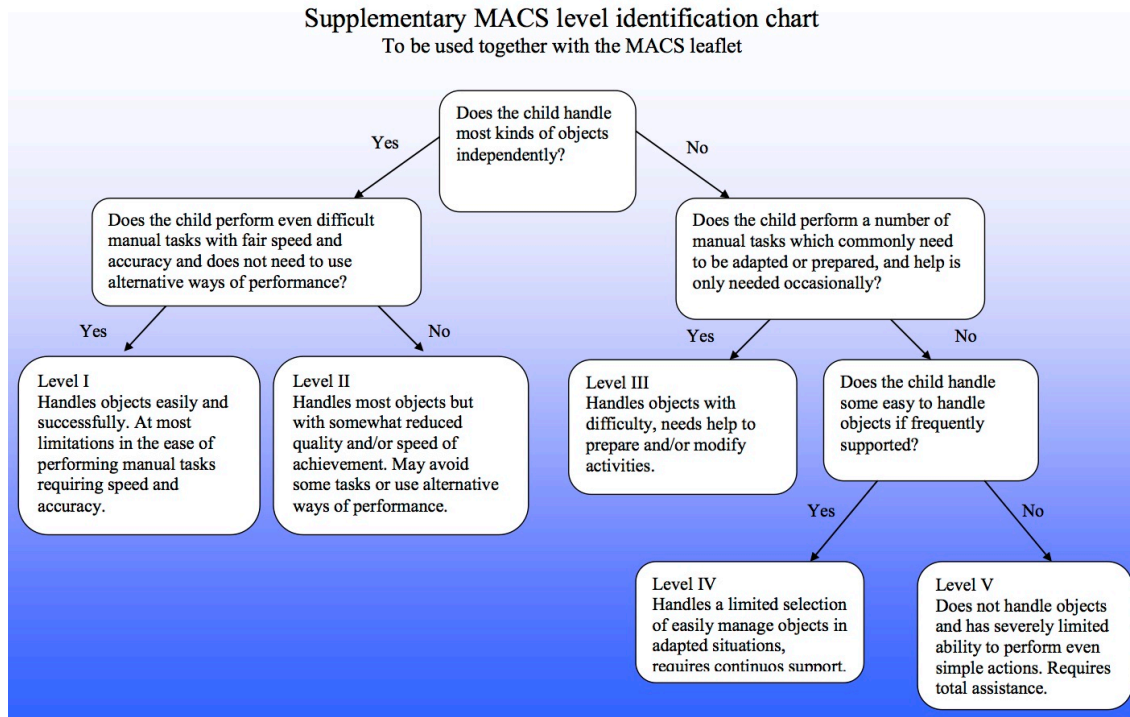
Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23
CanChild: www.canchild.ca

Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham,
The Royal Children's Hospital Melbourne ERC151050

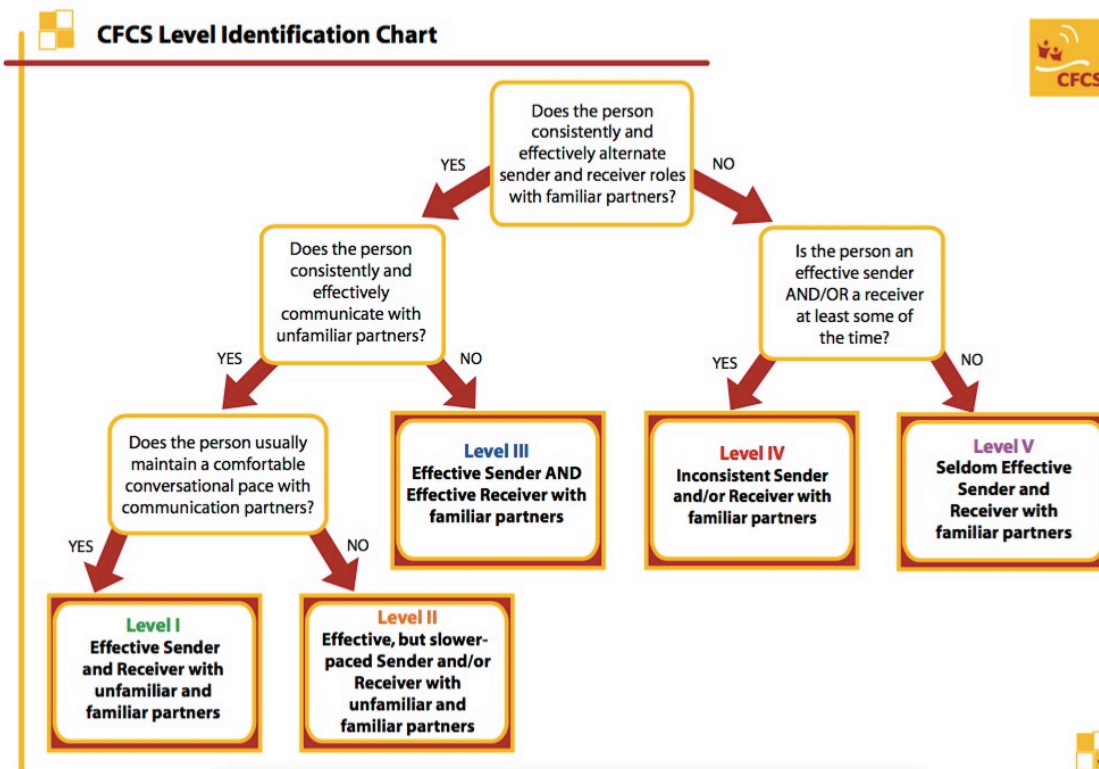
Retrieved from CanChild website on April 8, 2016:

https://www.canchild.ca/system/tenon/assets/attachments/000/001/399/original/GMFCS_English_Illustrations.pdf



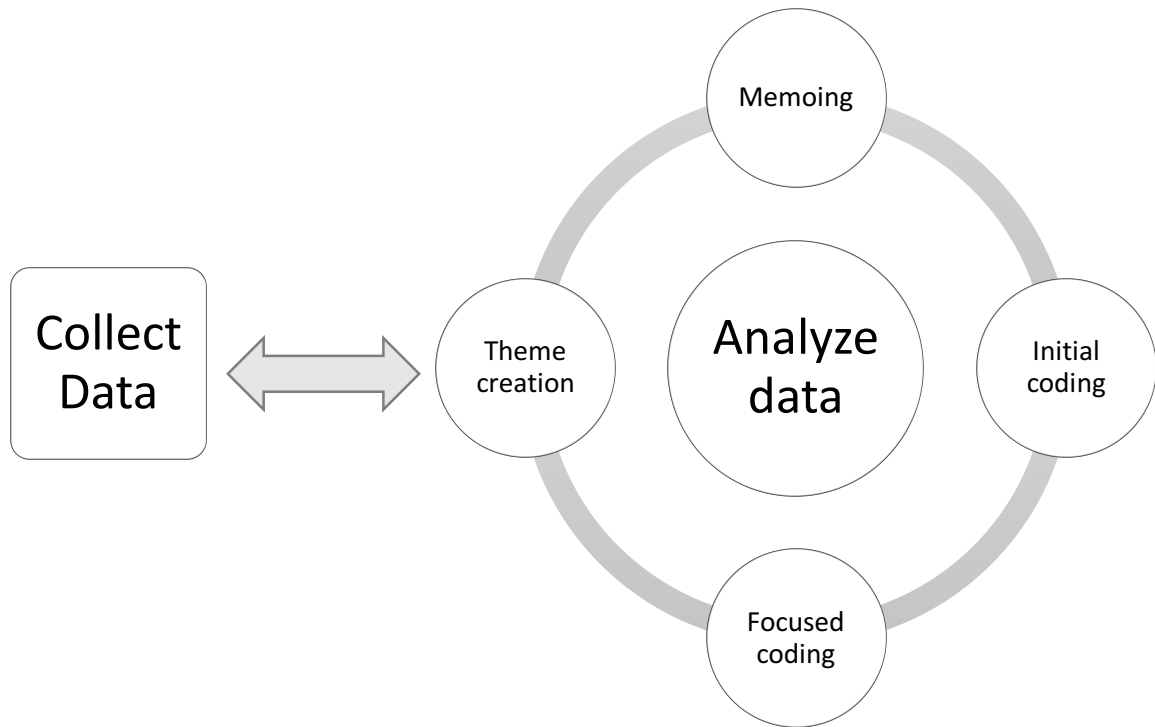
Field trial version

Retrieved from MACS website on April 8, 2016:
<http://www.macs.nu/level-identification-chart.php>



Retrieved from CFCS website on April 8, 2016:

http://cfcs.us/wp-content/uploads/2014/02/CFCS_English_2011_09_01.pdf

Appendix B: Illustrated Constant Comparative Analysis Process

Adapted from: Charmaz, K. (2014). An invitation to grounded theory. In K. Charmaz (ed.). *Constructing grounded theory* (2nd ed.), (p. 18). Los Angeles, CA: SAGE.

Appendix C: Telephone Script for Participant Recruitment

OnTrack coordinator: “Hello, may I please speak with [**potential parent participant’s name**]?”

(If potential participant IS NOT HOME, ask if there is a better time to call back. Do not leave a message. If potential participant IS HOME, continue with the conversation)

“Hi [**potential parent participant’s name**], my name is [**name of OnTrack coordinator**] and I am calling from Thames Valley Children’s Center as [**option (1) the TVCC OnTrack study coordinator; OR option (2) the TVCC research contact person**]. I’m calling because I have been asked on behalf of a student and her supervisor at Western University to help find clients who might be interested in a research study on understanding your preferences for receiving and using information related specifically to your child’s cerebral palsy. Would you be interested in hearing more about this study?”

(If NO) “Thank you for taking a moment to hear about this opportunity today, good-bye.”

(If YES) “If you participate in this study, there are three components involved. First, we would ask you to complete a short questionnaire to obtain information about your demographics. If you participated in the OnTrack study, we would already have this information on file so you would not have to complete this step. The second part would be a 5-item questionnaire about your information preferences, which would ask questions like whether you would rather have information in a hard-copy like a pamphlet, or electronic copy, like an email. This questionnaire would be mailed to you with a stamped envelope for return. Finally, you would be asked to participate in an interview with Tianna Deluzio, the student conducting the research, to talk about your answers to the questionnaire and to learn more about your and your child’s past experiences with therapists giving you information about your child. This interview could be set up at Western or in your home – whichever is preferable to you and it would last between 60 and 90 minutes. If you are interested in participating, a more detailed letter of information will be sent to you in the mail that will contain all of the information about the study, as well as a contact number if you have any questions. Would you like to be sent a letter of information to further consider participating in this study?”

(if NO) “Thank you for your time. Have a good day! Good-bye.”

(if YES) “Thank you for your interest! As I said, a letter of information will be sent to you in the mail. If, after reading the letter of information, you wish to participate, please send the completed consent form and assent form (if your child is between seven and 18 years old) in the stamped and addressed envelope provided. This letter will be sent directly to Western and the researchers will follow up with you directly. If you decide not to participate, no action is needed. Thank you for considering this request.”

Appendix D: Demographic Questionnaire

Demographic Questionnaire

This form asks some general questions about your family and child. Some of the questions may seem personal, but we ask about this information to describe families that participate in this study. **This information will be kept completely confidential.** No names are attached to the form - only a number.

If you have any questions or concerns about this form, please contact Doreen Bartlett at (519) 661-2111 ext. 88953.

Child Information

1. What is your child's gender?

- Male
 Female
 Prefer not to disclose

The information in the next 3 questions will tell us whether the ethnic background of families living in North America are represented among the participants in this study. Your responses to these questions will not be discussed individually but will be reported as a summary for the entire group. We appreciate you sharing this with us.

(These questions have been adapted to include race and ethnicity questions used in the 2010 United States Census and the 2011 Statistics Canada Census)

2. Is your child of Hispanic, Latino, or Spanish origin?

- No, not of Hispanic, Latino, or Spanish origin
 Yes, Mexican, Mexican American, Chicano
 Yes, Puerto Rican
 Yes, Cuban
 Yes, another Hispanic, Latino, or Spanish origin - *Print origin, for example, Argentinean, Columbian, Dominican, Nicaraguan, Salvadoran, Spaniard, and so on:* _____

3. Is your child an Aboriginal person?

Note: First Nations (North American Indian) includes Status and Non-Status Indians

- No, not an Aboriginal person
 Yes, First Nations (North American Indian) If yes, please specify name of enrolled or principle tribe:
 Yes, Metis
 Yes, Inuk (Inuit) _____
 Yes, Alaska native
 Yes, other: _____

4. Is your child:

Mark more than one if necessary

- White
- South Asian (e.g. East Indian, Pakistani, Sri Lankan, etc.)
- Chinese
- Black, African American
- Filipino
- Latin American
- Arab
- Southeast Asian (e.g. Vietnamese, Cambodian, Malaysian, Laotian, etc.)
- West Asian (e.g. Iranian, Afghan, etc.)
- Korean
- Japanese
- Native Hawaiian or other Pacific Islander
- Other - please specify: _____

Parent/Caregiver Information

This section asks questions about YOU.

5. What is your relationship to this child?

- | | |
|---|--|
| <input type="checkbox"/> mother | <input type="checkbox"/> father |
| <input type="checkbox"/> adoptive mother | <input type="checkbox"/> adoptive father |
| <input type="checkbox"/> stepmother | <input type="checkbox"/> stepfather |
| <input type="checkbox"/> foster mother | <input type="checkbox"/> foster father |
| <input type="checkbox"/> grandmother | <input type="checkbox"/> grandfather |
| <input type="checkbox"/> other, please specify: _____ | |

6. What is your marital status?

- never married
- married or living with a partner
- separated
- divorced
- widowed

7. How old are you?

_____ years

8. What is the highest level of education you FINISHED?

- less than high school
- high school or GED
- community college diploma; technical degree/associate degree
- bachelors degree
- masters degree
- doctoral degree

The information in the next 3 questions will tell us whether the ethnic background of families living in North America are represented among the participants in this study. Your responses to these questions will not be discussed individually but will be reported as a summary for the entire group. We appreciate you sharing this with us.

(These questions have been adapted to include race and ethnicity questions used in the 2010 United States Census and the 2011 Statistics Canada Census)

9. Are you of Hispanic, Latino, or Spanish origin?

- No, not of Hispanic, Latino, or Spanish origin
- Yes, Mexican, Mexican American, Chicano
- Yes, Puerto Rican
- Yes, Cuban
- Yes, another Hispanic, Latino, or Spanish origin - *Print origin, for example, Argentinean, Columbian, Dominican, Nicaraguan, Salvadoran, Spaniard, and so on:* _____

10. Are you an Aboriginal person?

Note: First Nations (North American Indian) includes Status and Non-Status Indians

- No, not an Aboriginal person
 - Yes, First Nations (North American Indian)
 - Yes, Metis
 - Yes, Inuk (Inuit)
 - Yes, Alaska native
 - Yes, other: _____
- If yes, please specify name of enrolled or principle tribe:

11. Are you:

Mark more than one if necessary

- White
- South Asian (e.g. East Indian, Pakistani, Sri Lankan, etc.)
- Chinese
- Black, African American
- Filipino
- Latin American
- Arab
- Southeast Asian (e.g. Vietnamese, Cambodian, Malaysian, Laotian, etc.)
- West Asian (e.g. Iranian, Afghan, etc.)
- Korean
- Japanese
- Native Hawaiian or other Pacific Islander
- Other - please specify: _____

12. What is the total household income, before taxes?

- less than \$15,000
- \$15,000 - \$29,999
- \$30,000 - \$44,999
- \$45,000 - \$59,999
- \$60,000 - \$74,999
- \$75,000 - \$89,999
- \$90,000 or more
- prefer not to answer

Appendix E: Pre-Interview Questionnaire

Adapted from Sobo (2014).

Pre-Interview Questionnaire

Please answer the following questions as honestly as possible. If none of the answers match your intended answer, please fill out the "other" option. Please use the back to explain more if you wish to expand further. We will be able to discuss your answers during the interview.

1. What is the main reason you seek information about cerebral palsy?

- a) To learn more about cerebral palsy in general
- b) To learn more about cerebral palsy as it relates to my child
- c) I do not seek information about cerebral palsy
- d) Other: _____

2. When seeking information about cerebral palsy, what source do you prefer?

- a) Hard or written (pamphlet, print-out, etc.)
- b) Electronic (online, e-mail, etc.)
- c) Verbal information
- d) Other: _____

3. What type of content would you prefer to receive about cerebral palsy?

- a) Real stories from other parents with children with cerebral palsy
- b) Resources for further information and support in my city/region
- c) Information specific to my own child's development
- d) Other: _____

4. How much information would you like to receive about cerebral palsy?

- a) As little information as possible
- b) In-depth information, but no more than one or two pages
- c) As much information as possible
- d) Other: _____

5. How satisfied are you with the information you have now on cerebral palsy as it relates to *your child*?

- a) Not at all – I have barely any information or I have too much information
- b) Slightly – I have some information but not enough
- c) Just right – I have the information I need
- d) Other: _____



Appendix F: Semi-Structured Interview Guide

Sample 1 of 2: Interview Guide for Parent(s)/Guardian(s) and Child Together

Thank you for agreeing to participate in this study today with your child, [*name of child*]. Today we will be discussing your experiences with being given information from assessments related to [*name of child*]'s cerebral palsy. Examples of assessments include balance, range of motion, strength, endurance, motor function, self-care abilities and participation in recreation activities. I'll be asking to hear thoughts from both you and your child, [*name of child*]. I will be recording this interview so I can focus on the conversation and type it out later. I just want to remind you that you can choose not to respond to any question. After this interview, you will be given the written transcript of what we discuss today and you will have the option to include it in the study or remove any parts you wish. Are you ready to begin? [*answer any preliminary questions, ensure their willingness and comfort*]

[start here if child was involved in OnTrack study]

I understand that you participated in the OnTrack study in which many of the assessments I just listed were used. During the OnTrack study, the family feedback form reports were sent to families with some immediate, brief feedback about the visits. More detailed results will be available at the end of the study once they have completed all the visits over time for the large group of children in the study. Were there any times throughout the study that you wished you had more information, or that you knew more about what was going on in terms of [*name of child*]'s assessments and what they mean in relation to [*his/her*] life? [*probe their answers to learn more*]

[start here if child was NOT involved in OnTrack study and continue with this section if they were]

Thank you for completing the pre-interview questionnaire. I see that you responded _____ [*answer RE: question #5*]. Were there ever times so far in your experience with CP that you wish you had more information, or wish that the information you had was altered in some way to be more helpful to you? [*probe their answers to learn more*]

I would like to ask you about your thoughts on receiving specific information about [*name of child*]'s development based on assessments conducted by therapists [*if they participated in OnTrack, bring it up as an example if not responses not forthcoming*]. What are your feelings about having information about your child's development?

If you were given information about your child's development, how would you be intending to use this information?

You indicated on your questionnaire that you are interested in having _____ [*answer RE: question #3*]. When the OnTrack study is finished, we will have graphs to help us understand the average developmental course of subgroups of children with cerebral palsy (using the GMFCS, MACS and CFCS) and graphs to help us understand if children with cerebral palsy are developing ‘as expected’, ‘better than expected’, or ‘more poorly than expected’ on the measures we are using. Do you think these things would be useful to you? To your child? Why or why not? What would be more useful? Can you think of other things?

[*If not covered in their response, ask about preferred layout and design of information content*]

[direct question to child]

When you go see a therapist, like a PT or an OT, how do you feel? Do you like the way they talk about you? Do they talk to you or do they mostly talk to your parent(s)/guardian(s)? If you could change the way that went, what would you want to change?

[direct question to both child and parents]

Finally, I’d like end by going over your pre-interview questionnaire [*provide them with a copy of their questionnaire as a reminder of their answers*]. Is there anything from the questions here that you would like to expand on that we have not already covered?

Sample 2 of 2: Interview Guide for Child

[Wording will vary based on child's age and level of comprehension] Thank you for agreeing to talk to me today. I want to learn a little more about you and see what you think about some things. I am going to record this conversation, just so I can listen to it again later to remember everything we talk about. Is that okay?

[If child says NO, interview will end. If child says YES, continue to first question]

I'm going to ask you a couple questions, but there are no right or wrong answers to these questions. If you don't want to answer a question for any reason, that's okay and we can move on to another one. If you don't want to answer any more questions at all, we can stop. Do you understand? Do you have any questions for me? *[answer any preliminary questions, ensure their willingness and comfort]*

For my first question, I wanted to ask you about cerebral palsy. Can you tell me what you know about cerebral palsy? Is there any more that you would like to know, or are you happy with what you know?

When you go see a therapist, like a PT or an OT, how do you feel? Do you like the way they talk about you? Do they talk to you or do they mostly talk to your parent(s)/guardian(s)? If you could change that, what would you want to change?

When you have had assessments with therapists in the past, what are your memories of those experiences? *[probe positive or negative]*

Are you ever told what the assessment is for? Does the therapist explain their findings about you to you? *[If yes, probe to explain what they said and what more/less could have been said. If no, probe to explain how they feel about that and if they would want assessments explained.]*

Appendix G: Letters of Approval (TVCC and Western University)



June 6, 2016

Ms. Tianna Deluzio
Western University
Elborn College, Room 2300
London ON N6G 1H1

Re: How do individuals with cerebral palsy and their families prefer to receive and use evidenced-based information to individualize services to optimize outcomes?

Dear Ms. Deluzio,

On June 6, 2016 Thames Valley Children's Centre's (TVCC) Research Advisory Committee (RAC) reviewed and approved the above-named project. The Committee thought that the study would fill an important gap in knowledge and the literature with respect to how children, youth, and young adults with cerebral palsy and their parents prefer to receive and use evidenced-based information that is individualized to their ongoing needs.

Please be aware that the study cannot begin until the TVCC Research Program has received a letter of approval for the study from Western University's Health Sciences Research Ethics Board (HSREB).

The Committee had some feedback regarding your study that they would like me to pass on to you.

The Committee pointed out that Section 15 indicates that only investigators (Bartlett, Daya, and Lucy) would have access to participant information, yet Tianna Deluzio is listed as the Principal Investigator.

Members felt that the interview guides were quite wordy, and may be "lead" participants in terms of their answers.

Members also were not sure if there was a parent participant for youth/young adults aged 18 to 21 years, as this was not stated.

The Committee felt that the Letter of Information for youth/young adults aged 18 to 21 years should refer to a participant as a youth/young adult rather than a child.

Beyond
disability

It was noticed by the Committee that the study questionnaire does not include a question about the participant's age, but that this was information that the investigators planned to report.

At the completion of your study, TVCC would appreciate it if you would (1) present the research findings to staff members; (2) provide us with a copy of any final reports or articles that come out of the study, and information about any presentations that are made.

Please contact the Research Program upon the completion of the study to make arrangements for a presentation. The TVCC Research Officer will help you set a date, and will book a room and any audio-visual equipment you will need.

If you have any questions, please do not hesitate to contact me.

The Committee extends their best wishes for a successful project once the approval from the HSREB has been provided!

Yours sincerely,

Janette McDougall, Ph.D.
Researcher, Research Program
Chair, Research Advisory Committee
Thames Valley Children's Centre

Cc: Karen Lowry, Director, QM
Michelle Truppe, Director, ECS/FCS
Liz Lusk, Physiotherapist, Clinic/ECS



**Western University Health Science Research Ethics Board
HSREB Delegated Initial Approval Notice**

Principal Investigator: Dr. Doreen Bartlett
Department & Institution: Health Sciences/Physical Therapy, Western University

Review Type: Delegated
HSREB File Number: 108035
Study Title: How do individuals with cerebral palsy and their families prefer to receive and use evidence-based information to individualize services to optimize outcomes?
Sponsor: Canadian Institutes of Health Research

HSREB Initial Approval Date: July 04, 2016
HSREB Expiry Date: July 04, 2017

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Western University Protocol	Received 2016/06/14	
Letter of Information & Consent	Main	2016/06/14
Letter of Information & Consent	Parents	2016/06/14
Assent		2016/06/14
Data Collection Form/Case Report Form	Demographic Questionnaire - Youth Received 2016/06/14	
Data Collection Form/Case Report Form	Demographic Questionnaire - Received 2016/05/02	
Data Collection Form/Case Report Form	Pre-Interview Questionnaire - Received 2016/05/02	
Instruments	Interview Guide - Received 2016/05/02	
Recruitment Items	Phone Script - Received 2016/05/02	

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice Practices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

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

Ethics Officer, on behalf of Dr. Joseph Gilbert, HSREB Chair

Ethics Officer: Erika Basile ___ Nicole Kaniki Grace Kelly ___ Katelyn Harris ___ Vikki Tran ___ Karen Gopaul ___

Appendix H: Letters of Information and Consent, Letter of Assent



1

Letter of Information [Parents]

How do individuals with cerebral palsy and their families prefer to receive and use evidence-based information to individualize services to optimize outcomes?

Investigators: Doreen Bartlett, BScPT, MSc, PhD
 School of Physical Therapy, Faculty of Health Sciences
 Western University, London, Ontario
 [REDACTED]

Tianna Deluzio, BHSc (Honours), MSc Student
 Health & Rehabilitation Sciences Graduate Program, Faculty of Health Sciences
 Western University, London, Ontario
 [REDACTED]

Alisiyah Daya, BHSc (Honours), MSc Student
 Health & Rehabilitation Sciences Graduate Program, Faculty of Health Sciences
 Western University, London, Ontario
 [REDACTED]

Deborah Lucy, BScMR(PT), MClSc(PT), MSc, PhD
 School of Physical Therapy, Faculty of Health Sciences
 Western University, London, Ontario
 [REDACTED]

1. Invitation to Participate

You are being invited to participate because you and your child (who is between seven and 18 years of age) have been taking part in the OnTrack study and were recruited through the Thames Valley Children's Centre (TVCC) or you are known to the TVCC OnTrack coordinator because you and your child receive services through TVCC.

2. Purpose of this Letter

The purpose of this letter is to provide you with the information required for you to make an informed decision regarding participating in this research.

Participant Initials: _____

Version 07/04/2016

3. Purpose of this Study

There are three purposes of this study: first, to describe the specific format in which children and youth with cerebral palsy and their parents prefer to receive individualized assessment information about their children's development; second, to understand how children and youth with cerebral palsy and their families intend to use individualized evidence-based information pertaining to their development; and third is to gain insight on how children and youth with cerebral palsy wish to be represented in the individualized information presented to them in terms of being both comprehensive and respectful. The terms "individualized assessment information" or "individualized evidence-based information" refer to assessment findings and interpretations relating to balance, range of motion, strength, endurance, motor function, self-care abilities, and participation in recreation and leisure activities.

4. Inclusion Criteria

For this study, ten to 12 child-parent participant pairs will be recruited, consisting of children and youth with cerebral palsy and their parents (or legal guardians). Children and youth participants will be between seven to 21 years of age. All participants will have conversational level English.

5. Study Procedures

If you agree to participate, information about you and your child will be collected if you were not a part of the OnTrack study before the study visit. If you were a part of the OnTrack study, we already have this information in the study database from the first visit. A 5-item questionnaire will also be sent to you (as the parent) to obtain initial impressions of your individual preferences for receiving information. From the content of this questionnaire, a 60- to 90-minute interview will be set up to gain a more in-depth understanding of your and your child's information preferences. If your child is above the age of 12, you and your child will be asked if your child would like to participate in an interview with you, on his or her own, or both (perhaps first with you, and then being interviewed separately, if comfortable). Following the first interview, a second interview of no more than 45 minutes may be set up if there is further information to be gathered and/or to review information formatting ideas that are generated in the first interview. The interviews will be conducted by Tianna Deluzio. These interviews can take place wherever is most convenient to you: at Western University or at your home. After the

Participant Initials: _____

Version 07/04/2016

data have been collected and analyzed, you will be contacted again to discuss the findings of the study.

6. Possible Risks and Harms

Physical: There are no known physical risks associated with participation in this study.

Psychological: There is a small likelihood of psychological risk associated with participation in this study as some of the questions may delve into sensitive topics regarding the past, present, and future function of your child. If you or your child become distressed during the session, the interview can pause until you are comfortable to continue or stop altogether if you would prefer not to continue. If requested, those who experience distress will be referred to Doreen Bartlett for support.

7. Possible Benefits

You and your child may not directly benefit from participating in this study, but the information gathered may help to inform researchers and therapists on how to provide assessment information to children and parents in such a way that they can use it for the optimal development of their child.

8. Compensation

A \$20 gift card to Indigo Books & Music will be provided to each child participant at the end of the first interview. Child supervision will be provided for other children in the family by a co-investigator if needed, either in your home or at Western. If the interview takes place at Western, a parking voucher will be provided.

9. Voluntary Participation

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time while we are collecting data with no effect on you or your child's future care through TVCC. Once you have approved your transcript for accuracy, analysis will begin and we will not be able to withdraw data in efforts to protect the integrity of the research. You do not waive any legal rights by signing the consent form.

10. Confidentiality

Your confidentiality will be respected throughout this study. Only those individuals listed as investigators will be able to access your information. Your research records will be stored in a locked cabinet in a secure office in Elborn College at Western University in Room 2300 or in a secured Archives Storage Area at Western University in London, Ontario and will be destroyed

Participant Initials: _____

Version 07/04/2016

after 7 years. Audiotapes will be erased once they have been transcribed, reviewed, and approved by each participant. Any electronic documents pertinent to your participation in this study will be stored on a computer that is password protected. If you choose to withdraw from this study prior to sending approval of your interview transcript, your data will be destroyed. You will be asked to provide a pseudonym (a name other than your own or your child's) that we may use to identify you by when analyzing the data and preparing the final report. When the results of this study are sent out, neither your name nor any identifying information will be used.

Because this project is being coordinated through Western University, representatives of the University of Western Ontario Health Sciences Research Ethics Board may contact you or require to access your study-related records to monitor the conduct of the research.

11. Contacts for Further Information

If you require any further information regarding this research project or your participation in the study, you may contact Doreen Bartlett by telephone at (519) 661-2111 ext. 88953 or by email at djbartle@uwo.ca. If you have any questions about your rights as a research participant or the conduct of this study, you may contact the Office of Research Ethics at (519) 661-3036 or by email at ethics@uwo.ca.

12. Publication

The results of this study will be widely circulated. Please complete page 6 if you wish to receive a summary of this study's results.

13. Consent

Included with this letter is a consent form to sign indicating informed consent and willingness to participate in this study.

This letter is for you to keep.

Participant Initials: _____

Version 07/04/2016

Consent Form

**How do individuals with cerebral palsy and their families prefer to receive
and use evidence-based information to individualize services to optimize outcomes?**

Investigators: Doreen Bartlett, PT, PhD
School of Physical Therapy, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

Tianna Deluzio, BHSc (Honours), MSc Student
Health & Rehabilitation Sciences Graduate Program, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

Alisiyah Daya, BHSc (Honours), MSc Student
Health & Rehabilitation Sciences Graduate Program, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

Deborah Lucy, BScMR(PT), MClSc(PT), MSc, PhD
School of Physical Therapy, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

I have read the Letter of Information, have had the nature of the study explained to me, and I agree to participate. All the questions have been answered to my satisfaction. I will receive a signed copy of this consent form.

Name of Participant (Please print)

Signature of Participant

Signature of Investigator

Date

I understand that the interview will be audiotaped

Participant Initials: _____

Version 07/04/2016

Legally-Authorized Representative Information

Please return this information, in addition to the consent form, if you would like to receive a summary of the study results.

Name: _____

Email: _____

Phone: _____

Participant Initials: _____

Version 07/04/2016



Letter of Information [Ages 18-21]

**How do individuals with cerebral palsy and their families prefer to receive
and use evidence-based information to individualize services to optimize outcomes?**

Investigators: Doreen Bartlett, BScPT, MSc, PhD
School of Physical Therapy, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

Tianna Deluzio, BHSc (Honours), MSc Student
Health & Rehabilitation Sciences Graduate Program, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

Alisayah Daya, BHSc (Honours), MSc Student
Health & Rehabilitation Sciences Graduate Program, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

Deborah Lucy, BScMR(PT), MClSc(PT), MSc, PhD
School of Physical Therapy, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

1. Invitation to Participate

You are being invited to participate because you are known to the Thames Valley Children's Centre (TVCC) OnTrack coordinator, you have cerebral palsy, and you are between 18 and 21 years of age.

2. Purpose of this Letter

The purpose of this letter is to provide you with the information required for you to make an informed decision regarding participating in this research.

Participant Initials: _____

Version 07/04/2016

3. Purpose of this Study

There are three purposes of this study: first, to describe the specific format in which children with cerebral palsy and their parents prefer to receive individualized assessment information about their children's development; second, to understand how children with cerebral palsy and their families intend to use individualized evidence-based information pertaining to their development; and third is to gain insight on how children with cerebral palsy wish to be represented in the individualized information presented to them in terms of being both comprehensive and respectful. The terms "individualized assessment information" or "individualized evidence-based information" refer to assessment findings and interpretations relating to balance, range of motion, strength, endurance, self-care abilities, and participation in recreation and leisure activities.

4. Inclusion Criteria

For this study, ten to 12 child-parent participant pairs will be recruited, consisting of children and youth with cerebral palsy and their parents (or legal guardians). Children and youth participants will be between seven to 21 years of age. All participants will have conversational level English.

5. Study Procedures

If you agree to participate, demographic information about you will be collected before the interview. After the demographic questionnaire has been completed, a 60- to 90-minute interview will be set up to gain a more in-depth understanding of your information preferences. Following the first interview, a second interview of no more than 45 minutes may be set up if there is further information to be gathered and/or to review information formatting ideas that are generated in the first interview. The interviews will be conducted by Tianna Deluzio. These interviews can take place wherever is most convenient to you: at Western University or at your home. After the data have been collected and analyzed, you will be contacted again to discuss the findings of the study.

6. Possible Risks and Harms

Physical: There are no known physical risks associated with participation in this study.

Psychological: There is a small likelihood of psychological risk associated with participation in this study as some of the questions may delve into sensitive topics regarding your past, present,

Participant Initials: _____

Version 07/04/2016

and future experiences with CP. If you become distressed during the session, the interview can pause until you are comfortable to continue or stop altogether if you would prefer not to continue. If requested, those who experience distress will be referred to Doreen Bartlett for support.

7. Possible Benefits

You may not directly benefit from participating in this study, but the information gathered may help to inform researchers and therapists on how to provide assessment information to children and parents in such a way that they can use it for the optimal development of their child.

8. Compensation

A \$20 gift card to Indigo Books & Music will be provided to each child participant at the end of the first interview. If the interview takes place at Western, a parking voucher will be provided.

9. Voluntary Participation

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time while we are collecting data with no effect on your future care through TVCC. Once you have approved your transcript for accuracy, analysis will begin and we will not be able to withdraw data in efforts to protect the integrity of the research. You do not waive any legal rights by signing the consent form.

10. Confidentiality

Your confidentiality will be respected throughout this study. Only those individuals listed as investigators will be able to access your information. Your research records will be stored in a locked cabinet in a secure office in Elborn College at Western University in Room 2300 in London, Ontario and will be destroyed after 7 years. Audiotapes will be erased once they have been transcribed, reviewed, and approved by each participant. Any electronic documents pertinent to your participation in this study will be stored on a computer that is password protected. If you choose to withdraw from this study prior to sending approval of your interview transcript, your data will be destroyed. You will be asked to provide a pseudonym (a name other than your own) that we may use to identify you by when analyzing the data and preparing the final report. When the results of this study are sent out, neither your name nor any identifying information will be used.

Participant Initials: _____

Version 07/04/2016

Because this project is being coordinated through Western University, representatives of the University of Western Ontario Health Sciences Research Ethics Board may contact you or require to access your study-related records to monitor the conduct of the research.

11. Contacts for Further Information

If you require any further information regarding this research project or your participation in the study, you may contact Doreen Bartlett by telephone at (519) 661-2111 ext. 88953 or by email at djbartle@uwo.ca. If you have any questions about your rights as a research participant or the conduct of this study, you may contact the Office of Research Ethics at (519) 661-3036 or by email at ethics@uwo.ca.

12. Publication

The results of this study will be widely circulated. Please complete page 6 if you wish to receive a summary of this study's results.

13. Consent

Included with this letter is a consent form to sign indicating informed consent and willingness to participate in this study.

This letter is for you to keep.

Participant Initials: _____

Version 07/04/2016

Consent Form

**How do individuals with cerebral palsy and their families prefer to receive
and use evidence-based information to individualize services to optimize outcomes?**

Investigators: Doreen Bartlett, PT, PhD
School of Physical Therapy, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

Tianna Deluzio, BHSc (Honours), MSc Student
Health & Rehabilitation Sciences Graduate Program, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

Alisiyah Daya, BHSc (Honours), MSc Student
Health & Rehabilitation Sciences Graduate Program, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

Deborah Lucy, BScMR(PT), MClSc(PT), MSc, PhD
School of Physical Therapy, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

I have read the Letter of Information, have had the nature of the study explained to me, and I agree to participate. All the questions have been answered to my satisfaction. I will receive a signed copy of this consent form.

Name of Participant (Please print)

Signature of Participant

Signature of Investigator

Date

I understand that the interview will be audiotaped

Participant Initials: _____

Version 07/04/2016

Legally-Authorized Representative Information

Please return this information, in addition to the consent form, if you would like to receive a summary of the study results.

Name: _____

Email: _____

Phone: _____

Participant Initials: _____

Version 07/04/2016



Child Assent Form

**How do individuals with cerebral palsy and their families prefer to receive
and use evidence-based information to individualize services to optimize outcomes?**

Investigators: Doreen Bartlett, PT, PhD
School of Physical Therapy, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

Tianna Deluzio, BHSc (Honours), MSc Student
Health & Rehabilitation Sciences Graduate Program, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

Alisiyah Daya, BHSc (Honours), MSc Student
Health & Rehabilitation Sciences Graduate Program, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

Deborah Lucy, BScMR(PT), MClSc(PT), MSc, PhD
School of Physical Therapy, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

1. Why are you here?

The study team wants to talk to children and youth with cerebral palsy and their families to learn more about them. Tianna Deluzio is doing this study and would like to talk with you about your experiences with cerebral palsy.

2. What is this project about?

The study team wants to learn about how children and youth with cerebral palsy and their families can benefit from having individualized assessment information. By assessments, we mean information that therapists record about you, like how your balance is, how strong you

Participant Initials: _____

Version 07/04/2016

2

are, or how flexible you are. We want to figure out how you want to be given information and what you want to do with that information. We also want to learn more about how you feel about the information – if you like it or if you would like to change it.

3. What will happen during your visit?

If you agree to help and be a part of this project, you will participate in an interview with your parent(s)/guardian(s) that will be between 60 and 90 minutes. If we would like to talk with you again, you will be given the chance to participate in a second interview at a later date that will be no longer than 45 minutes. In these interviews, Tianna Deluzio will be asking you questions about your experiences. This will help her understand more about how researchers and therapists can give you and your family better information.

4. Will the project hurt you in any way?

This project will not hurt you or cause pain in any way. We will just be talking to each other. If you do not feel comfortable at any point while we are talking, we can pause or stop. No one will be mad if we stop and you will not get into any trouble.

5. Will your cerebral palsy get better if you are in the project?

This study will not make you move better. By helping and being a part of this project, the study team may find out something that will help other children like you later on.

6. What if you have questions?

You can ask any questions at any time, now or during the interviews. You can talk to your family or anyone on the study team. There are no bad questions. We want to answer any questions that you may have.

7. Can I change my mind about being in the study?

If you do not want to be in the project any more, you can say no. You can change your mind at any time. No one will be mad at you if you change your mind. If you do not want to be in the project, just say so. Even if you say yes today, you can say no at any time. It is all up to you.

This letter is for you to keep.

Participant Initials: _____

Version 07/04/2016

Assent Form

**How do individuals with cerebral palsy and their families prefer to receive
and use evidence-based information to individualize services to optimize outcomes?**

Investigators: Doreen Bartlett, PT, PhD
School of Physical Therapy, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

Tianna Deluzio, BHSc (Honours), MSc Student
Health & Rehabilitation Sciences Graduate Program, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

Alisayah Daya, BHSc (Honours), MSc Student
Health & Rehabilitation Sciences Graduate Program, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

Deborah Lucy, BScMR(PT), MClSc(PT), MSc, PhD
School of Physical Therapy, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]

I have had the project details read to me and I want to participate.

Name of Child (please print): _____

Child Signature: _____

Age of Child: _____

Date: _____

Signature of Person Obtaining Assent: _____

Date: _____

Participant Initials: _____

Version 07/04/2016

Appendix I: Transcribed Memos

Below is a sampling of some of the memos recorded throughout data collection and analysis. The memos are labelled with interview numbers for organizational purposes only – the number of the interview recorded below does not coincide with the order of the interviews. This was done in an effort to further prevent any identifying information from being revealed.

Interview 1

- Family very welcoming and thoughtful with responses
- Other child calling [child] away – could see she wanted to go play but she was also at least somewhat interested in participating because she stayed
- Father listened for first half from kitchen and participated in second half with us
- Both parents said their education level played role in their satisfaction with amount of info because they knew how to seek out more info/make use of more wordy info
 - o Didn't know what resources existed – they are from smaller area so this impacts resources
- “what will it look like when she's 18” was prominent question by them
- “has my name on it but it's not for me” important comment by child
- improve for next time – don't say “you guys” to address couples/family or “good” as a response to their answers

Interview 2

- child hesitant to participate at first but got more comfortable as interview went on
- father seemed adamant that their experience with getting info has not been ideal – lots of communication breakdowns
- parents both took on role of rewording questions to involve child
- “communication breakdowns” a big theme
- “always” wished they had more information – they've never been satisfied with what they've gotten
- suggested report card format – big!
- Lots of disappointed facial expressions from parents RE: inadequate information
 - o This was overall impression of interview
- To improve: need to be more familiar with CP studies (OnTrack etc.)

Interview 3

- Child was VERY animated and talkative

- Definitely impacted interview RE: distracting to others and getting off topic
- Mother seemed to focus lots on experience with being diagnosed – she may have misunderstood questions/I may have worded them poorly or she maybe just wanted to share her stories (totally okay)
- Older brother present for some of it – gave insightful comments
- Mother’s career related to children with disabilities (impacted her viewpoints)
- To improve: learn how to better handle confidentiality-related situations

Interview 4

- Mother very welcoming and kind, eager to discuss this topic and very bright re: CP and other development-related issues in children
- Child was older, so she was less concerned with getting info now as “he is where he is”
 - He interrupted a lot but was very funny and intrigued by conversations
- Idea of an IEP in addition to or similar to idea of report card to base information dissemination
- To improve: how to bring conversation back after interruption

Interview 5

- Child was very restless and either wanted direct questions or to go outside
- Mother seemed like she was interested but was having a hard time thinking on the spot – responded well to prompts and/or examples
- Child said she gets “nervous” re: therapy visits because she wants to be better, not because she doesn’t like therapists
- To improve: provide more time for responses, even if it is silent

Interview 6

- Child very bright and well-spoken
- Adult very proactive and supportive both in the interview and seemingly overall
 - Combined for a great interview
- Seemed very happy with the school and the healthcare experiences re: information accessibility
- Not shy which helps them advocate if/when necessary
- To improve: more follow-up questions for inquisitive children

Interview 7

- Not very much to say, but not in a bad way
- Seemed very content with services and information

- Child very resilient and parents encourage this
- Needed lots of probing to instigate some sort of detailed response
- Child a bit older so they were interested in information related to becoming young adult with CP – no longer a child!
- To improve: figure out how to ask question such that just “yes” or “no” are not first or only response

Interview 8

- child wanted to be outside with friend until needed
- mother often seemed to misinterpret question/get sidetracked on different story/topic
- did not seem very open to getting/using information, which made asking follow-up question hard
 - o said she knew what was best for her child
- child clearly did not want to answer questions – just wanted to give any quick answer and go back outside
- did not feel overall like a great interview
- to improve: can I keep child’s interest longer than a yes/no response?

Interview 9

- first interview to be done over the phone
 - o impacted ability to read facial and body expression throughout interview which can be a guiding factor in follow up questions/comments etc.
- child very enthusiastic, adult very positive and easy-going
- seemed fairly neutral on most question/topics
- to improve: how to better conduct phone interviews

Interview 10

- child not overly interested in participating but was present entire time
- adult quite happy with info but noted that it’s difficult knowing what exists and where to get it from
- made comments while I was on my way out, after recorder stopped, about information preferences and things she has liked in the past
 - o liked getting information that is one sheet, with clearly separated bullet points that only included the information that was necessary
 - o very straightforward, no extra or filler information

Appendix J: Transcribed Initial and Focused Codes

Initial Coding: Labels

1. Parents want concrete information
2. Bigger picture/how child fits in/gauge relative to others
3. Don't know what info to ask for if you don't know what's out there
4. General feelings re: info about CP-related development
5. Resources available in region
6. Seeking out own information
7. "Feel good story"/parents' experiences and anecdotes as resource
8. How will child look in future? What's next? (proposed info/next steps of OnTrack)
9. Language "developing as expected, better than expected..."
10. Child's preferences re: receiving info/format
11. parent preferences re: receiving info/format
12. Sharing info with others
13. Child's interactions with therapists
14. Respect re: child's CP-related info/interactions
15. Child preferences re: type of info about CP
16. CCAC
17. Stigma of CP/heterogeneity of CP
18. Parents want info for helping child understand
19. Have enough info?
20. Parent preferences re: type of info (i.e. child strengths, weaknesses, where to improve, etc.)

Focused Coding

I. Parent and Child Preferences for Information Format

- (10) Child's preferences re: receiving info/format
- (11) Parent preferences re: receiving info/format

II. Type of Information Parents and Children Want to Receive

- (1) Parents want concrete information
- (2) Bigger picture/how child fits in/gauge relative to others
- (5) Resources available in region
- (7) "Feel good story"/parents' experiences and anecdotes as resource
- (8) How will child look in future? What's next? (proposed info/next steps of OnTrack)
- (15) Child preferences re: type of info about CP
- (18) Parents want info for helping child understand

- (20) Parent preferences re: type of info (i.e. child strengths, weaknesses, where to improve, etc.)

III. Not Receiving Enough Information

- (3) Don't know what info to ask for if you don't know what's out there
- (6) Seeking out own information
- (19) Have enough info?

IV. Respecting Children with CP in Information and Interaction

- (9) Language “developing as expected, better than expected...”
 **Is there a pattern here related to the GMFCS level vs. what parents/child responds?
- (13) Child's interactions with therapists
- (14) Respect re: child's CP-related info/interactions

V. (4) General feelings re: info about CP-related development

VI. (12) Sharing info with others

VII. (17) Stigma of CP/heterogeneity of CP










Not specifically relevant to MSc:






- CCAC – communication breakdowns are common theme

Appendix K: Sample Mock-Ups















Samples based on a child in GMFCS level I. *Note:* both versions of mock-up 1 are included. A decision on which version of the mock-up to use will be made at a later date.

Mock-Up 1 – Version 1

CHECKING UP AND CHECKING IN Progress Report					 NOTES:
		Doing Less Than Expected	Doing as Expected	Doing More than Expected	
Name: _____ Age: ____ years, ____ months GMFCS: ____ MACS: ____ CFCS: ____ Date: _____ Completed by: _____ These results have been discussed with me: <input type="checkbox"/> _____ (parent) <input type="checkbox"/> _____ (child)					
BALANCE					
STRENGTH					
RANGE OF MOTION					
OTHER					

ENDURANCE 6-Minute Walk Test					
ENDURANCE Early Activity Scale for Endurance					
OVERALL HEALTH					
PARTICIPATION IN FAMILY AND RECREATIONAL ACTIVITIES					
PARTICIPATION IN SELF-CARE ACTIVITIES					

Mock-Up 1 – Version 2

CHECKING UP AND CHECKING IN Progress Report Name: _____ Age: ____ years, ____ months GMFCS: ____ MACS: ____ CFCS: ____ Date: _____ Completed by: _____ These results have been discussed with me: <input type="checkbox"/> _____ (parent) <input type="checkbox"/> _____ (child)		 Doing Less Than Expected	 Doing as Expected	 Doing More than Expected	 NOTES:
BALANCE					
STRENGTH					
RANGE OF MOTION					
OTHER					
ENDURANCE 6-Minute Walk Test					
ENDURANCE Early Activity Scale for Endurance					
OVERALL HEALTH					
PARTICIPATION IN FAMILY AND RECREATIONAL ACTIVITIES					
PARTICIPATION IN SELF-CARE ACTIVITIES					

Mock-Up 2

CHECKING UP AND CHECKING IN



On Track study reference percentiles fit nicely with the goals of regular check-ups and check-ins between children with cerebral palsy and their families and health care professionals: *Finding the balance between results of standardized assessments and the individual priorities and concerns of families.*

The On Track study research results for children with cerebral palsy give us a framework for developmental assessment, monitoring and individualized care. Check-ups and check-ins help us work toward the best possible development for your child. We can work together using the On Track study research results related to:

- **Balance abilities**
- **Strength**
- **Range of Motion**
- **Endurance**
- **Overall Health**
- **Participation in Family and Recreational Activities**
- **Participation in Self-care Activities**


The On Track Study (2012-2017) involved 708 children with cerebral palsy and their families, researchers and therapists from across Canada and the United States. Researchers created reference percentiles based on children’s assessments over a 12 month timeframe.

The percentile results are one tool that a therapist can use in collaborative discussions with a family to look at whether a child with cerebral palsy is doing as expected, more than expected, or less than expected, depending on his/her functional ability level. You and your child’s therapist can use the backside of this page to:

- **RECORD** your child’s current assessment scores and how your child is progressing in those areas, relative to what we might expect.
- **DISCUSS** your child’s strengths and important areas for improvement, and make notes to help individualize your child’s treatment plan.

For families who find it helpful, this type of developmental monitoring is a place to start the conversation about what we might expect to see based on assessments of children in similar functional levels of cerebral palsy.

To find out more, visit the On Track Study website: canchild.ca/en/research-in-practice/current-studies/on-track

CHECKING UP AND CHECKING IN Progress Report		Doing Less than Expected	Doing as Expected	Doing More than Expected	NOTES:
Name: _____ Age: ____ years, ____ months GMFCS: ____ MACS: ____ CFCS: ____ Date: _____ (DD-MM-YYYY) Completed by: _____ These results have been discussed with me: <input type="checkbox"/> _____ parent <input type="checkbox"/> _____ child					
BALANCE Early Clinical Assessment of Balance scored from 0 to 100 (higher score=better balance)	100		*		
STRENGTH Functional Strength Assessment scored from 1 to 5 (higher score=stronger)	5		*		
RANGE OF MOTION Spinal Alignment and Range of Motion Measure scored from 0 to 4 (lower score=fewer limitations)	0.46		*		
ENDURANCE 6-Minute Walk Test scored in feet (higher score =further distance)	1291.67		*		
ENDURANCE Early Activity Scale for Endurance scored from 1 to 5 (higher score=more endurance)	3.75	*			
OVERALL HEALTH Child Health Conditions Questionnaire scored from 0 to 7 (lower score=better overall health)	0.56	*			
PARTICIPATION IN FAMILY AND RECREATIONAL ACTIVITIES Child Engagement in Daily Life Measure scored from 1 to 5 (higher score=more participation)	68.2		*		
PARTICIPATION IN SELF-CARE ACTIVITIES Child Engagement in Daily Life Measure scored from 1 to 5 (higher score =needs less help)	82.8		*		
OTHER:					

Mock-Up 3

CHECKING UP AND CHECKING IN



On Track study reference percentiles fit nicely with the goals of regular check-ups and check-ins between children with cerebral palsy and their families and health care professionals: *Finding the balance between results of standardized assessments and the individual priorities and concerns of families.*

The On Track study research results for children with cerebral palsy give us a framework for developmental assessment, monitoring and individualized care. Check-ups and check-ins help us work toward the best possible development for your child. We can work together using the On Track study research results related to:

- Balance abilities
- Strength
- Range of Motion
- Endurance
- Overall Health
- Participation in Family and Recreational Activities
- Participation in Self-care Activities

The On Track Study (2012-2017) involved 708 children with cerebral palsy and their families, researchers and therapists from across Canada and the United States. Researchers created reference percentiles based on children’s assessments over a 12 month timeframe. Your therapist can share with you the reference percentile graphs for your child’s Gross Motor Function Classification System (GMFCS) level, and discuss with you how to interpret the graphs in terms of change in scores from one year to the next.

The percentile results are one tool that a therapist can use in collaborative discussions with a family to look at whether a child with cerebral palsy is doing as expected, more than expected, or less than expected, depending on his/her functional ability level. You and your child’s therapist can use the reference percentile graphs and the backside of this page to:

- **RECORD** your child’s current assessment scores and how your child is progressing in those areas, relative to what we might expect.
- **DISCUSS** your child’s strengths and important areas for improvement, and make notes to help individualize your child’s treatment plan.

For families who find it helpful, this type of developmental monitoring is a place to start the conversation about what we might expect to see based on assessments of children in similar functional levels of cerebral palsy.

To find out more, visit the On Track Study website: canchild.ca/en/research-in-practice/current-studies/on-track

CHECKING UP AND CHECKING IN Assessment

Name: _____ Age: ___ years, ___ months
 GMFCS: ___ MACS: ___ CFCS: ___ Date: _____
 Completed by: _____
 These results have been discussed with me:
 _____ parent _____ child

Your Child’s RESULTS

The shaded column gives your child’s score for each measure. Under the score we have indicated the confidence interval. Confidence intervals are a way to represent how “good” the score is; the larger the interval, the more caution is needed when using the score.



	Your Child’s Score (confidence interval)		Doing Less than Expected	Doing as Expected	Doing More than Expected
	Past	Most Recent			
BALANCE Early Clinical Assessment of Balance. Scored from 0 to 100 (higher score = better balance).	100	100		*	
STRENGTH Functional Strength Assessment. Scored from 1 to 5 (higher score = stronger).	5	5		*	
RANGE OF MOTION Spinal Alignment and Range of Motion Measure. Scored from 0 to 4 (lower score = fewer limitations).	0.54	0.46		*	
ENDURANCE 6-Minute Walk Test. Scored in feet (higher score = further distance).	1199.25	1291.67		*	
ENDURANCE Early Activity Scale for Endurance. Scored from 1 to 5 (higher score = more endurance).	4.5	3.75	*		
OVERALL HEALTH Child Health Conditions Questionnaire. Scored from 0 to 7 (lower score = better overall health).	0	0.56	*		
PARTICIPATION IN FAMILY AND RECREATIONAL ACTIVITIES Child Engagement in Daily Life Measure. Scored from 1 to 5 (higher score = more participation).	64.3	68.2		*	
PARTICIPATION IN SELF-CARE ACTIVITIES Child Engagement in Daily Life Measure. Scored from 1 to 5 (higher score = needs less help).	79.4	82.8		*	
OTHER:					

Supporting Your Child’s DEVELOPMENT

We encourage you to talk to your child’s therapist about how these results compare to your child’s daily performance in different settings at home, school, and in the community. Discuss how you can work together to support your child’s development.

NOTES:

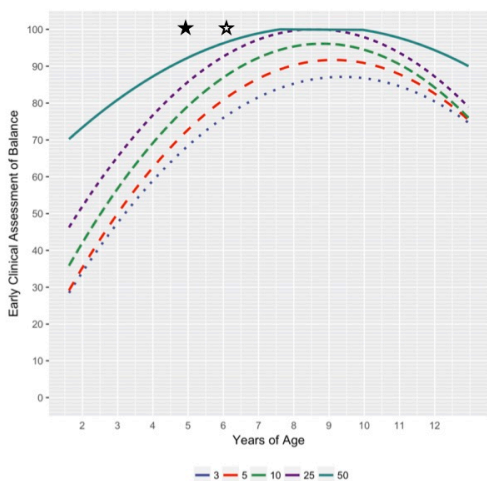
Mock-Up 3 – Percentile Graphs

GMFCS Level I

- ★ Most recent percentile
- ★ Past percentile

Balance

Early Clinical Assessment of Balance

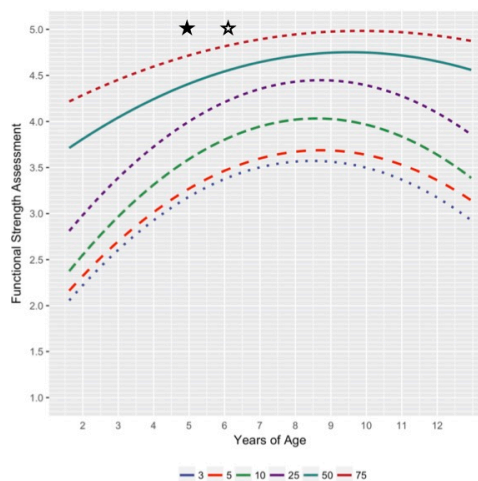


Doing Less than Expected	below -14 percentiles
Doing As Expected	in between
Doing More than Expected	above +20 percentiles

Difference between percentiles: 0

Strength

Functional Strength Assessment

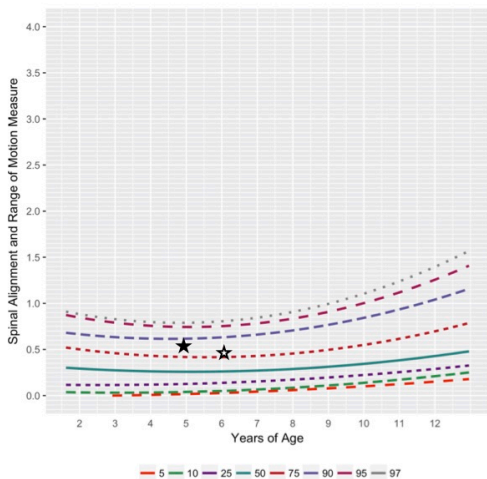


Doing Less than Expected	below -24 percentiles
Doing As Expected	in between
Doing More than Expected	above +30 percentiles

Difference between percentiles: 0

Range of Motion

Spinal Alignment and Range of Motion Measure

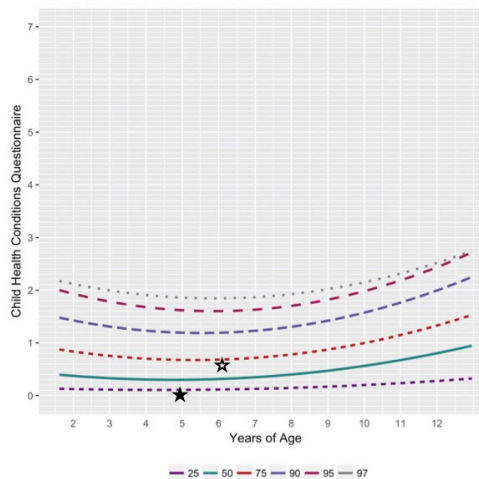


Doing Less than Expected	above +23 percentiles
Doing As Expected	in between
Doing More than Expected	below -31 percentiles

Difference between percentiles: -10

Overall Health

Child Health Conditions Questionnaire



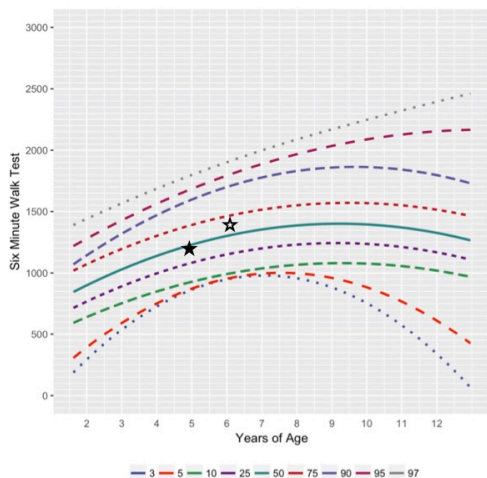
Doing Less than Expected	above +21 percentiles
Doing As Expected	in between
Doing More than Expected	below -27 percentiles

Difference between percentiles: +46

GMFCS Level I

Endurance

6-Minute Walk Test

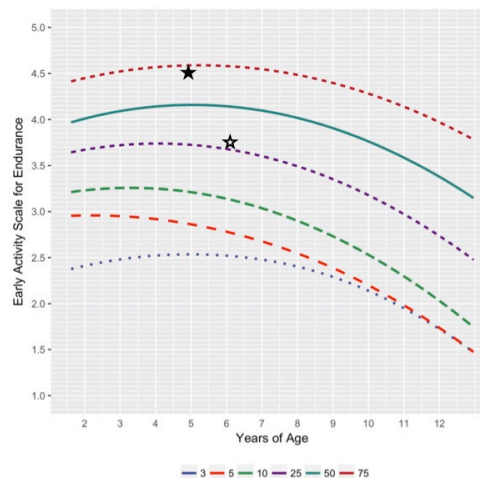


Doing Less than Expected	below -26 percentiles
Doing As Expected	in between
Doing More than Expected	above +28 percentiles

Difference between percentiles: +4

Endurance

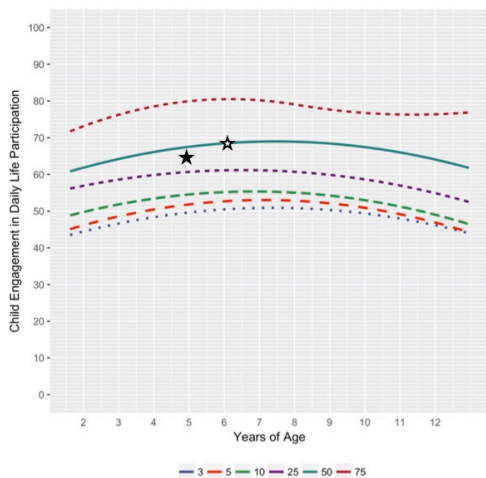
Early Activity Scale for Endurance



Doing Less than Expected	below -24 percentiles
Doing As Expected	in between
Doing More than Expected	above +36 percentiles

Difference between percentiles: -37

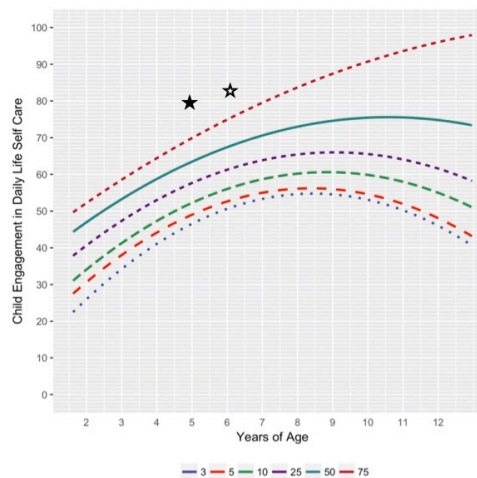
Participation in Family and Recreational Activities. Child Engagement in Daily Life Measure



Doing Less than Expected	below -23 percentiles
Doing As Expected	in between
Doing More than Expected	above +31 percentiles

Difference between percentiles: +10

Participation in Self-Care Activities. Child Engagement in Daily Life Measure



Doing Less than Expected	below -13 percentiles
Doing As Expected	in between
Doing More than Expected	above +37 percentiles

Difference between percentiles: -2

Curriculum Vitae

- Name:** Tianna D. B. Deluzio
- Post-secondary Education and Degrees:** The University of Western Ontario
London, Ontario, Canada
2011-2015 BHSc
- The University of Western Ontario
London, Ontario, Canada
2015-2017 MSc
- Honours and Awards:** Western Graduate Research Scholarship
2015-2017
- Queen Elizabeth II Aiming for the Top Tuition Scholarship
2011-2012
- Western University Scholarship of Excellence
2011-2012
- Related Work Experience:** Teaching Assistant
The University of Western Ontario
2016-2017
- Research Assistant
The University of Western Ontario
2016-2017
- Presentations:**
- Deluzio, T.,** Daya, A. & Bartlett, D. How do children with cerebral palsy and their families prefer to receive and use evidence-based information?
- Child Health Symposium, Arthur and Sonia Labatt Health Sciences Building
London, ON, May 26, 2017 [*Oral Presentation*]
 - Child Health Symposium, Thames Valley Children's Centre
London, ON, May 26, 2016 [*Oral Presentation*]
 - CanChild Family Engagement Day, Ron Joyce Children's Health Centre
Hamilton, ON, April 2, 2016 [*Poster Presentation*]
 - Faculty of Health Sciences Research Day, Western University
London, ON, March 22, 2016 [*Poster Presentation*]
- Daya, A. **Deluzio, T.** & Bartlett, D. How to facilitate the uptake of research evidence to optimize outcomes for children with cerebral palsy within the OACRS centres
- CanChild Family Engagement Day, Ron Joyce Children's Health Centre
Hamilton, ON, April 2, 2016 [*Poster Presentation*]
 - Faculty of Health Sciences Research Day, Western University
London, ON, March 22, 2016 [*Poster Presentation*]