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Using a Deliberative Dialogue to Facilitate the Uptake of Research Evidence in Rehabilitation for Children with Cerebral Palsy

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences

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Abstract

This study explores how to facilitate the use of research evidence to optimize outcomes for children with cerebral palsy (CP) in practice. Findings from two studies were used as the basis for exploring how to comprehensively assess developmental trajectories of children with CP and plan individualized interventions. Seventeen affiliated stakeholders (e.g. physicians, senior leadership, frontline clinicians, families and youth with CP) participated in this study.

Data from a deliberative dialogue and interviews were analyzed using grounded theory methods with a pragmatic perspective. The results highlighted that all areas of practice must engage in knowledge translation to be effective. Stakeholders outlined roles and responsibilities of actors within pediatric rehabilitation, including children and families, service providers and administrators and government representatives. Strategies for knowledge translation were considered among stakeholders and described in the results.

This study provides an evidence base to promote knowledge translation for these two studies and in pediatric rehabilitation.

Key Words:

cerebral palsy, knowledge translation, rehabilitation, pediatric rehabilitation, deliberative dialogue, evidence-informed, stakeholder roles

Dedication

I would like to dedicate this thesis to my sister, Alilah Daya.

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Foremost, I'd like to express my deepest gratitude to my supervisor, Doreen Bartlett, for her continual support and guidance throughout this (very iterative) process. It's been a true privilege and honor to work with you as your final graduate student. I am grateful for the time, dedication and support you continuously provided in every facet of my degree. I would also like to extend my gratitude to Drs. Deb Lucy and Jennifer Boyko for their guidance and support.

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My appreciation extends to my parents, Abrine and Karim, and to my sister Alilah. Your sacrifices and belief in me have propelled me to pursue a higher education and the opportunity to follow my dreams. Thank you, I hope I have made you proud.

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I am grateful and blessed to be able to carry my experiences completing this MSc in my future endeavors.

Table of Contents

| | |
|--|-------------|
| Abstract..... | i |
| Dedication | ii |
| Acknowledgements | iii |
| Table of Contents..... | iv |
| List of Tables | vii |
| List of Figures..... | viii |
| List of Appendices..... | ix |
| List of Terms and Abbreviations..... | x |
| Chapter 1: Introduction | 1 |
| 1.1 Evidence-Informed Practice | 1 |
| 1.2 Cerebral Palsy | 3 |
| 1.3 Move & PLAY Study..... | 4 |
| 1.4 OnTrack Study..... | 5 |
| 1.5 Ontario Association of Children’s Rehabilitation Services | 7 |
| 1.6 Knowledge Translation for Move & PLAY and On Track Studies..... | 8 |
| 1.7 Summary..... | 10 |
| Chapter 2: Literature Review..... | 11 |
| 2.1 Deliberative Dialogue..... | 11 |
| 2.1.1 Deliberative Dialogue as a Data Collection Strategy | 13 |
| 2.1.2 Deliberative Dialogue as a Knowledge Translation Strategy | 14 |
| 2.1.3 Use of Deliberative Dialogue in Health Research | 15 |
| 2.2 Key Features of a Deliberative Dialogue Approach | 16 |
| 2.2.1 Prior to Dialogue Activities | 16 |
| 2.2.2 During the Dialogue..... | 19 |
| 2.2.3 Post-Deliberative Dialogue Activities..... | 20 |
| 2.3 Summary..... | 20 |
| 2.4 Research Question and Purpose..... | 21 |
| Chapter 3: Methodology | 22 |
| 3.1 About the Author | 22 |
| 3.2 Grounded Theory Methodology | 23 |

| | |
|---|-----------|
| 3.3 Pragmatism..... | 25 |
| Chapter 4: Methods | 27 |
| 4.1 Planning Framework | 27 |
| 4.2 Study Sample: Deliberative Dialogue Participants..... | 30 |
| 4.3 Deliberative Dialogue Process/ Data Collection | 33 |
| 4.3.1 Prior to Dialogue Procedure | 33 |
| 4.3.2 During the Deliberation..... | 35 |
| 4.3.3 Post Deliberation..... | 36 |
| 4.4 Analysis | 37 |
| 4.4.1 Memo-ing..... | 37 |
| 4.4.2 Coding | 38 |
| 4.4.3 Constant Comparative Analysis | 38 |
| 4.4.4 De-briefing..... | 40 |
| 4.4.5 Authenticity and Credibility | 40 |
| 4.5 Ethical Consideration | 42 |
| Chapter 5: Results | 43 |
| 5.1 Interrelationship Among Stakeholders..... | 43 |
| 5.2 Roles of Stakeholders in Knowledge Translation | 46 |
| 5.2.1 Youth with Cerebral Palsy | 46 |
| 5.2.2 Parents and Families..... | 47 |
| 5.2.3 Children’s Treatment Centres..... | 49 |
| 5.2.4 Service Providers | 50 |
| 5.2.5 Service Managers/Administrators..... | 52 |
| 5.2.6 Government Policy Representatives | 53 |
| 5.2.7 Researchers..... | 54 |
| 5.3 Barriers in Knowledge Translation..... | 56 |
| 5.3.1 Lack of Time..... | 56 |
| 5.3.2 Limited Allocation of Resources..... | 56 |
| 5.3.3 Accessibility of Research | 57 |
| 5.3.4 Tension over Mandates..... | 58 |
| 5.4 Strategies to Implement Knowledge Translation..... | 60 |

| | |
|---|-----------|
| 5.5 Sustaining the Use of Research Evidence | 67 |
| Chapter 6: Discussion..... | 69 |
| 6.1 Emphasizing Roles and Responsibilities..... | 69 |
| 6.2 Overcoming Barriers | 73 |
| 6.3 Strategies to Implement Knowledge Translation..... | 74 |
| 6.4 Reflection on Deliberative Dialogue as a Data Collection Strategy | 77 |
| 6.5 Limitations..... | 79 |
| 6.6 Implications | 80 |
| 6.7 Future Work..... | 82 |
| 6.8 Conclusion | 83 |
| References..... | 85 |
| Appendices..... | 93 |
| Curriculum Vitae..... | 155 |

List of Tables

| | |
|--|----|
| 4-1 Planning Committee Meeting Proceedings | 29 |
| 4-2 Participant Categories..... | 32 |
| 5-2 Suggested KT Tools Emerged from the Dialogue | 61 |

List of Figures

| | |
|--|----|
| 3-1 The Grounded Theory Process, illustrated (Charmaz, 2014) | 24 |
| 4-1 Deliberative Dialogue Process, illustrated..... | 33 |
| 5-1 Bronfenbrenner’s Ecological Theory Adapted to this Study, illustrated..... | 45 |
| 6-1 Adapted Theory with Inserted Intersections..... | 70 |

List of Appendices

| | |
|--|-----|
| Appendix A: Review of Knowledge Translation Practices at the Clinical and System Levels of Cerebral Palsy Rehabilitation..... | 93 |
| Appendix B: Permission to use Figure 3-1: The grounded theory process, illustrated (Charmaz, 2014)..... | 108 |
| Appendix C: Research Team and Planning Committee Members..... | 109 |
| Appendix D: Deliberative Dialogue Agenda..... | 110 |
| Appendix E: Semi-Structured Interview Guide..... | 112 |
| Appendix F: Recruitment Emails..... | 114 |
| Appendix G: Letter of Information and Consent..... | 117 |
| Appendix H: Issue Brief..... | 124 |
| Appendix I: Deliberative Dialogue Summary | 145 |
| Appendix J: Ethics Approval..... | 154 |

List of Terms and Abbreviations

| | |
|------------------------|--|
| CanChild | CanChild Centre for Childhood Disability Research |
| CEOs | Chief Executive Officers |
| CP | Cerebral palsy |
| CTC | Children's Treatment Centres |
| GMFCS | Gross Motor Function Classification System |
| ICF | The International Classification of Functioning, Disability and Health |
| KTA | Knowledge-to-Action |
| Move & PLAY | Movement and Participant in Life Activities of Young Children |
| OnTrack | Developmental Trajectories of Impairments, Associated Health Conditions, and Participation of Children with Cerebral Palsy |
| OACRS | Ontario Association of Childhood Rehabilitation Services |
| WHO | World Health Organization |

Chapter 1: Introduction

In this chapter, I will provide an overview of the importance of evidence-informed practice within the rehabilitation sector. I outline this research study by defining cerebral palsy and describing the context of the work.

1.1 Evidence-Informed Practice

The terms “evidence-based practice” and “evidence-informed practice” are often used interchangeably, although they hold distinct definitions. It is central to recognize the difference between both practices in the context of this work, to better understand knowledge translation efforts. The original definition of evidence-*based* practice by Sackett and colleagues (1997 p.71), emphasizes the “conscientious, explicit and judicious use of current evidence in making decisions about care of individual patients”. Evidence-based practice has received a fair amount of criticism for not fully incorporating unique characteristics of patients and health providers, overlooking research flaws, making exaggerated claims about evidence and for requiring time, resources and supervision (Rubin, 2007). Furthermore, evidence-based practice may be difficult to implement due to the potential for outdated information of findings (Rubin, 2007). Evidence-*informed* practice is the awareness of integrating best research evidence with clinical expertise, patient values and needs in the delivery of appropriate care (Nevo & Slonim-Nevo, 2011).

The purpose of evidence-informed practice is to optimize positive patient outcomes based on research and experience collectively, rather than the precedence of research evidence

over other factors (Nevo & Slonim-Nevo, 2011). Evidence-informed practice is arguably more inclusive as it encourages clinician experiences, case-studies, empirical findings, narratives and patient values and contexts.

Healthcare decision-makers and administrators recognize the value of evidence-informed information for various reasons. Research evidence is expected to inform health care professionals and health service delivery personnel to more effectively and positively influence their practice and organization (Cameron, Russell, Rivard, Darrah, & Palisano, 2011; Glegg, 2010; King, Wright, & Russell, 2011; Menon, Korner-Bitensky, Kastner, McKibbin, & Straus, 2009). In fact, it is commonly understood that health care professionals have a responsibility to use evidence in practice to ensure their services are appropriate and safe (Cameron et al., 2011; Glegg, 2010; Menon et al., 2009). Although there has been a rapid expansion in the evidence base available to health service delivery personnel and clinicians, many challenges emerge in attempts to stimulate the uptake from research evidence into frontline care delivery (Graham et al., 2006; King et al., 2011; Novak, 2014).

In physical therapy, the use of research evidence influencing best practice has become increasingly important over the past two decades (Deville, McEwen, Arnold, Jones, & Zhao, 2015; Schleifer Taylor, Verrier, & Landry, 2014). Despite physical therapists having a positive attitude towards evidence-informed practice, the implementation of this evidence has proven to be quite complex. Literature suggests wide variations and gaps between research and practice in physical therapy service delivery (Deville et al., 2015), as healthcare professionals are not regularly accessing best practice evidence to guide

clinical decisions (Graham et al., 2006). Many studies have concluded that there is a need to increase the use of evidence-informed information in pediatric rehabilitation (Albrecht, Archibald, Snelgrove-Clarke, & Scott, 2015; Jones, Roop, Pohar, Albrecht, & Scott, 2015). In this context, this gap may negatively impact assessments and services provided to children with cerebral palsy who require individualized care.

1.2 Cerebral Palsy

Cerebral palsy (CP) is a non-progressive neurological condition that affects the infant or child brain and persists throughout one's lifespan. After many attempts to define the disability, an international consensus process described CP as: "a group of permanent disorders of the development of movement and posture causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication and behavior, by epilepsy, and by secondary musculoskeletal problems" (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007 p.9). Furthermore, the effects of CP are heterogeneous and are often manifested along with other comorbidities, making it a difficult disability to categorize and define. For example, CP can manifest itself alongside many impairments such as cognitive, speech, visual, hearing, epilepsy, gastrointestinal, growth, and more (Odding, Roebrock, & Stam, 2006).

Given that CP is the most common childhood physical disability, occurring in 2 to 3 per 1,000 live births (Odding et al., 2006), understanding how to implement best practice research into clinical settings is an important task (Sakzewski, Ziviani, & Boyd, 2014).

Due to the nature of CP, children must be considered on a case-by-case basis, thus requiring individualized care to accommodate their unique characteristics. As it stands, some evidence shows that outdated clinical care is being provided to children with CP (Novak, 2014). A two-fold gap exists within CP rehabilitation: 1) the need for rehabilitation practices to individualize care for each child with CP; and; 2) a lack of successful knowledge translation strategies to mobilize research evidence to facilitate best practice efforts.

Best practice promotes quality care delivery and is defined as the integration of evidence-informed information and clinical expertise (Russell et al., 2010). In pediatric physical therapy, best practice includes conducting examinations, evaluations and diagnosis, planning intervention and measuring overall outcomes of a child (Saleh et al., 2008). Rehabilitation efforts must incorporate all aspects of body function as well as activity, participation, personal factors and environmental factors. (Saleh et al., 2008). The context of this MSc thesis is facilitating the use of research evidence produced by two studies informed by the International Classification of Functioning, Disability and Health (ICF) created by the World Health Organization (WHO) (World Health Organization, 2002) which are described next. These studies respond to the first gap within CP: the need to provide individualized care to children and their families by painting a comprehensive picture of a child's unique characteristics and needs.

1.3 Move & PLAY Study

Move & PLAY (**M**ovement and **P**articipation in **L**ife Activities of **Y**oung Children with **C**erebral **P**alsy) (CanChild, 2016a) was a study that followed a large number of children

with CP (n= 429) in sites throughout Canada and the United States. The goal of the project was to understand the factors associated with motor function, self-care, participation and play of young preschool children. More specifically, the study assessed the effects of child factors, family ecology, and rehabilitation and recreation services on children's outcomes described in the previous sentence. Participants of this study were visited three times over the course of a year in which therapists assessed spasticity, quality of movement, balance, distribution of involvement, strength, range of motion, gross motor function and motor classification, as well as children's playfulness. Parents provided information about children's adaptive behavior, family functioning, services received, and children's participation in self-care and recreation and leisure. Study results confirmed how complex factors impacting the outcomes of young children with CP really are (Bartlett et al., 2014a, 2014b; Chiarello et al., 2016). Within its assessments, the study incorporates aspects of the ICF (World Health Organization, 2002) and encourages therapists to consider the child, family and environmental factors (including services) in their practice to provide context-based interventions for children with CP. The conceptual model tested in this study provides therapists and families with the realistic expectations associated with individualized goal setting and clarifies intervention needs for children with CP.

1.4 OnTrack Study

The OnTrack study (Developmental Trajectories of Impairments, Associated Health Conditions, and Participation of Children with Cerebral Palsy) (CanChild, 2016b) aims to describe changes in balance, range of motion, strength, endurance, number and impact of

health conditions, self-care and recreation and leisure in young children with CP aged eighteen months to eleven years. Some participants were carried on from the Move & PLAY study, while others were recruited from multiple sites within Canada and the United States. Therapists delivered assessments evaluating primary and secondary impairments such as balance, range of motion and strength. Parents were also included in this study by completing questionnaires regarding their children's endurance, health conditions, self-care and leisure at the same assessment periods as the therapists.

Researchers were able to assess a larger subsample of 524 families for a total of five times in six month intervals and an additional 199 families twice over one year. The data from this study describe for children with CP (1) average functioning on longitudinal growth curves at each of the five functional levels using the Gross Motor Function Classification System (GMFCS) (Palisano, Rosenbaum, Bartlett, & Livingston, 2008) (obtained with 5 data points) and (2) percentile curves to interpret individual children's progress (obtained with two data points) (per Hanna, Bartlett, Rivard, & Russell, 2008).

The ultimate goal of this program of research is to allow families and service providers to work collaboratively on decision-making for services for individual children that best fit families' individual goals. Move & PLAY offers information about a variety of factors that are associated with outcomes of motor function, self-care, participation in leisure and play for children in two functionally distinct groups: those who can walk independently without aides and those who require either a gait aide or a wheelchair for mobility.

OnTrack provides information to assist with interpretation about individual children's change over time. Together, these two studies provide a range of psychometrically sound

measures that are brief to administer to assess each child with CP comprehensively, understand unique determinants of selected activities and monitor change over a range of developmental domains to optimize service delivery and outcomes for individual children. The implementation of these two findings will be applied to the context of the Ontario Association of Children's Rehabilitation Services.

1.5 Ontario Association of Children's Rehabilitation Services

The Association of Treatment Centres of Ontario was officially incorporated in 1978 and renamed as the Ontario Association of Children's Rehabilitation Services (OACRS) in 1996 (OACRS, 2010). The association represents the interests of 21 Children's Treatment Centres (CTCs) around the province of Ontario by providing leadership and influencing the policy, programs and funding of each centre. Together, the CTCs provide therapy and other services to over 65,000 children with physical, developmental and communication needs (OACRS, 2010). Children and youth served at CTCs have a broad range of developmental limitations such as autism, muscular dystrophy, developmental delay and CP. Offered services range from physiotherapy, occupational therapy, social work, seating services and recreation therapy to other medical services (OACRS, 2010).

The OACRS centres were selected for this project due to aligning goals between the association and motivation behind the Move and PLAY and OnTrack studies. Such motivations include a commitment to provide comprehensive family-centered services, appreciation of the unique differences of all children and families and the willingness to optimize potential in the youth they serve (OACRS, 2010). In their mission statement, OACRS states that its members strive to influence public policy, to advance provincial

partnerships and to pursue excellence, innovation and accountability to support change. Governance at OACRS includes a board of directors, a leadership council, an OACRS secretariat and a family advisory council (OACRS, 2010). Given that OACRS represents 21 child health centres around the province of Ontario, this project has the potential to be disseminated to a very large population of children with CP.

1.6 Knowledge Translation for Move & PLAY and On Track Studies

Given the culmination of the final OnTrack study and the completion of the Move & PLAY study, the next step is to understand how to encourage the uptake of this research evidence and accompanying tools to reach wide and consistent use within rehabilitation centres around Ontario. The tools and products produced in the Move & PLAY and On Track studies are an appropriate means to explore the overall research question to mobilize these study results into practice. To achieve the goal of improving rehabilitation efforts for children and youth living with CP through these products, their use in practice must be implemented. This process, commonly referred to as ‘knowledge translation’, has been defined as “the exchange, synthesis and ethically-sound application of knowledge – within a complex system of interactions among researchers and users – to accelerate the capture of the benefits of research” (Government of Canada, 2005). The purpose of knowledge translation efforts is ultimately to enable knowledge creation to be used in practice to reach the people or purpose it was intended for. Knowledge translation is known to be complex within the healthcare field, given the pace of innovation and research combined with other multifaceted realities of health systems (Oborn, Barrett, &

Racko, 2013). A more extensive Knowledge Translation Literature Review is contained in *Appendix A*.

Graham and colleagues (2006) have developed the Knowledge-to-Action (KTA) process to provide clarity of the complex process of mobilizing evidence into practice. The framework highlights key elements that are believed to assist in navigating this process. Once knowledge has been created through inquiry, synthesis and products/tools, it is subject to the action-cycle, which is the application phase of knowledge translation.

As outlined in the KTA model by Graham et al. (2006), the action process must adapt to local knowledge and assess barriers to knowledge use. Furthermore, the action cycle must intentionally involve stakeholders and tailor knowledge for those for whom it is intended (Graham et al., 2006). The phases of the KTA process are dynamic in nature and may overlap and influence one another in a non-linear fashion.

More specifically, the action phase contains the following non-linear steps: identification of the problem, adapting to local context, assessing barriers to knowledge use, selecting, tailoring and implementing interventions, monitoring knowledge use and finally sustaining knowledge use (Graham et al., 2006). Applying the KTA framework to the context of this research, ‘knowledge creation’ has been produced through both the Move and PLAY and On Track studies. This study investigates some aspects of the action phase cycle including identifying the problem, assessing barriers and suggesting potential implementation interventions.

1.7 Summary

Given that motor development for children with CP can be manifested to varying degrees, it is problematic to assume correlation patterns between measures across children. CP must be considered on a case-by-case basis as should each child's developmental abilities and progress. Products from the Move & PLAY and OnTrack studies address this need and promote individualized care to suit the needs, abilities and goals of children with CP and their families. The overall purpose of the project presented in this thesis is to understand how to facilitate the uptake of research evidence into practice, while also contributing to the knowledge translation literature. A deliberative dialogue was used as a method of data collection in this research and is discussed in detail in the following chapter.

Chapter 2: Literature Review

In this chapter, I discuss the use of deliberative dialogue as a data collection strategy to gather various perspectives in CP to inform knowledge translation efforts for both studies (Move & PLAY and On Track) mentioned in the previous chapter.

2.1 Deliberative Dialogue

Deliberative dialogues have been previously used in public policy, environmental science and international relations for the purpose of understanding a topic and exploring implementation considerations (Boyko, Lavis & Dobbins, 2014). Health systems are complex in nature, involving the interactions of many relationships, roles, administrative bodies and inherent organizational structures. Plamondon, Bottorff, and Cole (2015) explain how ‘relational nature’ is central to human existence and knowledge and thus critical to implementations within health systems. Plamondon et al. (2015) state: “We understand relationality to be a stance of being intentionally attuned to the interdependent nature of connections between people, ideas, organizations, bodies of knowledge and contexts” (pp. 3). By focusing on learning-centered strategies that empower relationality, we may overcome structural silos and obstacles to catalyze systematic change (Plamondon et al., 2015). Deliberative dialogue is a type of relational activity in which individuals with different perspectives concerning a common topic convene to engage in a conversation regarding a particular issue (Boyko, Lavis, Abelson, Dobbins, & Carter, 2012). Combined perspectives and contextual understanding of the topic improves our capacity to move along the KTA process (as discussed in Chapter 1) (Plamondon et al., 2015).

The strategy does not follow a one-size fits all approach; however, recent research has explored key features within the health systems context. Invitees of a deliberative dialogue are purposefully and strategically chosen to include all perspectives of a particular topic, to engage people who naturally have something to say and to include people who are influencers within the particular topic field (Moat, Lavis, Clancy, El-Jardali, & Pantoja, 2014). Given that these individuals have a distinct investment or connection to the matter, they are commonly referred to as ‘stakeholders’.

Deliberative dialogues provide a platform for stakeholders who may not have an opportunity to engage in cross-disciplinary discussions, to learn from one another in a safe and confidential environment. The purpose of a deliberative dialogue is to brainstorm about a current topic by exploring associated challenges and opportunities (Lavis, Boyko, & Gauvin, 2014). Deliberations are not to be mistaken as ‘debates’. In debates there are ‘winners and losers’, whereas in a deliberative dialogue there are upsides and downsides to each and every perspective (Lavis et al., 2014). All situations, ideas and solutions are included as a part of the conversation. A deliberative dialogue is different from a debate, as the goal is not to end with a general consensus or to reach an ultimate conclusion (although this may naturally emerge). Rather, it is an initiative to stimulate innovative thinking among researchers, stakeholders and policy makers (Lavis et al., 2014). Deliberative dialogue is a pragmatic approach to initiating a conversation around a challenging topic that may be seen differently by various stakeholders. Recently, deliberative dialogue has been explored as both a data collections strategy as well as a knowledge translation strategy.

2.1.1 Deliberative Dialogue as a Data Collection Strategy

In their study examining the mobilization of family violence evidence into public health and practice, Boyko, Kothari and Wathen (2016) investigated the experience, usefulness and emerging themes of a deliberative dialogue conducted specific to this topic. The results were favorable, claiming that participants anticipated using the knowledge shared at the deliberation. After interviewing deliberation participants, authors of the paper concluded that deliberative dialogues may be a meaningful way for ‘collaborative sense making’ (Boyko et al., 2016). This ‘sense making’ refers to the importance of an individual’s understanding of a particular issue as a stepping stone in the progression of new ideas and interventions (Boyko et al., 2016).

In their knowledge translation article exploring the notion of analyzing data generated through deliberative dialogues, Plamondon et al. (2015) highlight the advantages of deliberative dialogues as a data collection strategy. Authors characterize this use as ‘compelling’ due its collaborative approach to bring together: “a group of informed, knowledgeable, and experienced people who can lend their deep tacit knowledge to the contemplation of evidence as it related to action” (Plamondon et al., 2015; pp. 1537). Tacit knowledge refers to knowledge that is developed through an individual’s experiences in a particular position and may be more difficult to communicate in written form compared to explicit knowledge (Kothari, Hovanec, Hastie & Sibbald, 2011). Applying such value on tacit knowledge from stakeholders involved in the topic facilitates the progression of action-oriented health research to ultimately integrate this knowledge into practice. For

the purpose of this study, a focus was set on deliberative dialogue used mainly as a data collection strategy to inform knowledge translation understanding and efforts.

2.1.2 Deliberative Dialogue as a Knowledge Translation Strategy

In itself, deliberative dialogue is a form of knowledge translation due to its nature of convening stakeholders from all perspectives and enabling the distribution and sharing of information among them. By engaging in conversation, participants are able to share and absorb tacit knowledge from one another and are given the opportunity to consult explicit knowledge from background documents (to be discussed in this Chapter). Participants may potentially feel empowered and return to their daily context and reflect or apply information that was shared at the dialogue, thus beginning the process of knowledge mobilization (Boyko et al., 2012). This process aligns directly with the very definition of knowledge translation of relaying information to the people and impact for which it is intended (Government of Canada, 2005).

A process entitled ‘capacity building’ influences intended effects of a dialogue that may be categorized into three interrelated groups: short-term individual-level, medium-term organizational-level and long-term system-level (Boyko et al., 2012). The process is reflective of a deliberative dialogue used as a knowledge translation strategy and is formed by the inclusion of appropriate a stakeholder mix, the Chatham House Rule and accessible evidence (Boyko et al., 2012). Further description of these pre, during, and post-deliberative activities are contained in 2.2.

In the short term, the effects include heightening personal capacities to tackle the issue at hand, fostering mutual understanding and empowerment, gaining insight into the various perspectives surrounding a common issue and cultivating relationships among a variety of stakeholders (Boyko et al., 2012). In the medium term, or at the community / organizational level, intended effects include strengthening community and organizational capacity, promoting the ability to develop policy options and encouraging actions when a relevant policy window regarding the topic opens (Boyko et al., 2012). Finally, in the long term, deliberative dialogue is intended to strengthen “system-capacity to make evidence-informed decisions” (Boyko et al., 2012, p.1940, Figure 1). Approaching expected effects with a pragmatic lens, in this study I strive to initiate capacity building at the individual level as a first step towards evidence-informed decision-making.

2.1.3 Use of Deliberative Dialogue in Health Research

Literature suggests that deliberative dialogues have the ability to address three main factors that influence the use of research in health policymaking. These factors include interactions between researchers and policymakers, timeliness of information and communication between various stakeholders regarding beliefs, values and interests (Lavis et al., 2014). Such facilitations are made possible through providing an opportunity for researchers and policy members to interact with one another. Fostering such relationships can propagate mutual understanding among stakeholders who may lack the opportunity to discuss relevant health topics in an environment conducive to ‘boundary-crossing dialogue’ (Boyko et al., 2012). Through this interaction, participants

gain new perspectives, share their views and are empowered to cultivate needed change in their distinct areas of practice (Boyko et al., 2012). Fostering empowerment is a fundamental aspect of a deliberative dialogue, as stakeholders often overcome their sense of ‘powerlessness’ (Boyko et al., 2012) and are more inclined to take action towards a common goal. Due to the existing realities of knowledge mobilization within health systems, this type of empowerment is critical to implementation efforts. Although this particular example is related to health policymaking, it is significant in the context of this study as the implementation of research evidence into a provincial association such as OACRS will also be influenced by structural and political similarities.

2.2 Key Features of a Deliberative Dialogue Approach

Deliberative dialogues do not follow a rigid structure as they are adaptable to the context in which they are used. However, there are some characteristics that are constant in a large portion of deliberative dialogue proceedings. The deliberative dialogue approach constitutes of actions pre-dialogue, during the dialogue and post-dialogue.

2.2.1 Prior to Dialogue Activities

2.2.1.1 Planning Committee and Preparatory Documents.

Various bodies of literature have alluded to the use of planning or ‘steering’ committees to prepare for the deliberative dialogue. This committee is generally comprised of a mix of relevant stakeholders who may assist in confirming adequate representation among stakeholders, sending out invitations, and informing how the discussion can cater to all diverse participants (Lavis, Boyko, Oxman, Lewin & Fretheim, 2010). The planning

committee may also play a role in approving preparatory documents often distributed prior to the dialogue. Such documents outline research evidence providing background information about the issues to be discussed. The document may also contain a list of topics to be examined to ensure that important materials have already been grasped and acknowledged by the participants (Lavis et al., 2010).

2.2.1.2 Arranging an Appropriate Meeting Environment

In a study outlining deliberative dialogue as a mechanism for knowledge translation and exchange in the health system, key features of this process were highlighted (Boyko et al., 2012). First is the importance of an appropriate meeting environment that is conducive to engaging in dialogue. Some of these examples include: appropriate materials (e.g., paper, note pads), structure of the event in terms of time, appropriate venue and facility, technical requirements and evaluation (Boyko et al., 2012). Notably, the most important aspect of an appropriate meeting environment is fostering trust and participants' confidence to speak up (Boyko et al., 2012).

2.2.1.3 Inviting a Mix of Stakeholders

Ensuring that a mix of relevant stakeholders are engaged throughout the deliberative dialogue process is another way to successfully execute this method for data collection. Boyko et al. (2012) state that participants must reflect relevant interests and must represent their perspectives in a balanced manner. Once the meeting environment is conducive to open deliberation, and relevant stakeholders are in attendance, the discussion must effectively address the current situation of the issue at hand. Evidence

must be accessible for all participants to better understand the topic, in order to better engage in dialogue (Boyko et al., 2012).

Other relevant aspects of deliberative dialogue include participants who are committed to valuing knowledge and working together to address challenges, transparency regarding the motives behind the discussion (e.g. for government or institution) and how the topic fits into a larger political agenda. Deliberative dialogues may consist of various participant group sizes, ranging from 5 to 10 or 20 to 30 contributors (Boyko et al., 2012). There are mixed opinions regarding which group size to select. For example, it is easier to include every participant's perspective in the discussion within a smaller group of individuals. However, some argue that smaller groups may not include the essential diversity in stakeholders, whereas a larger group will less frequently engage all participants, but potentially generate more novel ideas (Boyko et al., 2012).

2.2.1.4 Preparatory Documents

Past deliberative dialogues have included the distribution of documents that could potentially enhance the experience of stakeholders at the dialogue. Such documents have previously included evidence briefs, issue briefs, or any other background materials to set the stage for the topic to be discussed (Boyko et al., 2014). Furthermore, 'preparatory documents' can include any informative document that keeps the participation of stakeholders as transparent as possible, in order to maintain a safe and open environment for collaboration (Boyko et al., 2014).

2.2.2 During the Dialogue

2.2.2.1 Supporting Transparent Dialogue

Often mentioned in relation to deliberative dialogues is the ‘Chatham House Rule’. This ‘rule’ is a practice often associated to successful involvement within local governments, commercial organizations and research organizations (Chatham House, 2016). The Chatham House Rule declares that participants are free to use the information received at the event, with the agreement that neither the identity nor the affiliation of a speaker will be disclosed (Chatham House, 2016). Additionally, specific comments are not to be linked to a particular stakeholder (Chatham House, 2016). This rule is also often mentioned in studies employing deliberative dialogues (Boyko et al., 2014; Lavis et al., 2014; Lavis et al., 2010). Given that the goal at a deliberative dialogue is engaging in meaningful discussion, the rule assists participants in openly voicing their honest perspectives and opinions at the event.

2.2.2.2 Engaging an Effective Facilitator

Discussion topics and engagement from participants are moderated during the event by a facilitator. According to Boyko et al. (2012, p.1491), a good facilitator displays the following characteristics: “skilled, knowledgeable and neutral”. The main goal of the facilitator is to ensure structure and to foster mutual understanding and innovative thinking. Other duties include being attentive to the conversation, piecing together aspects of the issue and ensuring that all participants are involved in the discussion (Boyko et al., 2012). It is also suggested that the selected facilitator is knowledgeable

about the subject as well as its political situation, in order to successfully interpret and guide the conversation. It is imperative that the facilitator remain neutral, refrain from offering their own ideas and stray clear of influencing the discussion to any extent (Boyko et al., 2012).

2.2.3 Post-Deliberative Dialogue Activities

Certain tasks carried out after the deliberative dialogue help to create footprint of the discussion and provide opportunity for further input. This is a time in which organizers should consider the conversion of the discussion into a written format (e.g. posting the summary described above online) for participants to review and provide feedback and to highlight and initiate further actions (Boyko et al., 2012). Post-deliberation activities from past studies have comprised further data collection through interviews outlining personal insights drawn from the event, a publicly accessible dialogue summary, personalized briefings to stakeholder groups or updates on new literature concerning the topic (Boyko et al., 2012).

2.3 Summary

Overall, deliberative dialogue is a promising approach that can be used to gather information about, understand and take action on complex health issues. One such issue is moving research findings related to CP into practice given varying stakeholder perspectives within the fields of CP and pediatric rehabilitation. It allows for boundary-crossing dialogue to exchange ideas and initiate preliminary ideas toward common interests and goals.

2.4 Research Question and Purpose

The question to be addressed in this thesis was as follows: How can we facilitate the use of research evidence, such as that produced by the Move & PLAY and On Track studies, in services offered through the Ontario Association of Children's Rehabilitation Services Centres to optimize outcomes of individual children with cerebral palsy? In this study, all steps of the deliberative dialogue process formed the data to be analyzed to further understand how to facilitate knowledge translation within this sector of the health system. Specifically, a deliberative dialogue was planned and executed as a data collection strategy and sources of data collected included meeting summaries, fields notes and interviews.

Chapter 3: Methodology

In this section, I describe the position and personal stance of the primary investigator of this study. I also provide general information about grounded theory methodology, the constructivist perspective and pragmatism.

3.1 About the Author

As a Bachelor of Health Sciences graduate, I have a keen interest in optimization and innovation within the health stream. Knowledge translation is currently at the forefront of healthcare and gaining popularity as researchers discover that publishing evidence is no longer the final step to impacting practice outcomes (Rosenbaum, 2005). As the OnTrack study is wrapping up, this knowledge translation project was a timely opportunity to combine my interests to form an exciting study. Cerebral palsy (CP) is a disability that is close to my heart, as my younger sister was diagnosed with CP, epilepsy and developmental delay from a young age. My personal experiences have sparked my commitment to positively contribute to the field of CP, specifically, and pediatric rehabilitation, in general.

A strength I carry is that I do not currently hold a clinical background, therefore I do not hold any preconceived notions about the way services are presently delivered in pediatric rehabilitation. I bring a novel perspective to this topic, with an open mind. Furthermore, from a methodological perspective, I would situate myself as a constructivist grounded theorist (Charmaz, 2006). From a pragmatic standpoint, I desire balance between what I

wish to impact and the true outcomes of this project. My ontological position works well with the methodologies I have chosen to guide this research.

The opportunity to pursue a master's degree while combining my interests and personal curiosities have made me very excited for this study. I was able to bring a fresh perspective to the discussion as a new non-clinician researcher and my familiarity with CP granted me with a compassionate outlook as the sibling of a child with a disability. My lived experiences enabled me to be realistic about the true outcomes of this study and inspired me to produce quality work for the field of pediatric disability, rehabilitation and knowledge translation.

3.2 Grounded Theory Methodology

Grounded theory has informed the methodological choices and assessments made throughout this project. Charmaz (2014) described grounded theory as a method consisting of systematic guidelines that are flexible in gathering and interpreting qualitative data. The research is grounded in the data, meaning that constructed ideas emerge mainly from the data itself. This methodology is inductive in nature and requires iterative steps between data and investigation, as the analysis emerges. The theory interprets *how* participants explain statements and *how* they explain their actions (Charmaz, 2014). Given that grounded theory often answers questions pertaining to *how*, the researcher has no preconceived concepts to 'prove' or 'disprove' (Mills, Bonner, & Francis, 2006). The grounded theory process is illustrated in Figure 3-1.

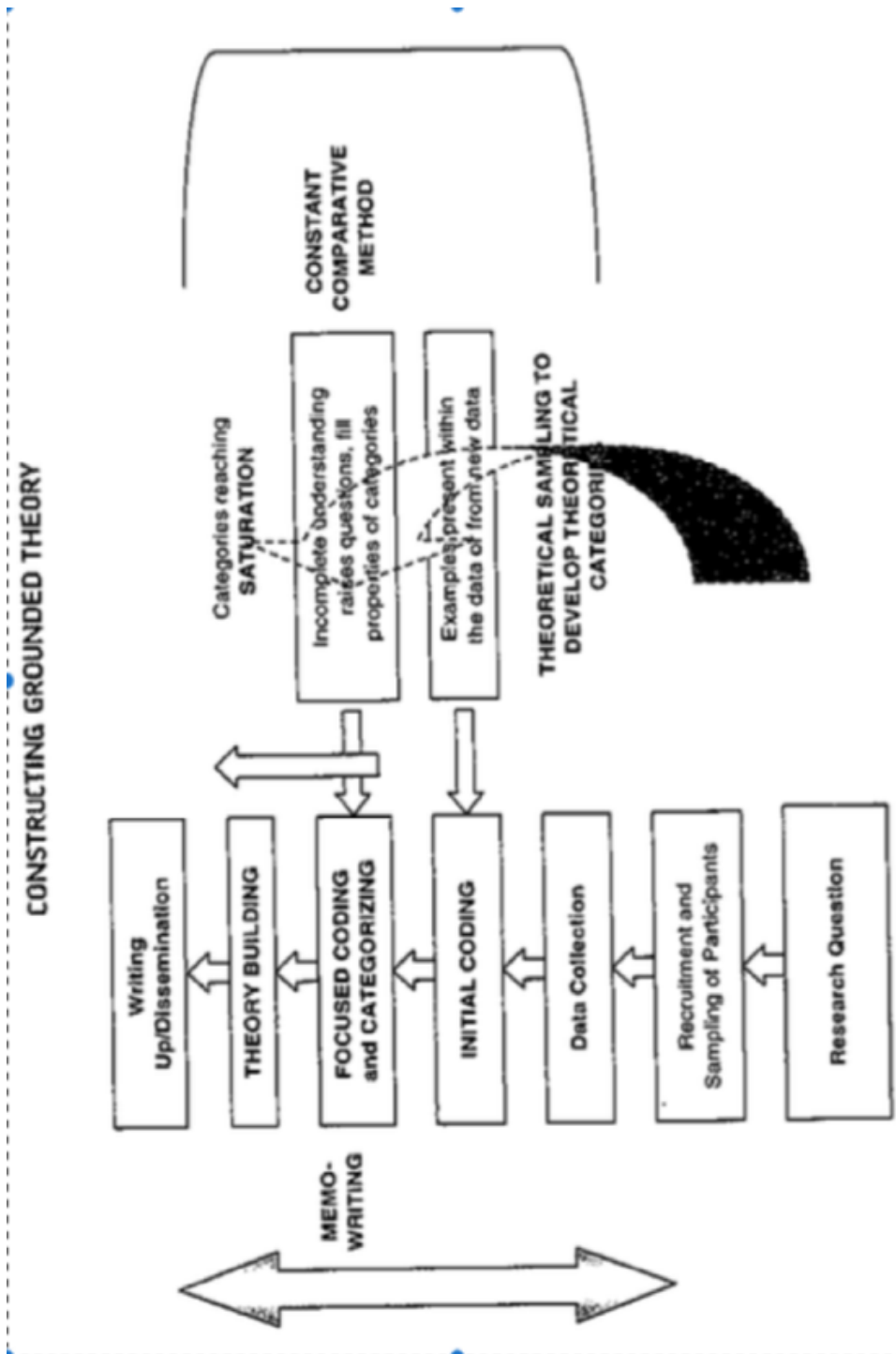


Figure 3-1: The grounded theory process, illustrated (Charmaz, 2014). (Reproduced with permission, *Appendix B*).

Findings are gathered through what researchers hear, see and sense during their data collection. Observations, interactions, interviews and documents are often used by grounded theorists, however given the flexibility of grounded theory, researchers bring an open attitude and approach to the study (Charmaz, 2014). To constructive grounded theorists, social interactions, sharing perspectives and interpretive understanding are highly valued in research (Charmaz, 2014). Constructivism rejects the existence of an objective reality, and rather accentuates multiple individual realities influenced by context (Mills et al., 2006).

Grounded theory is consistent with the individual realities that exist within CP rehabilitation. As discussed in Chapter 1, CP is highly heterogeneous and each child and family must be considered individually. This research involved numerous stakeholders within the OACRS centres from families, youth with CP, policymakers, service providers and administrators, who each experience different realities within the context of pediatric rehabilitation. Given that this research considers complex realities, a pragmatic lens was applied to the research to ensure practicality and feasibility of the study. Suitably for this work, deliberative dialogue as a method for data collection is also consistent with the grounded theory methodology, as the goal of deliberative dialogue is to enhance one's understanding of a particular topic through the examination of multiple perspectives (Charmaz, 2014; Lavis et al., 2014; Plamondon et al., 2015).

3.3 Pragmatism

Pragmatism acknowledges the practical consequences of reality with the intention of discovering 'truth' in the solutions of the problems faced in clinical practice (Shaw,

Connelly, & Zecevic, 2010). This emerging research paradigm rejects strict knowledge criteria and is more concerned about finding all possible ‘truths’. The flexible nature of this paradigm enables the researcher to consider all possible avenues for obtaining and analyzing data (Shaw et al., 2010). Most importantly, pragmatism is an appealing choice for practical research as it is often grounded in realistic expectations and considers the realities of the ‘real-world’.

Chapter 4: Methods

In this section, I outline the methods that were used to plan and implement the deliberative dialogue. More specifically, I provide a detailed description of the context of the study, the study sample, and the qualitative, exploratory methods for data collection and techniques for data analysis based on grounded theory and pragmatism.

4.1 Planning Framework

As described in Chapter 2, the purpose of a planning committee presents the opportunity to consider multiple perspectives to appropriately shape the deliberative dialogue. The planning committee fits into the larger picture of ensuring a thorough and comprehensive design for the dialogue. A planning committee was strategically chosen to reflect varied perspectives concerned with knowledge translation and CP. Committee members' unique perspectives guided the content and structure of the half-day deliberative dialogue that took place on November 18, 2016. Three one hour-long meetings were held in the six months prior to the half-day deliberation. Two of these meetings were conducted prior to submitting details for ethics approval.

Planning for the deliberative dialogue and this thesis also included the assembly of a Research Team consisting of the primary investigator, an MSc Student Collaborator, the Thesis Supervisor, a Deliberative Dialogue Consultant and an MSc Thesis Advisor. The Research Team worked closely with the primary investigator and were involved with preliminary concepts and drafts. The planning group was formed of some members of the Research Team in conjunction with stakeholders holding the following titles: Best

Practice Committee member of OACRS, Physical Therapy Professionals, OnTrack Parent Collaborator, OnTrack Assessor, OnTrack Coordinator and Research and Knowledge Exchange Consultant (who was also the facilitator for the deliberative dialogue). For a list of names and titles of Research Team members and planning committee members please see *Appendix C*. Some invitees held several positions and brought multiple perspectives to planning the discussion. Committee members were chosen due to their affiliation with either the OnTrack study, OACRS or having a vested interest in methodologies chosen to guide this research. This notion of a planning committee is consistent with steering committees formed prior to organizing a deliberative dialogue, as explained in the literature. Importantly, this planning team did not solely act as a consulting body to the research, but rather played a large role in shaping the deliberative dialogue. Meeting memos from the committee meetings were later consulted as a source of data for analysis.

In the first planning meeting we refined and approved the research questions for the deliberative dialogue. The roles of each member of the planning committee were elucidated and an overview of deliberative dialogue was explained to the participants. This meeting also provided an opportunity for participants to discuss and rank which stakeholders should be invited to the deliberative dialogue to ensure that an appropriate mix of stakeholders would be represented. Furthermore, a draft agenda was generated at this meeting and dates for the subsequent planning group meetings were chosen. Tentative dates for the deliberative dialogue were discussed and an Issue Brief was distributed at the end of this first meeting for planning members to reflect upon at the

following meeting. The purpose and characteristics of this Issue Brief will be discussed further in 4.4.1.2.

At the second meeting, participants reviewed the Issue Brief and provided their feedback on necessary changes. This meeting also focused on refining the agenda for the day of the deliberative dialogue (e.g. how to start the conversation regarding CP and knowledge translation; please see *Appendix D* for the Deliberative Dialogue Agenda) and finalized the list of participants to contact for the deliberation, as well as narrowing tentative dates to 2 or 3 possibilities. The final task for the second meeting was to review and approve the semi-structured telephone interview guide (contained in *Appendix E*) that was used after the deliberative dialogue. A third meeting consisted of refinements and planning logistics for the day of the dialogue. Subsequently, all potential participants were contacted through email (contained in *Appendix F*). Signed consent forms were collected on the day of the deliberative dialogue. Letter of Information and Consent are contained in *Appendix G*. These proceedings are summarized in table 4-1.

Table 4-1: Planning Committee Meeting Proceedings

| | |
|--|--|
| <p>Planning Committee Meeting 1 Objectives</p> | <ul style="list-style-type: none"> • Discuss and agree on each member's role within the planning committee • Refine and approve the research questions for the deliberative dialogue • Describe and discuss the deliberative dialogue • Discuss and rank potential stakeholders to explore appropriateness of stakeholder mix • Generate draft agenda ideas |
|--|--|

| | |
|---|---|
| | <ul style="list-style-type: none"> • Choose subsequent planning committee dates • Discuss tentative deliberative dialogue dates • Circulate draft Issue Brief after the meeting |
| Planning Committee Meeting 2 Objectives | <ul style="list-style-type: none"> • Review and provide feedback on Issue Brief • Refine deliberative dialogue agenda • Finalize a list of participants to contact for the deliberative dialogue • Review and approve a semi-structured telephone interview guide |
| Planning Committee Meeting 3 Objectives | <ul style="list-style-type: none"> • Discuss and refine logistics of the deliberative dialogue |

4.2 Study Sample: Deliberative Dialogue Participants

The deliberative dialogue provided a space and an opportunity for relevant stakeholders in research, pediatric rehabilitation and CP to come together and discuss knowledge uptake with one another. Targeted participants were mobilizers within pediatric rehabilitation including: young adults with CP, family members, physical and occupational therapists, physicians, professional practice leaders (OACRS), best practice committee member (OACRS), chair of clinical services committee, Chief Executive Officers (CEOs) of individual CTCs, the CEO of OACRS, a representative from the Ministry of Child and Youth Services, and clinical researchers. Up to eighteen stakeholders were invited to the half-day deliberative dialogue held at CanChild Centre for Childhood Disability Research (*CanChild*) affiliated with McMaster University in

Hamilton, Ontario on November 18th 2016. The *CanChild* venue is recognized for meetings among pediatric rehabilitation stakeholders.

A total of seventeen stakeholders (n=17) participated in the deliberative dialogue with all participants completing the semi-structured telephone interview subsequent to the dialogue (100% participation). The number of participants (n= 17) provided the study with an appropriate diversity of stakeholders while also remaining small enough to ensure all voices were heard. Participants included young adults with CP (n=3), family members of children and young adults with CP (n=3), ministry policy representatives (n=2), service providers (n=3), service managers (n=3), a service administrator (n=1), and healthcare or clinical researchers (n=2). It is important to note that most participants possessed more than one relevant perspective in their professional and private lives. In addition to the six primary categories, participants self-identified with the following perspectives that they believed impacted their perceptions towards CP and were reflected in their overall contribution in this study:

- knowledge translation professional
- government representatives with experience as a former clinician
- former social worker
- planning committee member
- young adult with cerebral palsy who worked with youth with cerebral palsy
- parent of young adult with cerebral palsy who had a longstanding commitment to the OnTrack study and a member of the planning committee
- clinician with a sibling with a disability
- principal investigator of the OnTrack study
- longstanding clinical researcher specializing in CP

- clinician services supervisor for children with disability with background in health administration
- policy representative working closely with communities

To protect the confidentiality of participants, stakeholders have been grouped and will be referred to with respect to the associations in the table below. Participants have been grouped in one of six broad categories listed above as their primary perspective related to CP.

Table 4-2: Participant Categories

| Participant # | Primary Perspective Reflected at the Dialogue |
|----------------------|--|
| Participant 1-3 | Young adults with CP |
| Participant 4-6 | Family members of children/young adults with CP |
| Participant 7-9 | Service providers |
| Participant 10-12 | Service managers |
| Participant 13 | Service administrator |
| Participant 14-15 | Ministry policy representatives |
| Participant 16-17 | Healthcare/clinical researchers |

4.3 Deliberative Dialogue Process/ Data Collection

For clarity, below is a visual representation of key activities carried out throughout the entire deliberative dialogue process.

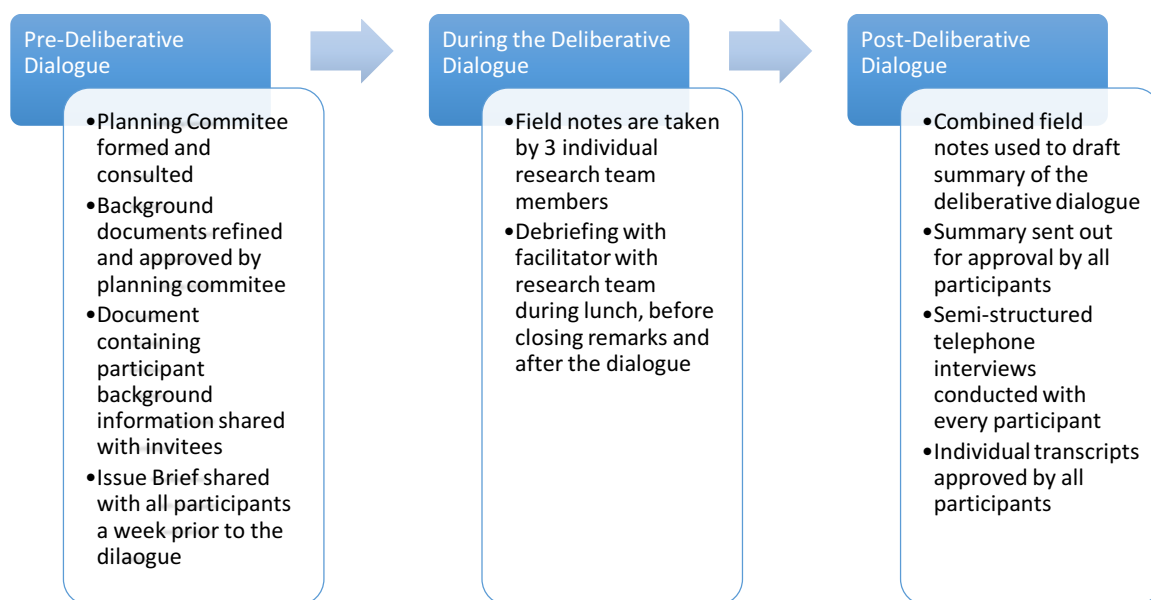


Figure 4-1: Deliberative Dialogue Process, illustrated.

4.3.1 Prior to Dialogue Procedure

4.3.1.1 Background information on participants

To ensure transparency, a document was shared with confirmed participants outlining which other stakeholders would be in attendance on the day of the deliberative dialogue. The document outlined the first and last name of every confirmed participant, along with the role/perspective they held in relation to the topic of pediatric rehabilitation. Providing this transparency to invitees ensured that there were no surprises on the day of the

dialogue, with intentions of fostering a safe environment where all participants felt comfortable expressing their opinions.

4.3.1.2 Issue Brief

A week prior to the deliberative dialogue, an Issue Brief was finalized by core members of the planning committee and distributed to participating stakeholders to outline background information regarding the Move & PLAY and the OnTrack studies (Issue Brief contained in *Appendix H*). Issue Briefs are a fairly new method of synthesizing research (Moat et al., 2014). This document typically contains information to clarify the main problem, outline what is known about the topic to date, specify opportunities to addressing the problem and highlight significant considerations pertaining to the topic (Moat et al., 2014). More specifically, this study's Issue Brief characterized: (a) why optimizing care for children with CP is of high priority within the OACRS centres, (b) why rehabilitation planning for children with CP is challenging for service providers, (c) an overview of the products of both the Move & PLAY and OnTrack studies and (d) the overarching questions to be discussed at the deliberative dialogue.

As expressed in the literature, information documents are typically used as primary inputs for deliberative dialogues and are meant to facilitate interactions among contributors across disciplines participating in the discussion (Moat et al., 2014). A study regarding the perceptions of briefs and deliberative dialogues found that briefs as an input into a deliberative dialogue were greatly favored by policy-makers, stakeholders and researchers (Moat et al., 2014). Notably, the use of Issue Briefs is consistent with

recommendations for successful deliberative dialogue outcomes as explained in Chapter 3.

4.3.2 During the Deliberation

4.3.2.1 Proposed Meeting Environment

The room in which the deliberative dialogue took place was a meeting-style room that was intimate and designed for collaboration (e.g., customizable layout, U-shaped set-up). Furthermore, the location was central for participants travelling from London, Toronto and from within Hamilton. As recommended in the literature, a facilitator with an understanding of both knowledge translation and CP holding no bias towards Move & PLAY, OnTrack or this research study was chosen to guide the conversation. Consistent with the Chatham House Rule and the candid nature of deliberative dialogue, no video filming or audiotaping was permitted in the venue, to ensure that participants felt comfortable vocalizing their experiences and opinions (Chatham House, 2016). Additionally, this ensured that the privacy of those participating was protected and further encouraged honest contributions.

The deliberative dialogue followed the structure outlined in the approved agenda, while remaining flexible enough to accommodate emerging topics related to the overarching questions. Time-stamped field notes were taken by both MSc students and the OnTrack Project Coordinator and were later used in the production of the dialogue summary. Interestingly, both additional note takers share significant life experiences with either a best friend or a child with a diagnosis of CP. The primary researcher, MSc Student

Collaborator, Thesis Supervisor, OnTrack Project Coordinator and the OnTrack Parent Collaborator debriefed with the Research and Knowledge Exchange Consultant and Facilitator and the Deliberative Dialogue Consultant at the end of the day of the dialogue to gain some insight into their observations and perspectives.

4.3.3 Post Deliberation

4.3.3.1 Summary of Deliberative Dialogue

This discussion, along with the combination of all three sets of field notes, formed the basis of the draft summary of the deliberative dialogue. The summary was reviewed by the Research Team within a week of the event and then circulated to all participating members for review, feedback and approval. This summary contained in *Appendix I* was an output of the deliberative dialogue to provide participants with an overview of the proceedings they were instrumental in achieving. The approved summary was used in conjunction with fields notes from the day of the dialogue towards analysis.

4.3.3.2 Telephone Interviews

Post-deliberation interviews were held with each participant individually over the telephone. Interviews were held 21 to 30 days after the deliberative dialogue to ensure that participants had sufficient time to reflect on the discussion but before too much time had passed. The interviews were semi-structured and evaluated participants' perceptions regarding the discussion, as well as knowledge translation and best practices in CP pediatric rehabilitation. The allocated time for these interviews were 60 to 90 minutes. Charmaz (2006) recommended that novice researchers use an interview guide to increase

confidence and avoid derailment of the interview. Consistent with grounded theory, the interview approach included open-ended questions, non-judgmental questions and encouraged unanticipated testimonies (*Appendix E*). Through this approach, the interview elicited perspectives from each participant's subjective experiences as he or she reflected on the topic from the deliberative dialogue. All participants were sent their transcribed interview for approval of content and were given the opportunity to delete any part of their interview, if necessary, before analysis.

4.4 Analysis

The activities described above formed the data collection aspect of this research.

Consistent with the methodology of constructivist grounded theory, collected data were separated, sorted and synthesized through memo-ing, qualitative coding, constant comparative analysis and debriefing with the thesis supervisor (Charmaz, 2014).

Considerations for authenticity and credibility were also described.

4.4.1 Memo-ing

According to Charmaz (2006), analytic notes, also known as memos, are a pivotal step between data collection and analysis in grounded theory. Memos are used to track and guide a researcher's emerging ideas through the data. More specifically, memos can illustrate a researcher's thought processes, explicate analytic notes, discover categories and build comparisons between data sets and other codes. Thus, the practice of memo writing was administered during and after meetings (Research Team planning committee

meetings and meetings with the thesis supervisor), during and after data collection, during and after interviews and during data analysis.

4.4.2 Coding

Described as a ‘discovery’ phase, coding in grounded theory aims to uncover the meaning of the data (Charmaz, 2006). Data collected from the deliberative dialogue and post-deliberation interviews were sorted and coded. Labels were placed on different themes as they emerged, raising further analytic inquiries. Similar emerging themes were sorted together improving quality of the data and providing a basis for precise comparisons (Charmaz, 2006). Analytics notes, as discussed above, provided greater insight into what aspects of the data should be explored next (Charmaz, 2014). Consistent with grounded theory, coding numerous comparisons heightened the understanding and analytic grasp of the data (Charmaz, 2006). Along with coding the data, constant comparative analysis is a common approach used to discovering themes and implications and is described next.

4.4.3 Constant Comparative Analysis

Constant comparative analysis is a common technique used in grounded theory (Charmaz, 2006). This method is often used as a way of coding for theoretical meaning, rather than simply ‘sorting’. First, the researcher begins with initial coding, a process by which collected data are classified with data of similar meaning. The next step, focused coding, is the process of exploring the most common codes from the initial coding phase to subsequently refine the analysis (Charmaz, 2014). A comparison approach was taken

when analyzing data from the deliberative dialogue against individual post-deliberation interviews. The process was iterative, meaning data sets were revisited on multiple occasions to further refine and construct the analysis. Finally, this technique sparked critical and analytic questions further stimulating the emergence of new themes.

According to Charmaz (2006), researchers can compare data to data to foster comparisons at each level of analysis. Greater detail of the analysis is described next.

I began by reviewing field notes from the deliberative dialogue and the dialogue summary to pull out themes raised from the discussion. I reviewed each interview transcript question by question, comparing responses to one another to establish an overview of each main question. I sorted and coded participant responses by question and then by emerging themes. I asked myself what role does each stakeholder in the relevant system play in facilitating the uptake of research evidence in clinical practice. I pooled together responses for each of these levels of influence, outlining major themes that emerged with respect to each stakeholder role.

Once roles were established, I reviewed the deliberative dialogue field notes, dialogue summary and interview transcripts to sort and code the barriers that stakeholders faced when attempting to implement change within practice. I then repeated the same process to sort and code for recommended strategies to inform ways in which we may overcome aforementioned barriers and create change and sustain use. Presenting the content of these topics in tables and through a figure allows the reader to understand the proximity of stakeholders in relation to the child with CP while also being a constant reminder that many areas of practice require engagement in order to implement change.

4.4.4 De-briefing

The primary researcher had the opportunity to debrief the Research Team regarding the notes taken and observations made during data collection. Additionally, debriefing occurred with the facilitator of the deliberation immediately after the deliberative dialogue which stimulated novel themes or observations. Finally, ongoing debriefing was held with the thesis supervisor as the analysis proceeded.

4.4.5 Authenticity and Credibility

Authenticity and credibility was promoted in various ways throughout the entire project. Authenticity was promoted through member reflecting during the deliberative dialogue by the facilitator and again during post-deliberation telephone interviews. The term 'member reflecting' is a process that is pragmatic in nature as it accommodates the belief that multiple realities do exist (Tracy, 2010). This means that the researcher ensured that the interpretations made in the study were consistent with the views of the participants. This not only allows the researcher to be reflexive, but also ensures that the analysis is authentic and thus meaningful for the participants (Tracy, 2010). Participants had the opportunity to reflect on the summary that was distributed to them after the deliberation and before the phone interviews, to ensure that the data were consistent with what they intended to convey.

Credibility was promoted through time-stamped memos transcribed by three individuals during the deliberative dialogue who were knowledgeable about the study: the primary researcher, the MSc Student Collaborator and the OnTrack Project Coordinator. This

helped to ensure that the data analysis was soundly-based. Finally, extensive time allocated to post-deliberation interviews reflecting on the summary and adding further comments regarding the discussion topic as well as debriefing with participants, researchers and the facilitator supplemented the credibility of the study.

4.4.5.1 Rigor and Reflexivity

Given that all deliberative dialogue decisions were shaped in collaboration with the planning group, the structure of the deliberation was extensively mapped out. Forming these steps with the perspectives of many stakeholders in different positions and ensured that the deliberative dialogue was thorough and critically reflective of the needs of all dialogue invitees. On the day of the data collection, the primary researcher, an MSc Student Collaborator and the OnTrack Project Coordinator took time-stamped notes to document information and statements disclosed as the deliberation unfolded, without identifying stakeholders to their comments. Having three individuals who are familiar with the study and conscious of relevant information ensured that field notes were rigorous. These field notes were generated as part of the data collection for this study and were used to construct a summary of the deliberative dialogue. Furthermore, all researchers collecting field notes brought different perspectives to what they chose to include in the data collection, ultimately increasing the potential to grasp distinct key themes. Observers were as neutral as possible and captured statements while being mindful of the context in which they were stated (Charmaz, 2014).

Intended reflexivity to promote authenticity of this research was acknowledged and promoted throughout the study. The researcher's values, experience, knowledge and

postulations were described in Chapter 3 (3.1), to ensure transparency of the researcher's position. Reflexivity was continued throughout the entire project through dated memos, member reflecting and tracking of the researcher's assumptions and co-creation of research findings. Memos included reflections on emerging themes, approaches, changes and rationales regarding the planning, data collection and the analysis process.

4.5 Ethical Consideration

This proposal was approved by the Health Sciences Ethical Review Board (HSRB) at Western University responsible for ensuring compliance of studies involving human participants prior to implementing this research. The planning group met twice prior to ethics submission to ensure that all ethical bases had been discussed and were well designed. The HSRB ethics approval is contained in *Appendix J* which includes approval of *Appendices D, E, F, G and H*.

Chapter 5: Results

Themes that emerged in the constant comparative analysis can be grouped in terms of interrelationship among stakeholders, roles and responsibilities of stakeholders, barriers to KT, strategies to implement KT and sustaining use of research evidence. A model illustrating the first theme is described next.

5.1 Interrelationship Among Stakeholders

Given the use of a deliberative dialogue strategy, the intention of bringing together various stakeholders with diverse backgrounds was inherent in the design of the project. Through the data, it became clear that every stakeholder position plays a distinct, collaborative and significant role in knowledge translation. This idea is exemplified succinctly in the following quote by Participant 7:

“So that was great, the diversity, because I think that’s what it’s going to come down to, that a lot of people have to change, not just one person or one area of practice”.

This particular notion sparked a realization that the results benefit from being viewed as layers of roles and responsibilities within a system of interacting and dynamic components. The results of the deliberative dialogue and post-dialogue interviews are modeled after Bronfenbrenner’s (1979) theory regarding the ecology of human development (in particular the study of infant development), in which he describes an ecological environment as ‘a set of nested structures, each inside the next, like a set of Russian dolls’ (pp. 3).

Bronfenbrenner's ecological system's theory conceptualizes a child's influential environment into different levels. In a simplified manner, the theory portrays the microsystem as the infant's immediate environment, relationships and organizations such as their immediate family or classroom. The next level, the exosystem, describes other people or places that influence the child such as extended family or the neighbourhood in which they reside. Finally, the macrosystem comprises a more remote set of people or organizations that have an eventual influence on the infant's development and wellbeing, this can include cultural values or governmental structures (Bronfenbrenner, 1979).

These layers are interconnected systems that share a reciprocal relationship such that behaviors ultimately, positively or negatively, affect one another. It is imperative to note that layers of influence surrounding the child represent proximity to child's environment and not levels of importance or growing influence.

Parallels have been drawn between Bronfenbrenner's theory and a lens through which we consider supporting children with disabilities, by acknowledging one's surrounding environment as a contributing factor to their capabilities (Skelton & Rosenbaum, 2010).

Bronfenbrenner's theory also reflects many aspects of the WHO's ICF framework with respect to multiple factors interacting with one another to influence an individual's reality and potential outcome (Skelton & Rosenbaum, 2010).

Similarly, Bronfenbrenner's ecological system's theory parallels the health system's complex layers which ultimately influence a child's service provision and overall wellbeing. In this context, I recreated this theory by inserting a child with CP at the centre of the framework, surrounded by relative layers of proximity. Levels of stakeholders are

separated by dotted lines to signify their interrelationship with one another. The focus remains with the child at the centre, whose context and individuality influences all stakeholder groups. All actors in turn influence behaviors among each other, ultimately affecting the child. Stakeholder levels range as follows (in order of proximity) to the child: parents and families, service providers, service managers, service administrators and ministry policy representatives. Figure 5-1 is a recreation of Bronfenbrenner's theory in the context of a child with CP.

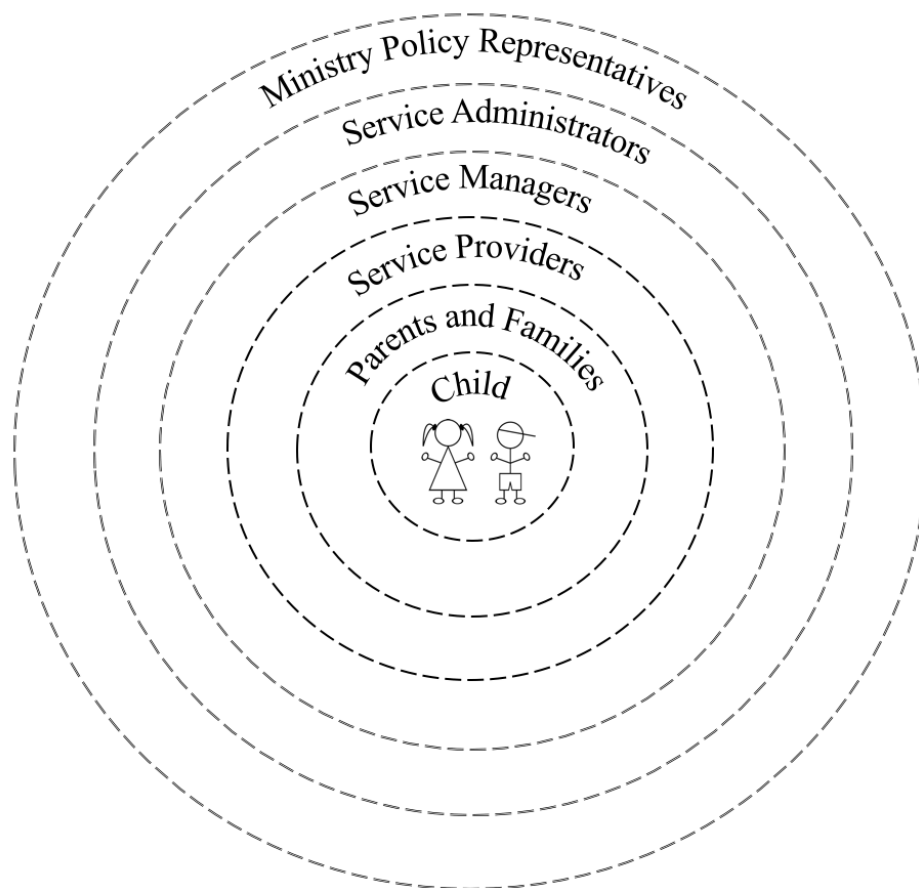


Figure 5-1: Bronfenbrenner's Ecological Theory Adapted to this Study, illustrated.

In this diagram, the child with CP is placed at the centre, surrounded by layers of influences that form his or her unique realities. Specifically, each child is surrounded by outer layers declining in proximity to their environment, including: parents and family members, service providers, service managers, service administrators and finally the government. The data from the research conducted for this thesis has uncovered that knowledge translation in rehabilitation requires a shared effort by all stakeholders working towards best practice outcomes. We must focus our attention on how each level, organization or area of practice can play a role in facilitating the uptake of research evidence into clinical practice. Researchers were not added to the figure as primary stakeholders because they are often creators of the knowledge to be considered. Their position in KT however is equally important and will be discussed in this chapter and the next.

5.2 Roles of Stakeholders in Knowledge Translation

5.2.1 Youth with Cerebral Palsy

As previously described, the child with CP is placed in the centre circle, influencing and influenced by the behaviors and interactions of and between all external circles.

Depending on their age and capacity to communicate, youth with CP can play a role in engaging in their own assessments and interventions. Able individuals with CP can advocate for their causes to help bridge the gap and champion the use of research evidence into their care. One participant shared:

“If we can get children and parents to understand what’s offered and if they see a value in it, then it’s actually the families themselves that can be the biggest advocates for sustaining use”. - Participant 17

Youth also have a role in participating in research and in being a part of the execution stage of implementing research. Child experiences have the potential to place pressure upon clinicians to look into more research and apply it to their practice. One participant discussed their experience with a service provider:

“The best physiotherapists I think I’ve ever had are the ones who would joke around with me and would allow me to see any sort of document or notes that they’d make about me in my later life. And that transparency of information was really big and I cannot stress it enough”. - Participant 3

Initiating interest and further probing about assessments and care plans is a step towards ensuring that youth themselves have a voice in the conversation. Youth who are able to, are encouraged to ask questions, get involved and remain engaged throughout all services they receive.

5.2.2 Parents and Families

As mentioned in the child group, parents also play a large and influential role in the use of evidence-informed practice by exercising advocacy for their children with CP. There is an inequity within CP that may be addressed in the same way autism groups have contested for awareness and action. Participant 11 shared the following example:

“You’ve got a very vocal group of parents who have kids with autism, but the parents of kids who have Cerebral Palsy are just trying to get through the day”.

In fact, autism has gained momentum through advocacy, even reaching policy efforts towards better recognition and care. The following quote by Participant 12 exemplifies this notion:

“Autism recently has been a good example—how there [are] competing pressures in a policy division to respond from a political perspective, respond to what they’re hearing on the ground from children and families, and develop solid policy that will make a difference on the ground for all families”.

By accessing resources available to them such as educational workshops and by referring to the *CanChild* website for information and updated research, parents can advocate for their children with CP. Knowledge translation can be facilitated through fostering relationships, a notion that parallels the following comment made by Participant 3:

“...advocates are one of the greatest allies for fostering relationships”.

Fostering relationships by connecting with other families has also been demonstrated to be an effective way in which parents can share and gain information regarding new evidence and possibilities for their own children. Ultimately, it can be very powerful for parents to probe, push and ask questions in order to stimulate change within clinicians.

5.2.3 Children's Treatment Centres

Before elaborating on the roles of service providers, managers and administrators, it is important to acknowledge the context in which they work, specifically the CTCs and OACRS.

Participants expressed that a culture that encourages and expects people to ask questions is a way in which knowledge translation efforts can be successful. Commonly associated to individual CTCs was the notion of instilling a cultural shift within centres towards making this a possibility. Participant 13 shared in reference to CTCs:

“I do strongly believe, if it's not in people's performance plans, they're probably not going to pay as much attention to it as if it is [...] so I think it needs to be valued all the way up the chain, at the supervisory level and then the higher levels as well, it needs to be part of the culture of an organization [...] if your boss two levels up isn't focused on what's the most up to date evidence, chances are you won't be either”.

Many participants expressed that frontline care workers have limited ability to instill this culture on their own and the capacity to participate in KT endeavors would have to be mandated from above, as *“something that is part of your practice”* (Participant 7).

Furthermore, the organization has a responsibility to ensure that their staff are confident in their ability to search and share new evidence relevant to their practice. Another way in which CTCs can play a role in KT, is by demonstrating and sharing the ways in which they provide excellent care to families and communities. Sharing this type of information

with other CTCs and at conferences and talks allows other centres to learn from what is already working in similar settings.

Given that OACRS advocates for individual CTCs, the association can promote a culture shift within individual centres by advising and ensuring that KT endeavors are shared across centres. In addition, OACRS can play a supporting role in KT implementation activities. Participant 9 shared:

“And hopefully through OACRS if we’re given more emails and you know, new research that’s out there, then hopefully that’ll motivate clinicians to make changes in their practice”.

OACRS must also establish trusting relationships between organizations who live and breathe research such as *CanChild* and continue to work on projects with researchers. The association can also play a role in building bridges between individual centres and facilitate CTCs’ responsibilities of sharing information and KT strategies, by hosting research days and representing the sector.

5.2.4 Service Providers

Service providers must play a role of educating themselves and their clients regarding new research evidence as it emerges. They must see the need for change and adopt appropriate changes in their own practice. Participant 7 shared:

“I think it just... it may come down to the personal clinician, they need to be on board and to be motivated to look and not just get stuck on the same

thing and to look at new research and what's working and that's not working and not just doing the same thing if it's not working”.

Meeting with other service providers and touching base with their colleagues as new research emerges will make this new knowledge more accessible to all parties.

Taking this a step further, a service provider's role is also to get new ideas into the hands of parents, and to be helpful in understanding and helping families. Participant 16 shared:

“As a clinician I want to be up to date and I want to know I'm doing the right thing. But I shouldn't be so proud that I ignore parents who come along who have an equal and in fact a stronger reason to be up to date with what's going on because they have a child with this. I'm just a professional”.

In order to truly remain family centered, service providers must ask what child and family members need and actually listen and respond to their concerns. Participant 16 continued:

“Help them frame their issues in ways that are helpful to them, try to help them address their questions their ways instead of being as prescriptive as we traditionally have been”.

This can be done in various ways, including directing families to other resources such as workshops and articles, and engaging everyone involved as much as possible—whether it be the parent or the child. Participant 6 shared their personal experience:

“I think a lot of the times as doctors and clinicians and what not if they are in a family atmosphere, they'll talk to the parents like the child or youth's

not even in the room and I think that's totally wrong, I think they have to engage with them right from the beginning as well and acknowledge that they are in the room and are an important part of the puzzle".

Building genuine relationships with clients must be continuous and built on trust that can strengthen practice and empower children and families. Service providers can also play a role in empowering clients and families by connecting willing families who share similar experiences to one another. By doing so, service providers present families with the opportunity to connect with each other and share knowledge and advocacy possibilities, so that they too can engage in mobilizing evidence and change.

5.2.5 Service Managers/Administrators

At the managerial/administrative level, stakeholders must be aware of how to search for novel evidence to inform frontline care workers. Participant 11 shared:

"I think at our level we need to be very informed on how to search for evidence, how to aggregate the evidence and how to inform practice through evidence. And I think... I hope that that's going on at other organizations".

This group must stay informed about new evidence but also understand and consider how clinical practice is structured and ways in which information can be easily relayed and implemented in a practical way. Participant 14 explained this in the following quote:

"If we could build things into our clinicians' every day routines and their sessions that they're already having with their families and add one thing at a time, I think that'll really make a difference versus telling them they have

to change everything that they're doing [...] I want to emphasize that we have to give our clinicians time. If we're expecting them to do this kind of stuff we have to build that time into what they're doing because you know I think the best thing is you do the research and you have this wonderful launch of a new care path or best practice or whatever, but the implementation phase of that is never honored."

Understanding clinicians' routines and concerns and only making necessary changes based on practical ways in which to accommodate these concerns are integral. Therefore, being present and aware of how behavior and organizational structures influence expectations and overall culture could assist in instilling a change.

5.2.6 Government Policy Representatives

Although there is an existing expectation for the government to use best practice evidence, there must be awareness and concrete recognition of the realities frontline care workers face in practice. Participant 8 shared:

"At a government and organizational level there needs to be recognition that this is a changing field and that people need time, and structure, and infrastructure to support new learning".

In practice, people need time to have productive discussions with colleagues and to keep up with new knowledge, therefore unwritten expectations are simply not enough on their own. Clinicians and service providers must be given time to actually read, learn and

integrate best practices and not just assume that they will do that on top of their existing workload. As Participant 3 illustrated:

“Policy itself needs to be as malleable as the world around it and as the lives of persons with disabilities and CP around it”.

Furthermore, policy must remain genuine as it endeavors to protect and serve youth with CP; the more genuine policy is, the more palatable it becomes to advocates and activists.

5.2.7 Researchers

A common concern related to research is the notion of comprehensibility and the bottom line of research evidence. If the goal of research is to ultimately stimulate change in order to benefit a population, all parties involved in the change must easily access and understand the bottom line. Researchers, similar to government personnel, must consider the realities of clinicians and other frontline care workers and present research evidence in more digestible ways. Participant 16 shared:

“If the researchers were doing a good job of providing an overview of their research and a two or three-page plain language bottom line summaries of things, then clinicians would at least know what research is showing”.

Often mentioned during the discussion was the notion of packaging materials in an understandable format, catering to all relevant parties. Participant 16 continued:

“But what’s particularly important [...] is that if you hear ideas that you like you have a responsibility, we have a responsibility to share these ideas with people who don’t yet know them [...] that includes parents, fellow clinicians, program managers, policy makers and so on [...] and think about

packaging the things we're finding that are clinically relevant in ways that are made actively accessible to families”.

Researchers have the responsibility of sharing their findings with relevant stakeholders, including accessibility and comprehensibility to families. In order to be accessible, the research must not contain jargon and engage families and youth in a creative way.

Another responsibility relevant to researchers is engaging families in research that is relevant to them. Asking those to whom the research impacts to help design the questions will ensure that the results are useful for them. By doing so, researchers can ensure authentic inclusion to benefit children and families, with meaningful and perpetual opportunities to share their experiences and perspectives. This way, families are engaged with the development of research on a continual basis and not solely the receivers of research outcomes. Participant 3 described this best,

“Because clinicians are people, policies are often fueled by emotion, if you can generate that emotion within research because it is so true and it is such a good idea, then we'll allow research to flow more fluidly into practice without as much of a fight or struggle for those who support it”.

Finally, when approaching research that touches on decision making or expanding and changing a service, researchers have the responsibility of investigating how such a change will benefit families. In order to maximize their impact, researchers need to understand how and if this change aligns with the current government agenda.

5.3 Barriers in Knowledge Translation

Given the intention of remaining pragmatic, we must recognize that the health care system in which cross-level interactions occur is multifaceted and complex; therefore, barriers to knowledge translation do emerge. In this research such barriers included: lack of time, limited allocation of resources, inaccessibility to research, and tension over mandates.

5.3.1 Lack of Time

A common challenge faced by various frontline care workers is the impression of not having enough time to complete all expected duties. Setting priorities is a way in which health providers address this concern. In such instances, seeing clients and families and completing reports take precedence over searching for emerging research evidence. Clinicians feel tied in such circumstances, as they have many clients to see and feel as though they are limited in time.

5.3.2 Limited Allocation of Resources

It is important to consider that individual CTCs serve youth with a myriad of different health conditions, not solely youth with CP. One must consider that resources are allocated throughout all OACRS centres. One participant pointed out that most CTCs actually see a smaller percentage of children with CP in comparison to other health conditions. This parallels advocacy matters previously mentioned in this chapter. Participant 13 stated:

“This group of people are really under the radar [...] They’ve been under the radar for many many years and I think we could be doing a lot better with this population. I mean, I can’t even imagine if somebody with cerebral palsy had 21 hours of intervention a week to work on their communication and social skills, what would that look like?”.

Although this may be a barrier when considering resources, Participant 13 emphasized that although the population may be small, they are still entitled to quality care:

“But as a manager I want to make sure that four percent is getting exactly what they should be getting and they’re getting consistent services and they’re getting the best service, and they’re getting evidence based service”.

Finding a way to ensure youth with CP are receiving best practice services, despite representing only a small percentage of clients served through OACRS, is a challenge and an important consideration in potential solutions.

5.3.3 Accessibility of Research

Commonly addressed in the dialogue and subsequent telephone interviews were concerns surrounding the accessibility of research information as a valuable resource for educating families as well as health professionals. Service providers expressed a major challenge in finding and using evidence-informed information was the lack of access to online research databases. Only service providers working through a centre with links or a liaison to a University Hospital had access to such databases, leaving out a number of professionals working outside of Universities and within the community.

Families and youth who are not involved in University organizations also lack access to online research databases. Most consultations made with research evidence are made through general google searches or referencing abstracts of potentially relevant articles.

Participant 5 shared:

“It’s a hit or miss. We will ask our medical personnel for recommendations but sometimes if you are looking at a certain topic it’s difficult to know how valid it is and to actually know if it’s a good site to visit. If it is a more accessible site that we knew, or something that really validated, I think that would be helpful.”

The problem with this remains that there is a lack of accessibility to research for people who it is meant to reach. Families and children may not be consulting peer-reviewed and legitimate forms of information which may present an additional barrier that families find it difficult to evaluate whether evidence is credible or not.

5.3.4 Tension over Mandates

There is an evident struggle between stakeholder groups to agree upon appropriate regulations throughout CTCs. Health professionals look towards centres to provide structure allowing them to have built in time for knowledge mobilizing activities outside of their scheduled routines of seeing clients. However, centres receive funding from the Ministry based on certain goals and requirements to be met. Ministry representatives operate by setting general guidelines based on relevant evidence, and leave the specifics to the professionals at individual CTCs to sort out. Participant 13 shared:

“When policy guidelines come out from any ministry, whether its health or [the Ministry of Children and Youth Services], or whatever ministry it is, policy direction from a ministry will give some outlines and expectations and guidelines for agencies in terms of what ministries expect to see happen. But there is always a recognition that there’s room for interpretation, number one, and room for individual agencies to also consider what they know about the community in which they work. So we may expect you to implement a multidisciplinary assessment, but that being said we’re not going to dictate that it must be these six types of professionals.”

On the other hand, is the belief that OACRS should take the lead on mandates and guidelines. As explained by Participant 14:

“I think it [strategies for change] needs to go to a provincial organization like OACRS who can have everybody sitting at the table from all of the CTCs and have a working group that actually includes some front line people that can say yeah, that’s definitely doable when we’re meeting these standards and these documentation standards, and this is what my week looks like, yeah I can definitely do that, but here is how we would need it to happen. Actually get front line involved in some of those conversations rather than always having it come from a management or Ministry level.”

The role of the Ministry is to contract with individual CTCs that must comply with the guidelines of providing the most up to date, relevant and appropriate services. It is

expected that CTCs will comply with general standards and requirements appropriate to each individual CTC based on their particular context.

From the Ministry's perspective, this mandate should be set through each CTC's accreditation requirements. Ministry representatives can promote knowledge translation and evidence-informed practice; however, they cannot mandate which evidence or research should be implemented. Given their position and minimal exposure to the execution of clinical practice, they are careful in their approach to not heavily set or interfere with mandates.

“So we're going to tell you that you must use evidence-based practice, but we're not clinicians, so we expect that you as a service provider do your research based on your discipline and know what those evidence-based approaches are” (Participant 13).

In reality, some CTCs may experience less financial flexibility in practice.

Participants shared that there may be limited choice to dictate how funds are spread across centres and departments.

5.4 Strategies to Implement Knowledge Translation

The deliberative dialogue provided a productive environment in which stakeholders discussed knowledge translation strategies to address the gap in researching, relaying and applying best practice evidence. Most ideas for strategies were generated at the deliberative dialogue and some were revisited during the telephone interviews.

Table 5-2 provides a list of potential strategies for knowledge translation separated in 3 categories: general tools for knowledge translation, strength-based strategies, and strategies to move evidence into practice. General tools for knowledge translation include methods to communicate research evidence to various stakeholders. Strength-based strategies utilize the strengths of different stakeholder groups to empower them towards change. Finally, strategies to move evidence into practice are ways in which we can understand and consider KT tools. Each suggested tool/suggestion is described in more detail in the following pages.

Table 5-2: Suggested KT Tools Emerged from the Dialogue

| <u>General Tools for Knowledge Translation</u> | <u>Strength-Based Tools</u> | <u>Strategies to Move Evidence into Practice</u> |
|---|------------------------------------|---|
| Archived Webinars | Social Media and Marketing | Creating Educational Opportunities |
| Knowledge Translation Summaries | Culture Shift and Services | Focus on <i>CanChild</i> Efforts |
| Research Positions | Engage Families and Youth | Knowledge Brokering |
| Collaborative Endeavors | Encourage Advocacy | Communication Efforts Targets Towards Young People |
| Connect with Parents Using Facebook Groups | Clinical services education | Efforts Geared to Clinicians |

Archived webinars: Webinars are online learning tools for service providers as well as parents to gain knowledge about a topic relevant to them. These tools are economical and

can be accessed at the user's preferred time and location, and at their own pace. For professionals, webinars are preferred to last about an hour in length. For families, an option to engage with the content and follow-up with a professional for clarification and questions would be ideal. Given that the *CanChild* website is familiar for both service providers and families, this website could potentially host webinar materials for easy access. This may allow CanChild to address the concern of families evaluating and accessing evidence that may not be credible information.

Knowledge Translation Summaries: Separate KT summaries can be designed specifically for families and for service providers, with open access to both. Summaries should focus on the bottom line and highlight key messages and courses of action for targeted groups including families, clinicians, policymakers and so on. Packages targeted towards youth should be short, concise, quick and entertaining. The information should be relayed in an interesting manner without being oversimplified.

Research Positions: A research position within each OACRS centre with duties to support families and professionals to find, understand, relay and integrate research evidence into daily routines would be helpful. This position has been used previously in several centres.

Collaborative Endeavors: Participants advocated for increased efforts for clinicians to collaborate with one another, across OACRS centres (with emphasis on engaging all centres). This effort would facilitate the normalization of knowledge translation behaviors by declaring that all centres are working towards the same goal.

Connecting Parents Using Facebook groups: Parents and families use Facebook groups to connect with one another and share information and sometimes research pertaining to their children's situation. Parents at the deliberative dialogue expressed the helpfulness of such connections between parents as they can also receive and provide advice from personal experiences.

Social Media and Marketing: The young adult group suggested relevant videos depicting relatable characters, images and content. Such examples include videos that are trending on YouTube such as 'Draw my life challenge' and 'Whiteboard videos'. The length must be short enough to retain the attention of young people. These videos can be broadcasted in waiting areas of medical offices (or anywhere youth/families may be present). Such videos are an invitation for youth and families to engage with information by attending an event discussing a relevant topic or visiting a website. Another option would be to share these videos of individual CTC websites with options to engage with the content through social media platforms such as Facebook and Twitter. Parent groups discussed that private Facebook groups are a good strategy for sharing information and keeping up to date with new issues. Such groups already exist and suggested videos described above may also be shared this way.

Culture Shift and Services: Stakeholders discussed the importance of emphasizing quality over quantity of services provided. To do so, clinicians must be given the opportunity to attend conferences, engage with educational materials and share knowledge with their colleagues. This subject also created a discussion regarding the accreditation at OACRS regarding the standard to include developmental monitoring measures. It must be

remembered that if something is not fundamentally *needed*, it may not be implemented. It was also suggested to explore the idea of an educational outreach service through the method of ‘train the trainer’ to teach healthcare providers how to use the On Track and Move and PLAY tools. Stakeholders identified that this method generally peaks interest at first, but loses momentum overtime. For clinicians and families, there must be a culture in which *CanChild* is recognized as an honest broker and should be known as a good place to start when looking for clinical answers. For researchers, it is important to remember to send executive research summaries to both the Board of Directors Chair as well as to the Chief Executive Officers of the OACRS centres. The role of the CEO at OACRS is to disseminate this information through many networks and pathways to get information out to all centres.

Engage Families and Youth: Cerebral palsy efforts require more engagement from child and families by creating a demand for improved services. Use of educational guidelines highlighting what to expect out of care and services, can support families to better advocate for their children’s and their own needs. Particularly, families and youth will know what to expect with respect to annual assessments, irrespective of their geographic location within the province. Furthermore, stakeholders expressed that when there is a need to consult families and youth, that it may be beneficial to do so separately (i.e. family advisory councils and youth advisory committees as separate entities).

This portion of the discussion evolved into describing ways in which we may move evidence into practice with respect to considerations noted in 5.2.2.

Encourage Advocacy: Advocacy is a way in which families and youth can raise awareness for CP. Advocacy can encourage additional funding and resources towards CP, more research pertaining to CP and an overall increase in knowledge so that families and youth can push and probe for best practice. Advocacy efforts, as discussed in 5.2.2, may influence policy decisions as well. Educational workshops and fostering relationships between families, parents, youth and service providers may facilitate ways in which stakeholders can become involved in advocacy.

Clinical Services Education: In order for health professionals to engage in searching and applying research evidence, they must know how to find and implement relevant information. Participant 9 shared the idea to begin educating students about knowledge translation:

“And maybe that’s starting, you know, in school, you know for students in school learning to kind of... I know there’s lots of research out there, but trying to implement actual research based treatment into learning for students”.

Another way to elicit education is by exposing more professionals and CTCs to participate in conferences. The benefits of conferences are two-fold. CTCs are able to share what is currently working in their practices and motivate other CTCs and professionals and this is a way in which they can be encouraged to sustain the use of their successful tools and behaviors. When those attending the conference return to practice, sharing knowledge gained with their colleagues is equally

important. This way we can leverage what is already being done in other CTCs in potentially similar environment and structure, instead of ‘reinventing the wheel’.

Creating Educational Opportunities: Educational materials should be combined with one-on-one sessions for clinicians, families and youth to understand the specifics of the information. Such sessions may highlight how the information is relevant to them specifically, and provide an opportunity to clarify questions.

Focus on *CanChild* Efforts: *CanChild* is a central source of information for all stakeholder groups serving children with disabilities. Clinicians of individual CTCs must know how to navigate the *CanChild* website to be able to access information themselves, as well as to relay or explain information to patients and families. Advertising the utility of the *CanChild* website to youth and families is also encouraged and could be done in waiting rooms. A *CanChild* and OACRS collaboration to create email blasts to inform families and clinicians about significant pieces of evidence to highlight key items and potential impacts of evidence was proposed to be useful. Participants recommended that different versions should be available for families and clinicians. Parent information sessions could also be held through *CanChild* and advertised on the website.

Knowledge Brokering: Knowledge brokering may assist in relaying information in lay terms so it is more effectively understood all stakeholders. It was discussed that this strategy would work well in combination with other strategies.

Communication Efforts Targeted Towards Young People: Given the need for youth to participate more in their care and advocacy, finding new and engaging ways to relay

information to this population will be important. Participants reinforced that these strategies must be relevant and short in length.

Efforts Geared Towards Clinicians: A reoccurring idea regarding this topic was the possible integration of scheduled learning blocks for clinicians to engage in knowledge translation materials such as webinars or using the *CanChild* website. Clinicians should also have adequate time to collaborate with other service providers to share information with one another. Furthermore, all information shared with parents should be shared with clinicians in order to keep them ‘in the know’.

Finally, some broader strategies mentioned included: exploring relationships between programs, supervisors, communities, and Ministries, valuing the knowledge of children, youth, parents, and families, and continuing to grow and expand the relationship between OACRS and *CanChild*.

5.5 Sustaining the Use of Research Evidence

Participants suggested that sustaining the use of research evidence in practice comes down to ongoing and consistent engagement in knowledge translation behaviors.

Creating a culture in which health professionals are encouraged and given the ability to explore and share evidence-informed practice was described as a crucial step to achieving sustainability. This culture must also extend beyond individual centres to all CTCs working together. Stakeholders shared that CTCs exchanging successful ideas and strategies with one another is part of sustainable effort towards the use of research evidence. In addition, engaging parents and families purposefully on an ongoing basis

establishes and maintains trusting relationships and better comprehension of needs, as well as increasing the potential to sustain positive behaviors.

Participant 14 shared:

“If you just make it [use of evidence-informed practice] part of their everyday practice and they sustain it because they’re going to see the results of it, but also make it practical, make it, you know, something that already it’s with what they’re doing, we’re already doing client reviews, well then tell me that at client review at three and a half these are the two things we have to make sure we talk about.”

Another method in which sustained use of KT and best practice methods can be promoted is through increasing competency among service providers to use evidence databases.

Some stakeholders shared that professional colleges should be responsible for ensuring that health service providers have the capacity to find, understand, relay, and use evidence in practice. Furthermore, stakeholders believe that KT strategies and mechanisms should be a part of continuing education for health professionals through their respective colleges.

Chapter 6: Discussion

In this chapter, I outline and discuss three themes that emerged from the results including emphasizing roles and responsibilities, overcoming barriers and strategies to implement KT. I reflect on using a deliberative dialogue as a data collection strategy and discuss the analysis of the data collected for this thesis. Limitations, implications and future directions are also described.

6.1 Emphasizing Roles and Responsibilities

Participants in this study were excited and pleased to engage in a discussion with a myriad of stakeholders from different areas relevant to their practices and lives. This type of boundary-crossing collaboration and discussion does not happen often enough in the rehabilitation field and, as experienced, can be of potential benefit to improving care. As described in Chapter 5, stakeholders represented in the figure are not the sole influences on the child. Other acting bodies also influence not only the child at the centre but also interact with all stakeholders. In healthcare in general, actors could include the *CanChild* Network (or another applicable research network), educators, external knowledge brokers, elected political parties, advocacy groups and more. These individuals or organizations represent intersections crossing and impacting all levels of influence. Such intersections are depicted in Figure 6.1 by the blue lines.

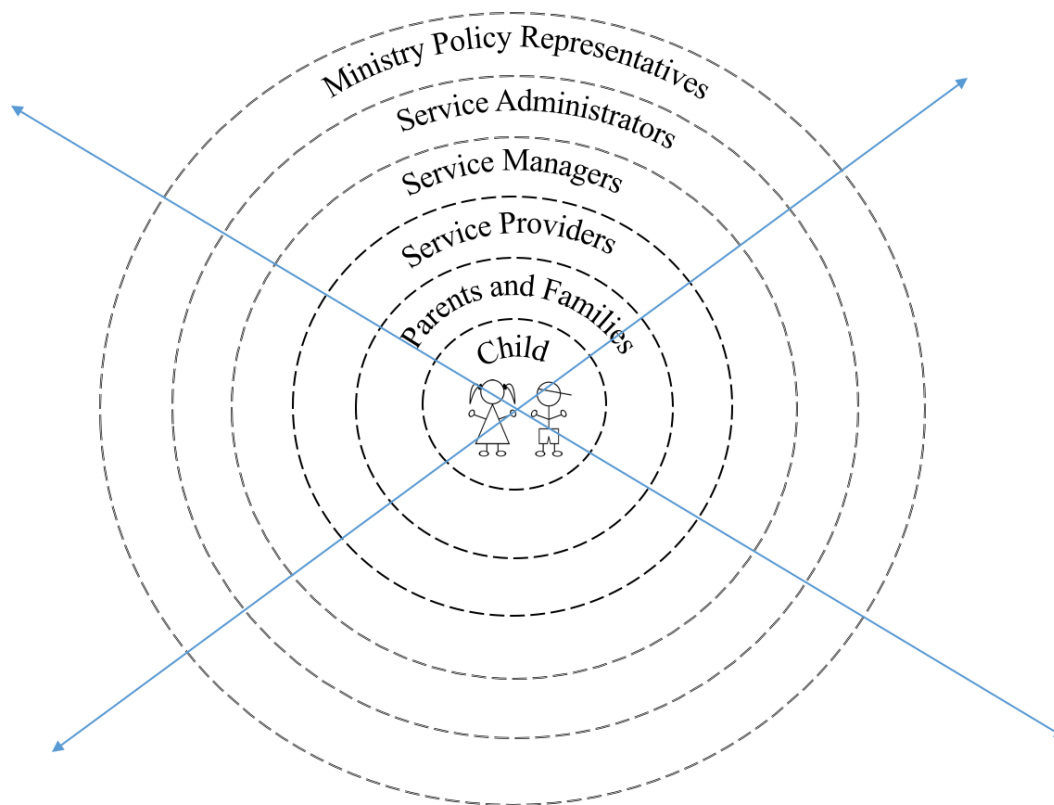


Figure 6-1: Adapted Theory with Inserted Intersections, illustrated.

The intersections embedded within the figure represent additional actors with whom the stakeholders may interact and who may make decisions in collaboration with stakeholders. In this context, relevant intersections are *CanChild*, OACRS and educators. *CanChild* offers resources and conducts relevant research within the field of disability and includes clinical researchers. It is important to note that OACRS is an intersection in this particular context as the association advocates for centres in which services are being provided to youth with CP. Finally, educators play a large role in ensuring that health professionals and families have the capacity to access the tools they may require to engage in KT. The figure above represents intersections and interactions that are dynamic

and loosely resembles the structure of an atom. Similar to the dynamics of the healthcare system, atoms contain other particles within them that are in a constant state of energetic movement, change and interaction.

In order to elicit change such an environment while remaining family-centered, actions must be taken to understand and respond to the needs of families and youth with CP. All stakeholders must play a collaborative part in ensuring a family-centered approach (Albrecht et al., 2015). For example, service providers have a responsibility of listening to families, and engaging the child and family members in their assessment and treatment plans. An emphasis in this research is put on improving research accessibility for all stakeholders, but especially families and youth. Packaging knowledge in a way that is useful and comprehensible can assist in keeping parents engaged and knowledgeable about their child's care by highlighting aspects such as credibility and bottom line (similar to the Cochrane Review). Stakeholders must understand that there is immense value in collaboration in order to achieve the appropriate use of best practice. This inter-relational and boundary crossing approach is illustrated in the adapted Bronfenbrenner figure contained in Figure 5-1.

Identifying the interrelationships among all stakeholders was the first theme to come out of this study. Service providers indicated the need for KT to be supported, encouraged and prioritized by service managers, administrators and individual CTCs. Stakeholders shared that a culture shift is required to facilitate evidence-informed decision-making to render KT efforts successful. Furthermore, stakeholders found it equally important for management and administrators to play a role in facilitating KT through culture shift,

practical considerations and an environment that supports the use of KT and best practice. Literature in this field suggests that leaders who encourage and prioritize implementation efforts experience positive implementation outcomes (Yost et al., 2015). Successful leaders who facilitate staff to use guidelines have been found to create a positive environment for best practice and influence organizational structures and processes (Yost et al., 2015). Successful KT implementation was also attributed to supporting staff in adjusting their workloads, permitting staff time to consider evidence and providing staff with appropriate resources. Together, study findings and existing literature support the notion of leadership roles to encourage and mobilize KT while adapting to the realities of practice.

Findings from this study suggest that service providers must be open to change and willing to alter the way in which they practice in order to provide quality care to patients. In this thesis, KT was found to require the investment and engagement of people in all areas of practice and organizational levels in order to be successful. As depicted in Figure 5-1, all stakeholders play a role in how care is delivered. However, their interactions with one another are important to consider as these relationships ultimately impact the care in that the child with CP receives. Such relationships are consistent with the notion of ‘relational nature’ discussed in 2.1, highlighting that relations are central to human existence and knowledge, and thus imperative for implementation efforts (Plamondon et al., 2015). Literature also parallels that perceived support from physicians, nurses and managers also facilitates KT (Pentland et al., 2011), further reinforcing the idea of collaboration and stakeholder relationships. The importance of developing quality

relationships and ensuring collaborative interactions among all participants in the health system emerged in this study and are also seen in the literature (Davis et al., 2003; Graham et al., 2006; Ryan et al., 2015).

Overall, literature pertaining to knowledge translation in the context of health and specifically in rehabilitation is scarce. Although the concept of collaboration has been associated with KT, there is little information about the roles and responsibilities of stakeholders involved in the uptake of research evidence. Given that every health system is unique and involves different actors and interactions, more specific research should be conducted in order to understand how all stakeholders can work together in order to instill change within practice. By understanding the roles and responsibilities of all actors within a given health system, all stakeholder may play their part in ensuring research is accessible through strategic packaging, support an environment that encourages change and establishing ongoing relationships to ensure family-centered care.

6.2 Overcoming Barriers

Recognizing existing gaps in care delivery allows stakeholders to promote appropriate change in a meaningful way. Leveraging existing facilitators that are already embedded within the context of practice is a feasible way to overcome barriers. The concept of using existing processes and building KT strategies to support the realities of practice was expressed by stakeholders in this study. Other recommendations for overcoming barriers include engaging local leaders in guiding change, engaging managerial and organizational stakeholders and developing the end users' ability to understand and critique research evidence. These findings mirror literature in the KT in healthcare field

and suggest that in order to render KT strategies more effective, we must first identify existing and potential barriers within practice and consider the realities of practice (Pentland et al., 2011). Such realities highlight the need to consider capacities such as time, financial requirements, technological and human resources to address common barriers within healthcare transformation (Pentland et al., 2011). As previously mentioned, acquiring leadership and organizational support as well as clinical-academic partnerships can assist in overcoming barriers. It is evident through the results in this study and reinforced in the literature that supporting dialogue among multiple stakeholder groups can allow us to shift barriers to implementation.

Through the engagement of leadership and families advocating for best practice care delivery, KT mobilization may be facilitated. Engaging different stakeholders towards a common goal and cultivating relationships amongst them forms ‘champions’ within KT who push towards change (Rosenbaum, 2005; Graham et al., 2006). Results from this study support the notion that partnerships among stakeholders contribute to the knowledge-to-action process by overcoming barriers.

6.3 Strategies to Implement Knowledge Translation

A takeaway strategy to improve knowledge translation efforts is the packaging and delivery of important messages towards all relevant parties. For service providers, we must consider their time-constraining schedules and deliver information in a succinct and bottom-line manner. For families, we must share knowledge in a manner that is easily understood, without being ‘dumbed down’, and invite families to discuss evidence further

with either a service provider, an administrator or a knowledge broker. And finally for youth, messages must be relevant, concise and relatable to the demographic.

As described by others (Pentland et al., 2011), stakeholders in this thesis shared that they would benefit from understanding how research is pertinent to them and how they can personally use the information in their own lives or in their own practice. This notion should also be extended to educational strategies such as workshops and focus on how educational materials are relevant to the stakeholders the evidence is targeting.

Paralleling the findings of this study, KT efforts are improved by tailoring techniques to specific audiences (Pentland et al., 2011). Based on the findings of this study, and the literature regarding strategies to implement KT, using multiple and mixed types of strategies that are both educational and hands-on, while respecting the needs of specific audiences is suggested.

Given the importance of considering the context in which service is provided, a multifaceted approach is necessary for knowledge transformation and implementation. Knowledge translation is not a singular approach but rather a combination of different strategies that include different stakeholders to truly elicit positive change (Pentland et al., 2011). Common strategies in the literature include face-to-face methods, educational outreach, reminders, multifaceted interventions, and marketing (Anaby, Korner-Bitensky, Law, & Cormier, 2015; Bornbaum, Kornas, Peirson, & Rosellaf, 2015; Cheung et al., 2012; Davis et al., 2003; Pentland et al., 2011). Furthermore, didactic educational KT strategies are minimally effective when used alone and should be used in conjunction with another active form of KT, rendering a more multifaceted approach to change

behavior (Glegg, 2010; Yost et al., 2017). Although this study did not delve into the specificities of educational KT strategies, there was an overall significant theme of recognising the context of practice that parallels the literature.

Knowledge brokering was mentioned by stakeholders within this thesis as a strategy for KT. Given the breadth of this study, knowledge brokering was not a central aspect of investigation and thus we did not gather extensive information regarding this strategy. According to existing literature, knowledge brokers are an excellent way to link researchers, users, policy makers and other decision makers and benefit KT endeavors (Pentland et al., 2011). Studies show that knowledge brokers can promote collaborative relationships, knowledge sharing and network building amongst stakeholders. Knowledge brokers work in building strong relationships across the field and earn credibility (Pentland et al., 2011). The notion of credible information and resources, building meaningful relationships and fostering cross-boundary collaboration were all themes that emerged from stakeholders within this thesis and may be facilitated through the use of knowledge brokers.

Organizational structures, leadership support and personal and interpersonal factors are consistent with current findings. However, reviewed literature mentions the role of leadership and less specifically the responsibilities of other acting influencers such service administrators, service providers or families and people receiving services (Pentland et al., 2011). These studies claim that actively and accurately targeting individuals and groups is a central characteristic of successful KT and also touches briefly on considering the format of research evidence. The literature resonates well with

the outcomes of this thesis, however does not specify *who* and *which* actors/groups are relevant to target within the healthcare field, such as care recipients and their families, or *how* to successfully format information to them in order to instill change.

6.4 Reflection on Deliberative Dialogue as a Data Collection Strategy

Prior to this study, the use of a deliberative dialogue as a data collection strategy is not known to have been used specifically within the field of rehabilitation. Given its use for facilitating action to transformation exchange among stakeholders from different backgrounds, deliberative dialogue is a promising way to approach knowledge translation for pediatric rehabilitation research uptake. Conducting this research offered the opportunity for relevant stakeholders to engage in conversation on how to actively stimulate the uptake of research evidence into practice.

Using a deliberative dialogue engaging a medium-sized group to collect data regarding the realities and possibilities of using research evidence in rehabilitation for children with CP was a success. Although not stated in this thesis, participants did complete an evaluation at the end of the dialogue and reported overall satisfaction with the half-day meeting. This method provided many insights into approaching the overarching research question and stimulated further notions and ideas regarding knowledge translation efforts for each distinct group of stakeholders. This was made possible due to the inherent nature of bringing together people with diverse backgrounds and perspectives to share their thoughts on KT and CP. Participant 9 shared:

“I think the fact that the members of the dialogue were quite diverse in terms of the perspective they were bringing, and also that some of them

were bringing multiple perspectives, I just thought it was a good way to go to gather information about the subject” [...] I often come away [from brainstorming meetings] more somewhat frustrated because I feel like oh my God, we’ve got all these new ideas and you just know that nothing’s going to happen [...] I didn’t feel that way when I left this meeting, but maybe because of the structure of the deliberative dialogue and knowing ahead of time we had stuff to read. The whole deliberative dialogue was fairly structured. Even though there was a lot of free flowing ideas and I wasn’t sure that we answered all, or came up with anything we should have... having it all pulled together and then knowing I’d have another opportunity to say something else if I needed to, like, during the interview was.... I felt good about what went on.”

The deliberative dialogue intentionally prepares participants beforehand with background information and provides transparency of how the day will unfold and who else will be at the table. Given that there were no surprises and that participants had the ability to safely share their opinions, come back to comments, reflect on the discussion and add additional comments after the event provided well thought out and authentic ideas to understand the chosen topic.

Overall, the deliberative dialogue was a successful method for gathering information regarding realities of practice, diverse perspectives and opening the conversation as a first step towards KT. Feedback from the deliberative dialogue

was positive and participants showed enthusiasm and excitement to be a part of a dialogue that allowed for cross-disciplinary conversation.

6.5 Limitations

Out of the total number of participants (n=17), 14 had the opportunity to access and review the shared summary of the deliberative dialogue (n=83%). Those who did not review the summary attributed this to trouble accessing the website where the summary was posted. These three participants were given an overview of the summary over the telephone at the beginning of the interview. This was a limitation to the interview portion of the study as participants did not have access to the summary first-hand. It is possible that reflections from these participants were incomplete, as stakeholders drew points for feedback based on memory and a brief verbal summary.

We must consider that although we had representation from families of children with CP, these are parents who had the capacity and willingness to join us in the study. A limitation of this mix of participants is the lack of representation of families who are less inclined to participate or unable to participate in this type of study. We must consider that family views conveyed in this study do not contain the first-hand opinions of certain families whose realities and capacity for participation may be vastly different. Participant 8 exemplified this in the following quote:

“I think we have sort of run amok between families who have one parent is at home are well educated, have good financial resources and are impassioned about their kid receiving the best services, and other families who have fewer resources, both parents work or there may be one single

parent. They have limited transportation, and sometimes they tend to be more reactive than proactive with their children's problems, simply because of the other constraints on their lives”.

Although we sent out invitations to people in individual CTC leadership roles (i.e., CEOs of OACRS centres), these potential participants were unavailable to partake in the deliberative dialogue. This was a limitation for the study as these individuals were not represented in the conversation despite their frequent mention by other participants. The notion of shift in culture and other comments specifically regarding distinct CTCs was often mentioned and having representation from head leadership of these centres would have been valuable to this study.

Finally, although grounded theory methodology was used to guide this work, I acknowledge that the results have not been displayed as an overarching ‘theory’, but rather as 5 themes (interrelationship among stakeholders, roles of stakeholders in KT, barriers in KT, strategies to implement KT and sustaining the use of research evidence), supported by a figure and a table as well as a narrative description and selected quotes.

6.6 Implications

In order to effectively implement the use of measures and tools created in both Move & PLAY and On Track studies, collaboration among all involved stakeholders will be required. A multifaceted approach combining education with relevant tools will likely yield positive KT results. Furthermore, strategies, messages and evidence should be tailored specifically for different stakeholders within pediatric rehabilitation. Involving

the child, parents and other family members along the way might enable sustained use of best practice efforts.

Specific to the Move & PLAY and On Track studies, involving OACRS, individual CTCs, *CanChild* as well as service providers, families and children with CP will be vital to the use of evidence within practice. The knowledge created through these studies should be communicated to all stakeholders in a way that is relevant and comprehensible to them. Families and youth need to understand the impact and value of the tools and measurements, so that they are able to request the delivery of comprehensive assessments. Using a combination of strategies mentioned in 5.3 and ensuring that communication is relevant, short, interesting and understandable is recommended.

Leadership within OACRS and individual CTCs must work with service providers to involve KT efforts within their existing schedules. As expressed by stakeholders, demands are already high while time and resources are limited within practice.

Implementation endeavors will therefore require effort from upper management to support and encourage KT and implementation of evidence.

In general, KT and implementation are social phenomena that benefit from interactions among all areas of practice within the health system, from policy all the way to practice. Cultivating relationships among silos in the health field and collaborating with as many relevant stakeholder groups and organizations is recommended.

6.7 Future Work

Given the limited studies pertaining to KT specifically in the field of CP and rehabilitation, future work in this area is required. This research highlights some areas in which KT evidence may benefit. Interesting and debated themes that arose from the research were evident tension over mandates and leadership. Designing research to dissect and analyze just how tensions are managed within health systems and how to mobilize change by leveraging mandates may enable health systems to successfully implement change.

It is commonly understood that research evidence must be formatted specifically for relevant stakeholders. However, there is limited research pertaining to how researchers and all other actors within the field can do so. Although this study provides an overview on how stakeholders would like to receive research evidence (i.e. short and relevant videos of children with CP and bottom line relevant to practice for service providers), the field of KT could benefit from a more in depth look on different methods of packaging and formatting research evidence to a myriad of different actors within the system, such as families, patients, service providers, administration and more.

In pediatric rehabilitation, parents and families take on a significant role in advocating for their children's needs in practice. Active endeavors to ensure parents and families have access to research evidence and are equipped with the education to find and effectively use the findings of research would be beneficial for children with CP. Furthermore, efforts should concentrate on assisting families as well as children and young adults with CP to advocate for their needs within the health realm.

6.8 Conclusion

The deliberative dialogue was successful in exploring roles and responsibilities of multiple stakeholders, barriers that need to be overcome and multifaceted strategies that must be used to ensure uptake of research evidence and its sustained use. This research highlights the importance of collaborative efforts towards successful knowledge translation. All areas within the health system must work together in order to manifest change within the dynamic field. Parents, families and children with CP must be engaged throughout the process as they are experts in their own needs. Research and informative materials must be packaged in accessible and comprehensible packages for each stakeholder position.

Families and youth with CP require information that outlines how the information is relevant to them, and how they are able to use it for their benefit. Service providers require bottom line information that is also relevant to their practice and the youth and families they are serving. Implementation efforts must be built in to existing processes while adapting to the realities of practice such as time constraints. Finally, roles and responsibilities that stakeholders hold in the process of KT emphasize that all stakeholders must work together in order to instill change. Although these roles may alter depending on the unique context of each health system, cross-boundary communication and collaboration is crucial for positive KT and implementation outcomes.

It is anticipated that this study will contribute to the field of pediatric rehabilitation, general rehabilitation and a broader knowledge translation and implementation science context. Given that this research is geared towards childhood rehabilitation centres in

Ontario (although still applicable to other health contexts), we expect that this research will impact the way in which the OACRS centres promote research uptake for children with CP and other childhood disabilities.

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Appendices

Appendix A: Review of Knowledge Translation Practices at the Clinical and System Levels of Cerebral Palsy Rehabilitation

This section provides an overview of current knowledge translation practices within cerebral palsy (CP) rehabilitation and establishes the current existing gaps in knowledge translation within the field of pediatric rehabilitation. The purpose of this section is to understand knowledge translation at the clinical level and system level.

Search Strategy

Databases accessed for the literature search included PubMed, CINAHL, Scopus, and MEDLINE. Search terms included combinations of “cerebral palsy”, “rehabilitation”, “pediatrics” and “knowledge translation”, “implementation science” and “knowledge uptake”, “knowledge broker”, “knowledge to action”, “knowledge gap” and “health knowledge”. Articles including pediatrics and child rehabilitation as well as articles discussing general knowledge translation in rehabilitation were chosen. Articles focusing on specific non-related adult health conditions were excluded.

Introduction to Knowledge Translation

As information networks develop to provide evidence-informed information into the field of rehabilitation, the more difficult it can become to navigate and implement new findings. The gap between what we know and what we do, especially in healthcare, is widening, as healthcare professionals are not regularly accessing best practice evidence to

guide clinical decisions (Graham et al., 2006). Many studies have concluded that there is a need to increase the use of evidence-informed information in pediatric rehabilitation (Albrecht, Archibald, Snelgrove-Clarke, & Scott, 2015; Jones, Roop, Pohar, Albrecht, & Scott, 2015). In efforts to address this gap, the concept of knowledge translation has gained some interest within the rehabilitation sector in the past decade (Jones et al., 2015).

Literature suggests that occupational therapy, speech-language pathology and physical therapy have their own unique gaps in evidence and practice, calling for varied knowledge translation strategies and further complicating the execution of knowledge translation efforts within rehabilitation (Jones et al., 2015). Although this concept can be represented by numerous terms, knowledge translation has been defined as “the exchange, synthesis and ethically-sound application of knowledge—within a complex system of interactions among researchers and users—to accelerate the capture of the benefits of research” (Government of Canada, 2005). In a statement issued by the Canadian Institutes of Health Research (CIHR) to promote the integration of knowledge into research, it was suggested that interactions be facilitated between researchers and the end-users of research to enhance knowledge translation outcomes (Government of Canada, 2005).

Knowledge Translation in Child Rehabilitation Settings

A systematic review completed by Albrecht and colleagues (2015) regarding knowledge translation strategies to promote research uptake in child health settings included a total of twenty-one relevant articles. This recent review concluded that the quality of

information pertaining to knowledge translation within pediatric rehabilitation is lacking and more research must be done in this field to advance how clinicians interact with research evidence. The review also indicated that child health settings are unique and therefore must be distinctly considered. Child health settings are interdisciplinary in nature and incorporate the expertise of various health professionals (King, Wright & Russell, 2011). A review of contextual and psychosocial factors impacting pediatric rehabilitation therapists' use of outcome measures found that child health settings include high emotional investment for frontline workers. Knowledge translation targeting care for this population must be interdisciplinary, including a mix of professionals involved with child health and must be based upon similar child health settings. Currently for children with disabilities, studies show that there has been a focus on short-term interventions due to financial and organizational constraints (King et al., 2011).

Types of Knowledge Translation Interventions Used in Rehabilitation

As discussed above, literature is scarce concerning knowledge translation efforts in pediatric rehabilitation regarding CP. Although studies targeting general rehabilitation are scarce, we must consult research with similar patient populations to gain some insight into what has already been explored in this sector. Some studies have been completed in rehabilitation settings and others in general clinical service delivery.

Use of Reminders

Evidence indicates that healthcare workers have been using reminders to uptake new research evidence into practice within various disciplines. Efforts have been depicted as

successful and positively influenced knowledge translation efforts in both child and adult health settings (Albrecht et al., 2015; Davis et al., 2003). An overview of systematic reviews of the effectiveness of reminders to alter clinical behavior was conducted outside of the rehabilitation context (Cheung et al., 2012). Data from this literature highlights the positive effects of reminders used in clinical settings to aid in the implementation of enhanced frontline practice. Reminders can be administered differently depending on the context in which they are implemented. Paper format or computerized reminders facilitate the barrier of information overload that some health providers may experience when adding a new step into their practice (Cheung et al., 2012).

Education Approaches

The knowledge implementation plan concerning participation of youth with disabilities by Anaby, Korner-Bitensky, Law, and Cormier (2015) involved evidence-informed learning groups geared towards clinicians. The goal of this study was to disseminate knowledge about participation and its impact on children with disabilities to rehabilitation clinicians. In this study, researchers found that frequent educational sessions served as facilitators to knowledge uptake. Other knowledge translation literature also points in this direction, illustrating that knowledge translation strategies are more effective if they are active and include educational outreach visits (Davis et al., 2003; Glegg, 2010).

A systematic search and narrative in pediatric rehabilitation found that the effectiveness of passive dissemination strategies such as the distribution of information and receiving information at conference-style meetings had limited effects on the audience when

compared against active efforts (Schleifer Taylor, Verrier, & Landry, 2014). According to this review, research should instead include active strategies such as identifying barriers and discussing plausible solutions to overcome them. Gaining useful knowledge empowered frontline workers to strengthen their personal identity as healthcare professionals. Another study examining knowledge translation of the Gross Motor Function Classification System (GMFCS) among pediatric physical therapists suggests that passive dissemination of information is only successful for broadening awareness; however, it was not shown to contribute to later stages of the knowledge translation process (Deville, McEwan, Arnold, Jones, & Zhao, 2015). A systematic review on translating knowledge in rehabilitation illustrates that education-only approaches are primarily used as knowledge translation strategies within rehabilitation disciplines (Jones et al., 2015).

Web Based Learning

A study focusing on evidence-informed practice within pediatric rehabilitation suggests that web-based learning is an effective strategy for informing professional development. Literature suggests that the combination of web-based interventions with other knowledge translation strategies increases outcome success, improves evidence-informed knowledge and has the potential to alter clinical behavior (Glegg, 2010). An interprofessional toolkit geared towards practitioners in the child and rehabilitation field was produced through this study, with results suggesting that the evidence-informed resources were highly accessed and useful for knowledge translation (Glegg, 2010).

Collaboration

Literature suggests that interdisciplinary teams are a successful strategy to include into knowledge translation implementation plans. Collaboration among a mix of professionals can lead to positive changes in research uptake with studies suggesting that this mix is in fact required in order to see greater uptake of information (Albrecht et al., 2015; King et al., 2011). Engaging in topic discussion with appropriate participants from clinical and non-clinical backgrounds has shown to improve reflection on knowledge and to increase the production of solutions addressing the gap between research and practice (Anaby et al., 2015; Ryan et al., 2015). Literature regarding continuing medical education suggests that knowledge translation strategies must include participants from health systems, health policy and patients in order to have meaningful impact (Davis et al., 2003; Graham et al., 2006; Ryan et al., 2015). Cultivating appropriate relationships between relevant stakeholders is the first step to promoting the uptake of new ideas and ‘champions’ who will apply research knowledge in their own practice (Rosenbaum, 2005; Graham et al., 2006). This type of partnership is shown to generate mutual understanding among stakeholders and to facilitate the knowledge-to-action process (Rosenbaum, 2005).

Use of Knowledge Brokers

Knowledge brokers have been used in multiple studies to increase research uptake within rehabilitation by working collaboratively with stakeholders. They have been defined as linking agents between research and practice and capacity builders who work to identify relevant stakeholders and organizations to bridge knowledge gaps with the appropriate people in the right context (Bornbaum, Kornas, Peirson, & Rosella, 2015). A recent

systematic review exploring the effectiveness of knowledge brokers as facilitators to knowledge translation in health settings has shown that although communication channels facilitated by knowledge brokers have been successful in initiating collaboration between researchers and practitioners, it has been difficult to evaluate the impact of knowledge brokers as knowledge translation strategies. Given the numerous factors involved in knowledge translation strategies within healthcare such as variability in healthcare contexts, more research must be done to interpret the impact that is attributed solely to the use of knowledge brokers (Bornbaum et al., 2015). Another common concern regarding knowledge brokers is the investment of cost-intensive resources to successfully execute this strategy (King et al., 2011).

Another study focused on administrator perspectives of knowledge brokering in children's rehabilitation highlighted useful information for ensuring that knowledge translation efforts are successful. Decision-makers participating in this study desired high quality evidence-informed recommendations that effectively state the direct impact of the research for policy and add value to therapists' work (Cameron, Russell, Rivard, Darrah, & Palisano, 2011). This group appreciated synthesized, easy to access information implemented in a peer-to-peer learning environment that encouraged teamwork and interdisciplinary information sharing (Cameron et al., 2011). Despite its ongoing use, other literature suggests that there is limited research to justify the use of knowledge brokers in pediatric rehabilitation context (Schleifer Taylor et al., 2014).

Barriers of Research Uptake

Lack of Time and Skill

A knowledge translation study focused on increasing research uptake targeting participation outcomes for children and youth with disabilities highlighted some barriers that clinicians in the study faced when requested to alter the way they practice. Literature from this study showed that barriers to change included time constraints and lack of skill (Anaby et al., 2015). Other studies also support these claims (Davis et al., 2003; King et al., 2011). The effectiveness of research uptake may also be limited by the clinical environment and the length of the process for adopting new practice methods (Davis et al., 2003). Knowledge translation strategies must therefore accurately target a need and must aim to understand and overcome such barriers to change (Davis et al., 2003). Some literature suggests that although therapists highlight time as a barrier, it is lack of knowledge that is the culprit for low research uptake (King et al., 2011). In fact, a recent study of pediatric rehabilitation therapists in Ontario found that time represented only 9% of the reason for low adherence to the use of implemented outcome measures (King et al., 2011). Therefore, solely disseminating awareness of best practice methods may not be enough and knowledge translation strategies may need to address heightening sense of skill and comfort in order to be successful.

Facilitators of Research Uptake

Stakeholder Engagement

Given the need for collaboration for effective knowledge translation, engaging stakeholders in a meaningful way to increase the likelihood of research uptake must be

considered. Stakeholders must be diverse in their professional roles and they must share features of or be involved with the population in which the research is intended to impact (Camden et al., 2015). A scoping review of strategies used to engage stakeholders in rehabilitation research has identified factors leading to improved engagement outcomes. Literature illustrates that communication abilities, culture, power sharing and resources are among the top factors that influence stakeholder engagement. Stakeholder roles should be communicated and agreed upon prior to the implementation of a knowledge translation strategy discussion, to ensure project feasibility and sustainability (Camden et al., 2015).

This scoping review by Camden et al. (2015) provides additional insight into the catalysts that expedite stakeholder engagement within health settings, which include having regular meetings, assigning clear roles, power sharing and providing adequate time and financial resources. Knowledge translation facilitators were compared to the factors mentioned above and illustrated the similarities between stakeholder engagement and knowledge translation facilitators. Despite what we know about stakeholder integration to increase research uptake, stakeholders are rarely meaningfully involved in research steps and implementation (Camden et al., 2015). The conclusion of this study indicated that more research must be conducted to better understand stakeholder engagement processes and evaluation methods (Camden et al., 2015).

Diffusion of Innovation Strategy

A recent knowledge translation strategy was implemented in a pediatric speech-pathology program in Ontario, to stimulate the uptake of standardized use of the Communication

Function Classification System (CFCS) for children with CP (Cunningham, Rosenbaum, & Hidecker, 2016). The lack of consistency in the use of this tool impacted the ability for therapists to classify, customize treatment and provide appropriate service delivery to children, which sparked the motivation for the following knowledge translation efforts. Researchers from this study used the diffusion of innovation strategy that outlined four main factors that influence the likelihood of knowledge adoption and maintenance. The first finding is that characteristics of the innovation of interest must be observable, offer relative advantage and be compatible, triable and simple. This means that the innovation must be visible to others, must be perceived as a superior method or idea than the one it supersedes, must be consistent with existing culture and values of the context in which it is being implemented, must be easily experimented with and must be straightforward and easy to use. The second finding draws attention to the importance of communication channels. Media channels were used to stimulate the spread of knowledge whereas interpersonal channels stimulate the adoption of knowledge or an idea. The third factor represents time, illustrating not only that knowledge translation can be a lengthy process, but also that individuals will adopt research at varying stages, some earlier than others. Finally, factors within a social system will influence knowledge translation, including cultural norms and the opinions of leaders and frontline workers (Cunningham et al., 2016; Rosenbaum, 2005)

The diffusion innovation strategy also describes the innovation-decision process which represents how knowledge has the capability to move into practice. This process begins with learning about an idea (knowledge), an opinion towards the idea (persuasion), the

adoption of an idea (decision), the application of an idea (implementation) and finally confirmation whether the idea is useful or not (Cunningham et al., 2016). This knowledge translation strategy was successful in this context and increased intention to use research in practice with this study.

Credibility of Knowledge

Participants in the knowledge implementation study for speech language pathologists found that clinicians were more receptive to leaders and implementers who were credible, likeable and who shared similar characteristics and value to them (Cunningham et al., 2016). This is consistent with the literature on the culture of health communication which exemplifies that if a message is disseminated by someone who bears these characteristics, the audience will receive the information with increased confidence (Cunningham et al., 2016). In fact, when therapists observe the value that their practice methods bring to families and organizations, they are more likely to continue the use of those methods.

Summary

There is limited evidence showing how to effectively move research into practice in a child health setting and only one recent article regarding the uptake of evidence-informed research for children with CP. Although literature outside CP can be consulted, the context for this population differs greatly due to the heterogeneity and the broad spectrum of the disability. Most of the literature in the rehabilitation field alludes to the need for further research regarding pediatric rehabilitation and effective knowledge translation strategies. Despite the limited evidence, several avenues are promising such as use of

reminders, active educational strategies to empower health professionals, interdisciplinary collaboration and stakeholder engagement. Given the complexity of the phenomena of knowledge translation, further study of how to facilitate the use of research evidence to optimize outcomes for children with CP is warranted, leading to the specific research question within the context of the Ontario Association of Children's Rehabilitation Services (OACRS) centres.

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Appendix B: Permission to use Figure 3-1: The grounded theory process, illustrated (Charmaz, 2014).

RightsLink order: 501261488 - Alisiyah Daya

2017-05-08, 4:28 PM

RightsLink order: 501261488

PermissionsUK <[REDACTED]>

Fri 5/5/2017 5:45 AM

To: Alisiyah Daya <[REDACTED]>;

Dear Alisiyah,

Thank you for your recent RightsLink order (#501261488). With regards to re-using Figure 1.1 "A visual representation of grounded theory" from the SAGE publication 'Constructing Grounded Theory', I am pleased to report we can grant your request without a fee as part of your dissertation.

Please accept this email as permission for your request as detailed below. Permission is granted for the life of the edition on a non-exclusive basis, in the English language, throughout the world in all formats provided full citation is made to the original SAGE publication.

Please note approval excludes any graphs, photos, excerpts, etc. which required permission from a separate copyright holder at the time of publication. If your material includes anything which was not your original work, please contact the rights holder for permission to reuse those items.

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Appendix C: Research Team and Planning Committee Members

| Name | Role(s) | Research Team Member | Planning Committee Member |
|------------------------|---|-----------------------------|----------------------------------|
| <i>Alisiyah Daya</i> | Primary Investigator | ✓ | ✓ |
| <i>Barb Galuppi</i> | OnTrack Project Coordinator | | ✓ |
| <i>Deb Lucy</i> | MSc Thesis Advisor | ✓ | |
| <i>Dianne Russell</i> | Research and Knowledge Exchange Consultant and Deliberative Dialogue Facilitator | | ✓ |
| <i>Doreen Bartlett</i> | Thesis Supervisor and Physical Therapy Professional | ✓ | ✓ |
| <i>Jennifer Boyko</i> | MSc Thesis Advisor and Deliberative Dialogue Consultant | ✓ | ✓ |
| <i>Marilyn Wright</i> | Best Practice Committee of OACRS Member, Physical Therapy Professional and OnTrack Assessor | | ✓ |
| <i>Tianna Deluzio</i> | MSc Student Collaborator | ✓ | ✓ |
| <i>Tina Hjorngaard</i> | OnTrack Parent Collaborator | | ✓ |

Appendix D: Deliberative Dialogue Agenda

Deliberative Dialogue – How can we facilitate the use of research evidence to optimize outcomes of individual children with cerebral palsy?

Friday, November 18th 2016

Guidelines

- ✓ *Respect the “Chatham House Rule”, a promise that the conversation today will stay in this room and will not be repeated outside of this room*
- ✓ *In the summaries of this discussion, names will not be linked to comments*
- ✓ *Participants will be respectful to one another, without making judgments*
- ✓ *All participants are free to be honest and say what they want*
- ✓ *All participants are encouraged to share their thinking and experiences*
- ✓ *All comments are valued, and all opinions will be respected*

Agenda for the Day

9:30 – 10:00 AM **CHECK IN/ REFRESHMENTS/ CONSENT AND COMPENSATION FORMS**

[Participants will check in by providing their names and submitting the signed consent forms provided to them in the invitation. Compensation forms will be distributed for collection later in the day. Coffee/tea and a small snack will be available.]

10:00 – 10:20 AM **WELCOME/ INTRODUCTION/ GROUND RULES/ ICE BREAKER**

[Introductions will be made by the facilitator orienting to what the day will look like. Safe spaces and ground rules will be discussed to ensure participants understand the confidentiality of the dialogue and feel comfortable engaging in discussion. An opportunity will be provided for participants to ask questions about the process to be used during the day. An ice breaker will be done to learn about the values each participant holds towards the topic.]

10:20 – 10:40 AM **BACKGROUND INFORMATION/ OVERVIEW OF EVIDENCE**

[The facilitator will introduce the topic for discussion. An overview of the evidence outlined in the Issue Brief that was pre-circulated prior to the meeting will be provided.]

This overview will include the OnTrack tools and measures and viewing of a videotape produced by parent collaborators on the importance of developmental check-ups.]

10:40 – 12:00 PM **DIALOGUE: CLARIFICATION OF THE
ISSUE/INTRODUCTION OF THE QUESTIONS**

[Participants will be asked to discuss what is known about the issue (i.e., the evidence presented in the Issue Brief) Prompts include: Is the evidence clear? What does the evidence mean to them? Are there questions to clarify the issue? Questions will be presented to the participants.

Deliberative dialogue question:

- *How can we facilitate the use of research evidence, such as that produced by the Ontario Motor Growth, Move & PLAY and On Track studies, in services offered through the Ontario Association of Children's Rehabilitation Services Centres to optimize outcomes of individual children with cerebral palsy?*

12:00 – 12:45 PM **LUNCH / REFLECTION**

12:45 – 2:30 PM **DIALOGUE: POTENTIAL OPTIONS/DIRECTIONS FOR
ACTION**

[Potential options/ directions for action were introduced in the Issue Brief and will be further explored to stimulate the conversation on additional ideas. Participants will engage in discussion in response to the question posed before lunch. The facilitator will ensure all voices are heard and all opinions are expressed. The facilitator will probe both positive and negative thoughts (i.e. facilitators and challenges) regarding existing and new options for use of research evidence.]

2:30 – 2:45 PM **BREAK**

[The facilitator and deliberative dialogue consultant will prepare a summary of the day.]

2:45 – 3:00 PM **SUMMARY OF THE DAY/ CLOSING REMARKS**

[The facilitator will wrap up the discussion with a summary of the deliberation. The facilitator will thank everyone for participating in the dialogue and will describe the next steps. Compensation forms will be collected. A copy of the signed consent form will be circulated to each participant.]

Appendix E: Semi-Structured Telephone Interview Guide

Hello _____, and thank you for your participation in the Deliberative Dialogue on *[insert selected date]* and for being available for this interview with me today.

Clearly this interview is not anonymous as I know who are you. However, the information that you provide will be kept confidential. I will be choosing an alternate name to refer to your contributions.

You were invited along with *[insert number]* others, as a stakeholder in the Deliberative Dialogue because of your position/experience as *(specific stakeholder role)*.

- Were there other things that you believe we should know, such as additional experiences, that impacted your perspectives and participation in the dialogue?

The guiding research question at the deliberative dialogue was: *How can we facilitate the use of research evidence, such as that produced by the Ontario Motor Growth, Move & PLAY and On Track studies, in services offered through the Ontario Association of Children's Rehabilitation Services Centres to optimize outcomes of individual children with cerebral palsy?*

After the Deliberative Dialogue, we sent out a summary of the ideas we talked about at the dialogue. Have you have had a chance do go through it?

[If yes, "Thank you". If no, "Let me begin by giving you the highlights of the summary"]

- I am interested in your overall reflection of the summary
 - Did the summary cover all the main/important points discussed at the dialogue?
[Probe as appropriate]
 - Is there anything you would add to the summary?

Let's go over the two secondary questions of the Deliberative Dialogue to get your thoughts or comments for each one.

- How can we stimulate the uptake of research evidence into clinical practice? Or how can all of us (that is, all of the stakeholders at the Deliberative Dialogue) ensure that research evidence is used in planning services with children and families?
[Probe with themes that came up in the Deliberative Dialogue]

- How can we sustain use of research evidence in practice? Or how can we ensure that all of us get in the habit of using research evidence on a regular basis?

[Probe with themes that came up in the Deliberative Dialogue]

[Probe for clarity and elaboration]

How well do you think the deliberative dialogue went?

- *[Probe negative or positive answers]*
- Do you think the discussion at the deliberative dialogue matched up well with the research questions?

Do you have any other thoughts about the Deliberative Dialogue and what has happened since then? Did the discussion bring about the changes for you personally?

[Probe answers]

Do you have any final suggestions related to the research questions?

- How to stimulate uptake of research evidence into clinical practice?
[Probe answers]
- How can we sustain use of research evidence in practice?
[Probe answers]

Do you have any general suggestions about how to create change when it comes to improving individualized care for children with CP and their families?

- *[Probe answers]*

Thank you very much for talking with me today. Once the interview has been typed out, I will be sending you a copy for your review.

Appendix F: Recruitment Emails

First Email

Subject Line: You are invited to a half day meeting – save the date

CanChild's [On Track Study](#) is a large multi-site collaboration involving researchers, therapists, families, and children with cerebral palsy (CP) from across Canada and the United States. The results will be available in 2017 and will add to the results already available from the earlier [Move & PLAY Study](#). Doreen Bartlett, MSc student Alisiyah Daya, and a research planning group are putting together a Deliberative Dialogue discussion for Friday, November 18, 2016 in Hamilton, Ontario.

A Deliberative Dialogue focuses on critical issues by bringing together research evidence and ‘stakeholders’ for a discussion to inform future actions and policy. The ‘stakeholders’ include representatives from many groups involved in or affected by decisions about the particular issue. The entire group learns from the different views and experiences and this collaboration can spark insights for practical solutions.

On November 18, we will be discussing ways to encourage youth with CP, their families, their service providers, and associated administrators and policy makers in Ontario to use the research evidence from *CanChild's* Ontario Motor Growth, Move & PLAY and On Track studies to support the goals of individual children with CP and their families.

A group of approximately 18 purposefully selected participants are being invited to participate in this discussion. Participants have been selected to ensure that we have representation across many backgrounds.

You have been invited to participate because we value your opinion. We hope that you will agree to share your perspective on behalf of [*specific respondent group* e.g. parents of youth with CP].

PLEASE REPLY BY INSERT DATE IF YOU ARE INTERESTED AND AVAILABLE TO COME TO HAMILTON FOR A DELIBERATIVE DIALOGUE DISCUSSION ON FRIDAY, NOVEMBER 18. Payment for your time, lunch, parking and transportation costs will be provided.

If I don't receive a reply, I will assume that you chose not participate in the Deliberative Dialogue.

Thank you for your consideration, Barb Galuppi

Second Email (send pending email response to first email):

Subject Line: Thank you for your interest in our Deliberative Dialogue – we value your ideas

Friday, November 18, 2016 at 10 am – 3 pm

CanChild, McMaster University, IAHS Building

Payment for your time, lunch, parking and transportation costs will be provided.

You are one of a group of up to 18 people invited to take part in this discussion. We have invited:

- parents of children with cerebral palsy
- young adults with cerebral palsy
- physical and occupational therapists and physicians all of whom work with children with CP
- representatives from the Ontario Association of Children’s Rehabilitation Services (OACRS) centres
- representatives from the Ministry of Child and Youth Services
- people with expertise related to services in rural areas

A Deliberative Dialogue focuses on critical issues by bringing together research evidence and ‘stakeholders’ for a discussion to inform future actions and policy. The Dialogue discussion has representatives from many groups involved in or affected by decisions about the particular issue. The entire group learns from the different views and experiences at the table. This collaboration can uncover unique understandings of the issue and spark insights for solutions and considerations.

In our Deliberative Dialogue, we will be discussing ways to encourage youth with CP, their families, their service providers, and associated administrators and policy makers in OACRS centres to use the research evidence from *CanChild*’s [Ontario Motor Growth](#), [Move & PLAY](#) and [On Track](#) studies in a family-centered way to support the goals of individual children with cerebral palsy and their families.

This discussion is being organized by a research planning group. The group includes a *CanChild* scientist and physical therapist from Western University, MSc Students, a deliberative dialogue consultant, a parent of a young adult with cerebral palsy, a project coordinator, a physical therapist who is a professional practice leader, and a facilitator who has expertise in facilitating research evidence into clinical practice.

Feel free to [email](#) us if you have questions.

The attachment contains a detailed Letter of Information and consent form. If you agree to participate, please respond to this email. We will be collecting signed consent forms at the Deliberative Dialogue discussion.

Sincerely,
Barb Galuppi

Third Email (forward Second Email with this note on November 9, 2016):

Subject Line: Background materials for the Deliberative Dialogue - November 18th

Thank you for your ongoing interest to be involved in our Deliberative Dialogue Discussion at McMaster University in Hamilton on November 18, 2016. We have attached background materials including an Issue Brief, a knowledge translation planning template, and driving directions for you to read ahead of time.

Feel free to [email](#) us if you have questions.

Sincerely,
Barb Galuppi

Appendix G: Letter of information and Consent

Page 1 of 7



Letter of Information

Facilitating the uptake of research evidence
in rehabilitation for children with cerebral palsy:
Combining deliberative dialogue and grounded theory approaches

- Primary Investigator:** Doreen Bartlett, BScPT, MSc, PhD
School of Physical Therapy, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]
- Co- Investigator** Alisiyah Daya, BHSc (Honours), MSc Candidate
Health and Rehabilitation Sciences Graduate Program,
Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]
- Co- Investigator** Tianna Deluzio, BHSc (Honours), MSc Candidate
Health and Rehabilitation Sciences Graduate Program,
Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]
- Co- Investigator** S Deborah Lucy, BScMR, (PT) MCISc, (PT) MSc, PhD
School of Physical Therapy, Faculty of Health Sciences
Western University, London, Ontario
[REDACTED]
- Co- Investigator** Jennifer Boyko, PhD
Postdoctoral Fellow, Faculties of Health Sciences and
Information & Media Studies
Western University, London, Ontario
[REDACTED]

Participant Initials: _____

Version Date: 19/09/2016

1. Invitation to Participate

You have been invited to participate in a deliberative dialogue regarding the topic of facilitating the uptake of research evidence in cerebral palsy into practice because you are either affiliated with the Ontario Association of Children's Rehabilitation Services centres, you have a vested interest in cerebral palsy, you are a healthcare professional who works with people with cerebral palsy, you are a parent of a child with cerebral palsy, you are a person with cerebral palsy (over 18 years of age) or you are an administrator in healthcare or policy.

2. Purpose of the Letter

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

3. Purpose of this Study

The purpose of this study is to provide stakeholders in pediatric rehabilitation and cerebral palsy an opportunity to engage in a deliberative dialogue regarding research uptake in the field of pediatric rehabilitation. The deliberative dialogue will provide an environment that is conducive to cross-disciplinary interactions among stakeholders in various positions. This study aims to address the following question: How can we facilitate the use of research evidence to optimize outcomes of individual children with cerebral palsy?

4. Inclusion Criteria

For this study, eighteen stakeholders will be invited to participate in the deliberative dialogue. The stakeholders must be affiliated with cerebral palsy, pediatric rehabilitation, or healthcare in general in Ontario in some way. All participants will be 18 years of age and older and will be able to understand and speak English.

5. Study Procedures

If you agree to participate in this study, you will be asked to attend the deliberative dialogue on November 18th, 2016 and engage in a discussion with other stakeholders about knowledge translation and cerebral palsy. The deliberative dialogue will be held at *CanChild* Centre for Childhood Disability Research on McMaster University's campus in Hamilton, Ontario. The event will be held between 10AM and 3PM.

Participant Initials: _____

Version Date: 19/09/2016

A week prior to the deliberative dialogue, an Issue Brief will be sent out to all participants to provide a background and overview of the subject for deliberation. In addition, a background document containing participants' full names, along with their perspectives, will be pre-circulated to provided to provide transparency on the range of stakeholders who will take part in the dialogue.

At the deliberative dialogue, a facilitator will moderate the conversation and prompt participation from all stakeholders.

All participants will receive assurance that no comment will be attributed to individual people; all contributions will be held confidential. The topics will include: a brief introduction, discussion of the problem, potential solutions to the problem and implementation considerations. Three members of the research team will take time-stamped field notes. All participants will complete a brief questionnaire about their perceptions of effectiveness of the deliberative dialogue.

A week after the deliberative dialogue you will be sent a summary outlining the main themes discussed at the event by email (we can not guarantee that this method of communication is secure). Ten to twenty days after the deliberative dialogue, you will be contacted for a telephone interview in which you will be asked to reflect on the dialogue and the summary

and will be asked to provide any additional feedback regarding the topic of the discussion. It is anticipated that the interview will take 60 to 90 minutes to complete. It is mandatory for this interview to be audio-taped to ensure accuracy. After the interview is transcribed, you will receive a copy of the transcript for your approval by email (again, we can not guarantee that this method of communication is secure) prior to analysis. After the analysis is complete, you will receive a summary of the results by email.

6. Possible Risks and Harms

We do not perceive any major risks in this study. Both the facilitator and the person conducting the interviews will ensure that the discussions will proceed without distress to participants.

7. Possible Benefits

You may directly benefit from this study as you will have the opportunity to engage with stakeholders from different disciplines and with young adults and families with children with cerebral palsy.

Participant Initials: _____

Version Date: 19/09/2016

You may gain novel insights into knowledge translation, cerebral palsy, evidence-informed decision-making, and rehabilitation.

The possible benefits to society may be that children with cerebral palsy receive individualized and appropriate care that fits their own needs and goals. Additionally, the field of rehabilitation may benefit from novel or expanded knowledge translation methods. Finally, the Ontario Association of Children's Rehabilitation Services centres may benefit from recommendations on how to optimize outcomes for children with cerebral palsy and other childhood conditions and how to facilitate research uptake within their centres.

8. Compensation

We anticipate that some participants may be able to take part in this project as a part of their typical employment (e.g. as a publically funded worker). However, if you are participating in this research outside of the scope of your typical employment, you will be compensated for your time at the dialogue and participation in the interview for a total of \$350. All participants will be provided a parking voucher, food during the day, and remuneration for travel costs.

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 with no effect on your future (care, academic status, or employment). You will have the opportunity to review your transcribed interview to remove any content. Once approved by you, all data will be analyzed. You do not waive any legal rights by signing the consent form.

10. Confidentiality

Please be advised that although the researchers will take every precaution to maintain confidentiality of the data, the nature of the deliberative dialogue prevents the researchers from guaranteeing confidentiality. The researchers will remind participants to respect the privacy of your fellow participants and not repeat what is said during the discussion to others.

All data collected will remain confidential and accessible only to the investigators of this study. When the results are published, your name will not be used. No video or audio recordings will be captured during the deliberative dialogue. The mandatory audio-taped interview will be deleted after your transcript has been approved by you. Your confidentiality will be respected throughout this study.

Participant Initials: _____

Version Date: 19/09/2016

De-identified research records will be stored in a locked filing cabinet, on a password-protected computer in a secure office in Elborn College at Western University in Room 2300, on a password-protected and encrypted laptop, and later in secure archives at Western in London, Ontario and will be destroyed after 5 years.

Given that 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 access to 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 [REDACTED] or by email at [REDACTED]. If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics at [REDACTED] or by email at [REDACTED].

12. Consent

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

This letter is yours to keep for future reference.

Participant Initials: _____

Version Date: 19/09/2016

Consent Form

Facilitating the uptake of research evidence
in rehabilitation for children with cerebral palsy:
Combining deliberative dialogue and grounded theory approaches

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

Alisiyah Daya

Tianna Deluzio

S Deborah Lucy

Jennifer Boyko

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

Date

Name of Person Obtaining
Consent (Please print)

Signature of Person Obtaining
Consent

Date

Participant Initials: _____

Version Date: 19/09/2016

Legally Authorized Representative Information

Please return this information, in addition to the consent form, so that we can contact you for the post-deliberative dialogue interview and so we can send you the summaries.

Name: _____

Email: _____

Phone: _____

Participant Initials: _____

Version Date: 19/09/2

Appendix H: Issue Brief



How can we facilitate the use of research evidence to optimize outcomes of individual children with cerebral palsy?

Context for this Issue Brief

PURPOSE: To give background information about the issue and considerations as a launching point for the discussion on November 18, 2016

- Describe the role of the Ontario Association of Children's Rehabilitation Services centres in providing services to children with CP in Ontario
- Summarize research products from the Ontario Motor Growth, Move & PLAY, and On Track studies at CanChild Centre for Childhood Disability Research
- Review the framework these research studies have created for developmental assessment and monitoring of motor function, self-care, participation in family and recreation activities and playfulness of young children with cerebral palsy
- Outline how this framework can be used to help individualize care for children with cerebral palsy by supporting therapists when working with families to make decisions about goals and strategies for intervention
- Present some ideas to start the conversation about facilitating the use of research evidence to optimize outcomes for children with cerebral palsy

Table of Contents

| | |
|---|----|
| KEY MESSAGES | 3 |
| FRAMING THE PROBLEM..... | 4 |
| Cerebral palsy is a ‘high priority’ concern for people in the OACRS centres | 4 |
| Rehabilitation planning with children with CP is challenging for service providers..... | 5 |
| The Ontario Motor Growth, Move & PLAY and On Track studies aim to fill gaps in knowledge | 7 |
| Knowledge Summary / Issue Summary..... | 11 |
| IDEAS TO START THE CONVERSATION ABOUT FACILITATING THE USE OF RESEARCH EVIDENCE TO OPTIMIZE OUTCOMES FOR CHILDREN WITH CP..... | 11 |
| Knowledge Brokering | 12 |
| Educational Outreach Visits | 8 |
| Mandated Comprehensive Annual Assessments | 8 |
| IMPLEMENTATION CONSIDERATIONS..... | 9 |
| SUMMARY STATEMENT | 9 |
| Acknowledgements..... | 10 |
| References | 10 |
| APPENDIX: Knowledge Translation Planning Template | 12 |

KEY MESSAGES

FRAMING THE ISSUE

Traditional techniques for disseminating research evidence have limited impact on clinical practice. The issue for discussion is how to facilitate the use of research evidence to optimize outcomes of children with CP who receive services in Ontario.

- CP is a high priority concern for people in the OACRS centres
- Rehabilitation planning with children with CP is challenging for service providers
- The Ontario Motor Growth, Move & PLAY, and On Track studies are research studies designed to fill gaps in the fundamental knowledge needed to best support children and families

Defining Terms

CanChild CanChild Centre for Childhood Disability Research, McMaster University

CP “Cerebral Palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitations, 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.”^{1,pg9}

GMFCS Gross Motor Function Classification System

KT Knowledge Translation

OACRS Ontario Association of Children’s Rehabilitation Services

RCT Randomized Controlled Trial

IDEAS TO START THE CONVERSATION ABOUT FACILITATING THE USE OF RESEARCH EVIDENCE TO OPTIMIZE OUTCOMES FOR CHILDREN WITH CP

Through research at CanChild and conversations with therapists and families involved in the research studies, we can start the conversation with some ideas to consider.

Knowledge Brokering – Knowledge brokers who specialize in the communication of findings to knowledge users in their own context could be used in OACRS centres to bridge the research-to-practice gap by using the Ontario Motor Growth, Move & PLAY, and On Track assessments and frameworks in intervention planning.

Educational Outreach Visits - A knowledge broker or a representative (researcher, assessor, or family member) from Move & PLAY and On Track study teams could provide interactive educational workshops at OACRS centres to provide information about using assessments and frameworks.

Mandated Comprehensive Annual Assessments - Policy could change to mandate comprehensive annual assessment and developmental monitoring of all children with cerebral palsy across OACRS centres. Therapists are often pressed for time to balance assessment, treatment, and referral within the allotted visit time.

IMPLEMENTATION CONSIDERATIONS

What considerations need to be kept in mind when thinking about ideas to address the issue?

- What will it cost and what staffing resources are needed?
- How much time will it take to get it into practice?
- Will it be effective in the short term and over time?

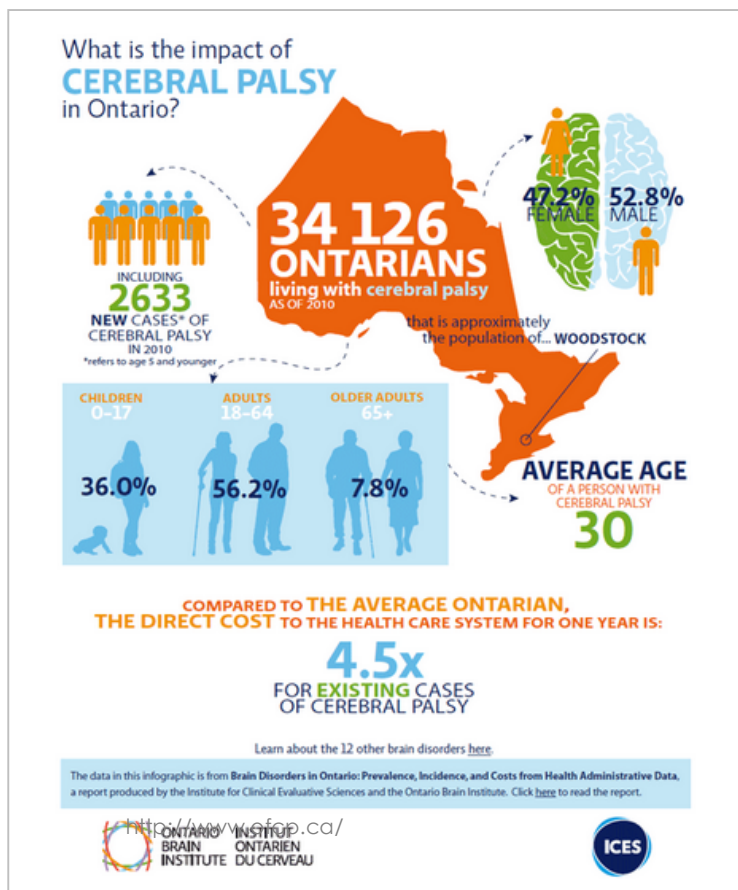
REPORT

Framing the Problem

Cerebral palsy is a 'high priority' concern for people in the OACRS centres

CP is the most common childhood neuromuscular condition seen by pediatric rehabilitation practitioners, including physical therapists, occupational therapists, and physicians.

Although CP is a non-progressive condition, functional decline by adulthood has been well reported.²⁻⁵ Recent research has suggested a decline in motor function that may begin as early as adolescence. Developmental patterns of motor function for children were graphed for all



five levels of the Gross Motor Function Classification System (GMFCS).⁶ Highest levels of functioning were shown to peak when children are 7 or 8 years old, followed by a decline in motor abilities for children and youth in GMFCS levels III, IV, and V.⁷

Three goals for early rehabilitation consistently identified by children with CP and their families^{8,9} are to:

- 1) optimize motor function
- 2) prevent the development of secondary conditions or impairments that impact life-long health
- 3) promote children's participation in their daily lives.^{10,11}

These goals are also consistent with the:

- **Equity Approach to Care** where appropriate individualized care is a key component.
- **OACRS Centres' Vision:** a world in which all children and youth have the best opportunity to reach their potential.

Rehabilitation planning with children with CP is challenging for service providers

The main challenge is that each child with CP is unique. CP is an umbrella term covering a wide range of gross motor as well as other developmental ability limitations resulting from impairment of the developing central nervous system in the early stages. Classification systems have been published over the last decade for movement,¹² hand,¹³ and communication¹⁴ abilities. Each of these systems groups the abilities of children with CP into five levels. For each system, level I describes children with the greatest functional abilities and level V describes children who rely on others and technology in every-day life. These three classification systems have been very useful for describing and understanding the varied performance of children with CP, and providing service providers with:

- enhanced communication among team members, including families
- a sharper ‘focus on function’
- assistance with realistic goal-setting
- assistance with intervention planning

As useful as these classification systems are, we know that ability levels vary widely from one child to the next. All three of the classification systems have five levels, so there are 125 possible combinations when we look at a child’s abilities on all three. In a large group of 671 children in the On Track study¹⁵ we observed 78 (62%) of the mathematically possible combinations. We would not expect to see all 125 combinations represented since some are functionally unlikely. We wanted to see if there were clusters of children (i.e. at least 5% of the sample) who shared a similar combination of abilities. About one in four children were clustered in this way, with the others showing more unique combinations, emphasizing how different individual children with CP truly are.

In ‘evidence informed practice’, clinicians are encouraged to use research evidence to help with decisions about interventions. The randomized controlled trial (RCT) research design has been widely accepted as the best way to test the effectiveness of an intervention. In an RCT, participants are randomly assigned to an intervention group or to a control group and the only expected difference between the groups is the effect of the intervention. RCTs are useful when you have a fairly uniform group of people and when the influences of other



personal or environmental factors are minimal. RCTs are less useful for understanding what is most effective for people with CP because there is such variation in how CP looks for each person. Our research has used an observational design or ‘comprehensive rehabilitation outcomes research’.¹⁶ It makes use of the other personal and environment factors and is structured around the World Health Organization’s “International Classification of Functioning, Disability and Health” (ICF).¹⁷ Comprehensive rehabilitation outcomes research is useful when you have a less uniform group of people (such as CP) and when there are significant personal and environmental influences.

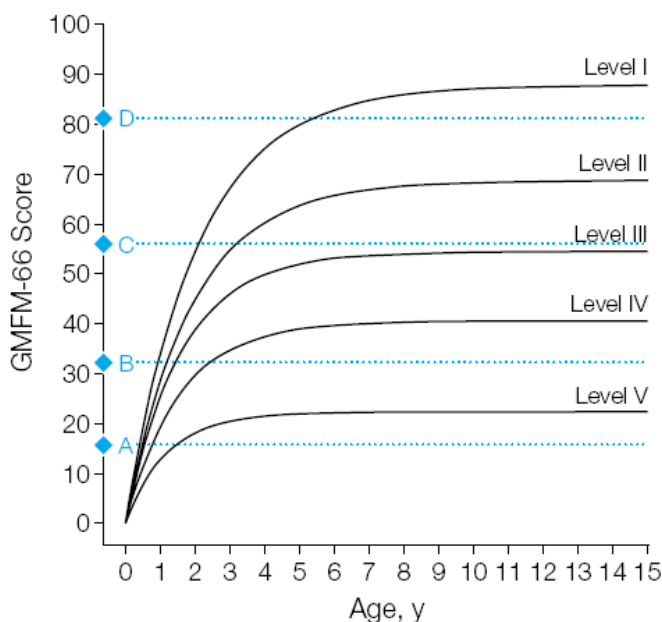
The Ontario Motor Growth, Move & PLAY, and On Track studies aim to fill gaps in knowledge to support children and families appropriately

The Ontario Motor Growth, Move & PLAY, and On Track studies provide new knowledge that increases our understanding of the complexities of CP. This helps us to support children and families appropriately.¹⁸ The findings from these studies add to what is known about comprehensively assessing children with CP and planning interventions to optimize outcomes. Knowledge products have been developed to support the use of knowledge in practice.

The Ontario Motor Growth Study¹⁹ was a longitudinal study designed to chart the gross motor progress of a randomly selected

sample of over 650 Ontario children with CP. In order to try to make the findings useful for all children with CP, the children who participated in the study were typical of children with CP across

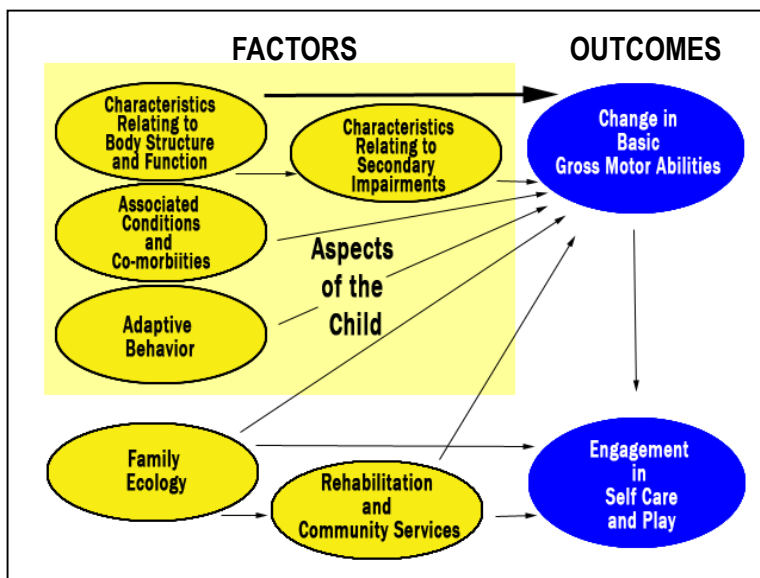
Figure 1. Predicted Average Motor Development by the Gross Motor Function Classification System Levels¹⁹



Ontario. Eighteen of the OACRS centres, and one additional therapy program, identified 2108 children in Ontario with CP under the age of 11 in 1996 when the study began.

Participants were randomly selected and invited to participate in the study. At the start of the study these children ranged in age from 1 to 13 years old and had a wide range of motor abilities. Assessments were done every 6 to 12 months over several years. Figure 1 shows the five Motor Growth Curves created to describe the patterns of motor development of children with varying "severities" of CP using the five levels of the GMFCS. The Motor Growth Curves track the average development of children in each level.

Figure 2. The Conceptual Model of the Move & PLAY Study (Chiarello et al. 2011)¹¹



The Move & PLAY

Study¹⁶ was designed using

comprehensive

rehabilitation outcomes

research to follow 430

children with CP aged 18

months to 5 years of age.

Reliable and valid measures

that are comprehensive

and brief to administer

were used to collect data at three points over one year. Data were collected on child, family, and service factors related to four outcomes: motor function, self-care participation, participation in recreation and leisure, and playfulness (Figure 2). The data were analyzed separately for children who are able to walk without a gait aide and for children who use either a gait aide or wheelchair for mobility. The factors associated with the outcomes differed depending on the group and also differ depending on the outcome. We believe these results are useful for service providers when working collaboratively with families on service delivery goals (e.g. realistic goal setting when the factors cannot be changed) and on strategies for individual children with unique characteristics (e.g. intervention planning when the factors can be changed).

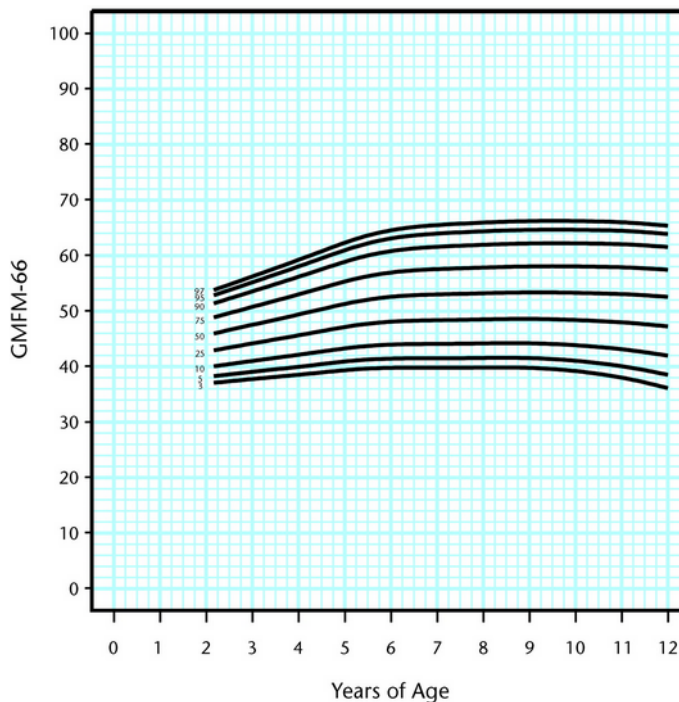
The On Track Study is currently in progress. Children in the On Track Study are 18 months to 12 years old. Our aim is to graph developmental patterns of balance, range of

motion, strength, endurance, and health conditions (all child factors in the Move & PLAY model). We will also describe outcomes of self-care participation and participation in recreation and leisure activities of children with CP. Six hundred and fifty-eight families have completed two assessments over one year. Four hundred and twenty-four families have completed five assessments over two years. We will create longitudinal growth curves¹⁹ using the same method as was done for the Ontario Motor Growth Study (Figure 1). Developmental curves use statistical analysis to link children in different classifications or ability levels. These will give an overall understanding of functioning of children in different groups. We will also create reference percentile graphs (Figure 3).²⁰ Percentile graphs show how children relate to other children with similar abilities and is comparable to the growth charts that are used to follow the height and weight of children as they grow. These will help to interpret how individual children change over time. Together, these results will enable us to understand average development of children in each of the five levels of the classification systems corresponding to various outcomes. These are guidelines for service providers to use when monitoring whether individual children are developing ‘as expected’, ‘better than expected’, or ‘more poorly than expected’ across the range of measures, as we are now able to do for gross motor function.²⁰

Knowledge Summary

- From the Ontario Motor Growth, Move & PLAY, and On Track studies, we have a framework for comprehensive developmental assessment and monitoring to optimize outcomes of motor function, self-care participation, participation in family and recreation activities, and playfulness of young children with CP.
- Therapists will be able to provide more information to families to assist with collaborative decision making about goals and strategies for intervention.
- Products from these three studies have the potential to significantly contribute to appropriately individualizing care for children with CP. Despite widespread use in research, these tools have made a slow progression into the clinical world.

Figure 3. Reference Percentiles for GMFCS Level III ²⁰



Issue Summary

- It is not clear how to disseminate this information in a family-centred way to support the goals of individual children and their families and ensure the information is used to support decision-making.
- The issue for discussion is how to facilitate the use of research evidence to optimize outcomes of children with CP who receive services in Ontario.

IDEAS TO START THE CONVERSATION ABOUT FACILITATING THE USE OF RESEARCH EVIDENCE TO OPTIMIZE OUTCOMES FOR CHILDREN WITH CP

Knowledge translation or KT happens when we move research findings from presentations

at academic conferences and from publications in professional journals, into the hands of people and organizations who can put it to practical use. We have attached to this report a Knowledge Translation Planning Template²¹ to help guide our dialogue through important components of the KT planning process. Through research at CanChild and in conversations with therapists and families involved in the research studies, we have come up with a few ideas to consider:

Knowledge Brokering

- A knowledge broker specializes in the communication of findings to knowledge users in their context.
- Knowledge brokers bridge the gap by linking research to practice. They have the potential to change behaviour by encouraging implementation of knowledge into practice and contextualizing research in practice. They do this by developing and strengthening skills, routines, and resources, empowering the people who have something to gain so they can see the fit with their existing routines.^{22,23}
- Knowledge brokers could be used in OACRS centres to bridge the research-to-practice gap by using the Ontario Motor Growth, Move & PLAY and On Track assessments and frameworks in intervention planning.
- In a 2009 study, where knowledge brokers were put in place, physical therapists reported increased knowledge and use of the pediatric measurement tools over the long term.²⁴

Educational Outreach Visits

- A knowledge broker or a representative (researcher, assessor, or family member) from Move & PLAY and On Track study teams could provide interactive educational workshops at OACRS centres to provide information about using assessments and frameworks.
- These outreach-type visits could focus on the knowledge products available for front line clinicians and parents (for example: Newsletters focused specifically for clinicians and families).
- Knowledge translation strategies are more effective if they are active and include educational outreach visits.²⁵⁻²⁷ We have seen this in various studies where regular educational sessions have helped to get information into use.

- In a 2010 study, it was found that a combination of interactive educational sessions, problem-based learning, networking, and newsletters improved physical therapists' actual knowledge regarding the specific assessments and treatments.²⁸

Mandated comprehensive annual assessments

- How often a child is scheduled for an OACRS clinic visit and the time allotted for the visit will vary across OACRS centres and across children. The age and needs of the child and the mandates and resources of the OACRS centre are some considerations. Therapists are often pressed for time to balance assessment, treatment, and referral within the allotted visit time.
- Policy could change to mandate comprehensive annual assessment and developmental monitoring of all children with CP across OACRS centres.
- Many of us will seek out health care when something needs attention, but people can also benefit from regular checkups to keep things running smoothly and to prevent problems. The American Physical Therapy Association is a strong advocate for annual physical therapy checkups. Broad health screening visits each year build ongoing relationships so therapists can work together with families to monitor a child's health over time. Staying connected in this way is especially helpful if referrals for evaluation and treatment, or referrals to other health care professionals, are needed.
- The developmental curves and percentile graphs fit nicely with the goals of regular check-ups and check-ins between children with CP and their families and health care professionals. This practice necessitates finding the balance between results of standardized assessments and the individual priorities and concerns of families.

IMPLEMENTATION CONSIDERATIONS

| Possible Options | Implementation Considerations |
|-----------------------------|--|
| Knowledge brokering | <ul style="list-style-type: none"> • brings high quality evidence to the right people, in the right way, to add value to therapists' work and see the direct impact of research for policy²³ • Funds and infrastructure supports are needed for creating knowledge broker positions within treatment centres²³ |
| Educational outreach visits | <ul style="list-style-type: none"> • Peer-to-peer learning environments encourage teamwork and sharing across disciplines²³ • Receiving information at conference-style meetings had limited effects on audiences²⁹ |

| | |
|---|---|
| | <ul style="list-style-type: none"> • Active strategies are needed to identify barriers and to discuss solutions to overcome them ²⁸ |
| Mandated comprehensive annual assessments | <ul style="list-style-type: none"> • Policy changes often take time to get into practice • Resources needs increase • Must consider shift in culture |

SUMMARY STATEMENT

This report provides a brief background of the Ontario Motor Growth, Move & PLAY, and On Track studies, the assessments they used, and their overall approach to comprehensive assessment and intervention planning. Materials from studies are typically presented at academic conferences and published in professional journals. Researchers want to make sure we are doing all we can to see that primary care teams and families are able to use the materials to work together on goals and interventions for individual children with CP. This Issue Brief has outlined the overarching questions, a few possible options, and considerations as a starting point for the deliberative dialogue conversation which will be focused on the following question: **How can we facilitate the use of research evidence, such as that produced by the Ontario Motor Growth, Move & PLAY and On Track studies, in services offered through the Ontario Association of Children’s Rehabilitation Services Centres to optimize outcomes of individual children with cerebral palsy?**

Acknowledgements

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Prepared by Doreen Bartlett, Alisiyah Daya, Dianne Russell, Barb Galuppi, Tina Hjoorngaard, and Jennifer Boyko. September 2016

The Ontario Motor Growth Study

<https://www.canchild.ca/en/resources/72-ontario-motor-growth-study>

The Move & PLAY Study

<https://canchild.ca/en/research-in-practice/current-studies/move-play-study-understanding-determinants-of-motor-abilities-self-care-and-play-of-young-children-with-cerebral-palsy>

The On Track Study is currently in progress

<https://www.canchild.ca/en/research-in-practice/current-studies/on-track>

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Knowledge Translation Planning Template©



INSTRUCTIONS: This template was designed to assist with the development of Knowledge Translation (KT) plans for research but can be used to plan for non-research projects. The Knowledge Translation Planning Template is universally applicable to areas beyond health. Begin with box #1 and work through to box #13 to address the essential components of the KT planning process.

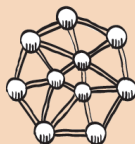
(1) Project Partners



- researchers
- consumers - patients/families
- the public
- decision makers
- private sector/industry
- research funding body
- volunteer health sector/NGO
- practitioners
- other



(2) Degree of Partner Engagement



- from idea formulation straight through
 - after idea formulation & straight through
 - at point of dissemination & project end
 - beyond the project
- Consider: Not all partners will be engaged at the same point in time. Some will be collaborators, end users or audiences, or people hired to do specific activities.

(3) Partner(s) Roles



- (1) What do the partner(s) bring to the project?
 - (2) How will partner(s) assist with developing, implementing or evaluating the KT plan?
- Action: Capture their specific roles in letters of support to funders, if requested.

(4) KT Expertise on Team



- scientist(s) with KT expertise
- consultant with KT expertise
- knowledge broker/specialist
- KT supports within the organization(s)
- KT supports within partner organization(s)
- KT supports hired for specific task(s)

(5) Knowledge Users (KUs)

Which KUs or audiences will you target?

- researchers
- health practitioners or service providers
- public
- media
- patients/consumers
- decision makers
 - in organization
 - in community
- policy makers
- private sector/industry
- research funders
- venture capitalists
- volunteer health sector/NGO
- other: specify _____

Consider: Have you included any of your audiences on your research team? If so, who and why (be strategic)?

(6) Main Messages

What did you learn, or what do you anticipate learning?

What messages do you anticipate sharing (up to 3 KU audiences can be included on this form)?

Audience 1 _____

Audience 2 _____

Audience 3 _____

OR

No idea yet; messages will emerge during research through collaboration with partners.

Consider: What can you feasibly do within this project, given time and resources? Aim for defining your Single Most Important Thing (SMIT) or Bottom Line Actionable Message (BLAM).

(7) KT Goals

What are your KT goals for each KU/audience?

| | | | | |
|-----------|--------------------------|--------------------------|--------------------------|-----------------------------------|
| Audiences | 1 | 2 | 3 | |
| | ↓ | ↓ | ↓ | |
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Generate... awareness interest |
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | practice change behaviour change |
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | policy action |
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Impart... knowledge tools |
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Inform... research product patent |
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | other ► _____ |

Consider: KT is applicable to all research; even single studies are shared via journal articles. However, intent to change practice, behaviour or policy must be supported by a body of high quality research evidence (synthesis). Always consider legal and ethical principles in your KT efforts.

(8) KT Strategy(s)

What KT strategy(s) will you use?

| | | | | |
|-----------|--------------------------|--------------------------|--------------------------|---|
| Audiences | 1 | 2 | 3 | |
| | ↓ | ↓ | ↓ | |
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Mostly Effective ¹ interactive small group educational outreach reminders |
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | IT decision support multi-prof collaboration mass media campaign financial incentive combined interventions |
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Mixed Effects ¹ conferences (didactic) opinion leaders champions educational materials patient-mediated interview performance feedback substitution of tasks peer reviewed publication |
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Limited Effects ¹ CQI - Continuous Quality Improvement |
| | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Effects Unsupported by Synthesis ² press release patent license arts-based KT social media networks communities of practice Café Scientifique webinar other ► _____ |

Consider: Multifaceted/combined KT strategies are more effective than single strategies.

NOTES

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(9) KT Process



When will KT occur?

- integrated iKT³ – researchers and research users will collaborate to shape the research process, e.g., setting the research questions, deciding the methodology, involvement in data collection and tools development, interpretation of findings and dissemination of research results
- end of grant KT³-KT undertaken at the completion of the research process
- both

Comment on the specifics of your KT procedures; describe how you are using iKT:



(10) KT Impact & Evaluation






(a) Where do you want to have an impact?

- healthcare/well-being outcomes
 - (clinical) practice
 - policies/systems
 - research & knowledge
- (b) How will you know if you achieved your KT goal(s)? Consider:
- reach indicators (# distributed, # requested, # downloads/hits, media exposure)⁴
 - usefulness indicators (read/browsed, satisfied with, usefulness of, gained knowledge, changed views)⁴
 - use indicators (# intend to use, # adapting the information, # using to inform policy/advocacy/enhance programs, training, education, or research, # using to improve practice or performance)⁴
 - partnership/collaboration indicators (# products/services developed or disseminated with partners, # or type capacity building efforts, social network growth, influencers, collaborativeness)⁴
 - practice change indicators (intent or commitment to change, observed change, reported change)
 - program or service indicators (outcome data, documentation, feedback, process measures)
 - policy indicators (documentation, feedback, process measures)
 - knowledge change (quantitative & qualitative measures)
 - attitude change (quantitative & qualitative measures)
 - systems change (quantitative & qualitative measures)

(c) Guiding Questions for Evaluation⁵

- 1) What internal/external factors do you need to consider? Where is the energy for this work? How have similar initiatives been evaluated in the past? (link this to partners, KUs)
- 2) Who values the evaluation of this initiative? What are they saying they need from this evaluation? (link this to partners, KUs)
- 3) Why are you evaluating? For program growth or improvement: accountability? Sustainability? Knowledge generation? (e.g., to know if the KT strategy met the objectives)
- 4) How will literature or existing theories inform how you evaluate the initiative?
- 5) Which questions/objectives are critical? (link this to KT goals, process, impact)
- 6) Will you focus on process or outcome information? What are your pre-determined outcomes? How will you capture emergent outcomes? Does this information already exist in your system? (link to methods, process, impact)
- 7) Will methods be quantitative, qualitative or mixed? Do tools exist or will you need to create your own? (link to KT methods)
- 8) What perspective or skill set do you need to help you reach your evaluation objectives? (link to partners, KUs)
- 9) How do your stakeholders wish to receive this information so that it will be valuable and useful to them? How will you engage them throughout? (link to partners, KUs)

| | | |
|---|--|--|
|  (11) Resources |  (12) Budget Items |  (13) Implementation |
| <p>What resources are required?</p> <ul style="list-style-type: none"> <input type="checkbox"/> board <input type="checkbox"/> financial <input type="checkbox"/> human <input type="checkbox"/> IT <input type="checkbox"/> leadership <input type="checkbox"/> management <input type="checkbox"/> volunteer <input type="checkbox"/> web <input type="checkbox"/> worker <input type="checkbox"/> other: <i>(list)</i> <div style="border: 1px solid black; height: 40px; width: 100%;"></div> <p style="text-align: right;">NOTES</p> | <p>What budget items are related to the KT plan?</p> <ul style="list-style-type: none"> <input type="checkbox"/> accommodation <input type="checkbox"/> art installation <input type="checkbox"/> evaluation specialist <input type="checkbox"/> graphics/imagery <input type="checkbox"/> knowledge broker <input type="checkbox"/> KT specialist <input type="checkbox"/> mailing <input type="checkbox"/> media release <input type="checkbox"/> media product (e.g. video) <input type="checkbox"/> networking functions <input type="checkbox"/> open access journal <input type="checkbox"/> plain text writer <p>Estimated costs for items listed</p> <div style="border: 1px solid black; height: 40px; width: 100%;"></div> <p>NOTE: Be sure to include all KT costs in your budget for funders</p> | <p>Describe how you will implement your KT strategy(s): What processes/procedures are involved? If practice or behaviour change is the focus, how will you ensure the knowledge (intervention) you are transferring retains quality, fidelity, sustainability?</p> <div style="border: 1px solid black; height: 150px; width: 100%;"></div> |

Barwick, M. (2008, 2013). Knowledge Translation Planning Template. Ontario: The Hospital for Sick Children.

1) Grol & Grimshaw 2003 *The Lancet*, 362(9394): 1225. 2) *KT strategies may have support from individual studies*. 3) CHFR <http://www.chfr.ca/29448.html>. 4) Sullivan, Strachan, & Timmons. *Guide to Monitoring and Evaluating Health Information Products and Services*. <http://www.infonotech.org/hipnet/MEGUIDE/MEGUIDE2007.pdf>. 5) Parker, K (2013). *KT and Evaluation*. Unpublished, courtesy of Knowledge Translation Professional Certificate, Learning Institute, Hospital for Sick Children.

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Appendix I: Deliberative Dialogue Summary



How can we facilitate the use of research evidence to optimize outcomes of individual children with cerebral palsy?

Deliberative Dialogue Summary

November 18, 2016

Summary of the Dialogue

On November 18th 2016, seventeen stakeholders with diverse perspectives convened at CanChild at McMaster University to engage in a deliberative dialogue about the issue of how to facilitate the use of research evidence to optimize outcomes of children with cerebral palsy (CP) who receive services in Ontario. Stakeholders included 3 Service Providers, 2 Researchers, 3 Service Managers, 1 Service Administrators, 2 Policy Makers, 3 Young Adults with CP and 3 Parents of an individual with CP. Participants were given name tags and colour-coded stickers to signify which perspectives they identified with. The deliberative dialogue opened with an introduction to the Chatham House Rule, reinstating that participants in the meeting should free to use the information received, but the identity/affiliation of the speakers and participants should not be revealed.

In an icebreaker activity, participants were asked to introduce themselves by first name and to declare which perspective they knew most about as well as which perspective they knew least about. Through this ice breaker, it was clear that many participants knew least about the development of policy into change in practice and about the lived experience of people with CP.

The dialogue established that there are many steps involved in getting research evidence into practice: from Research to Policy to Practice to People (youth and families).

The discussion reminded us that evidence is one factor in a political system but representatives also bring forward what they hear from constituents. This is an interesting tension for policy people to manage, representing both the evidence and the constituency.

Participants watched a short presentation highlighting the Background Information and Overview of Evidence from the Issue Brief circulated prior to the dialogue. This was followed by a short video called “Checking Up and Checking In: Partnering with Families of Children with Cerebral Palsy” to promote the developmental curves and percentile graphs being created in the On Track study which fit nicely with the goals of regular check-ups and check-ins between children with CP, their families, and health care professionals: Finding the balance between results of standardized assessments and the individual priorities and concerns of families.

Overall, participants were pleased with the multiple perspectives represented in the dialogue discussion, although younger children with CP might have been included as well.

DELIBERATION ABOUT THE ISSUE: CONSIDERATIONS AND CHALLENGES

Respecting and Accommodating Parents/Families:

- Parents all have different levels of understanding of and sensitization to research. It can be very difficult to find and understand research reports and to navigate the system. This can cause parents to feel disenfranchised and distrusting.
- Paring down research evidence to find how it applies to an individual is important in order for each person to see the relevance.

- In general there is a need for a more positive tone, both for clinical reports and conversations with youth and families with a strengths-based approach that focuses on abilities rather than limitations.
- The classification systems (For gross motor, manual and communication abilities) are positively worded and focus on the abilities more than the limitations. However, classifications may be most useful in early conversations for thinking about goals, and it may not be necessary to refer to them throughout care.
- Parents may feel resistant to evidence comparing children to any type of norms. No parent wants to see evidence that shows their child is not fitting, not measuring up, and may prefer individualized discussions and goals that are unique to the child.
- Some parents like the clarity, cleanliness, and simplicity of the medical model (including classifications, standardized assessments and norms).
- Respect the diversity of parent preferences and acknowledge that it isn't "one size fits all" and there isn't just one way to speak to parents.

Keeping Service Providers in the Know

- How do service providers access research and where do they go to help translate it so that they can speak knowledgeably to youth and families?
- Instructors and teaching institutions have the responsibility to educate new service providers about the need to spend time helping families to navigate and understand research findings – to empower themselves.
- Time is a major barrier for clinicians. There is an unwritten expectation to be up-to-date but yet there isn't much conversation or support for how to do that. We need to acknowledge that clinicians require built-in time to find information and to have collaborative discussions with colleagues about implementation strategies.

Accessibility of Research

- When researchers publish results in academic journals, they are not easily accessible especially for parents or members of the general public and they are generally not written in a user-friendly way.
- Research needs to be easy for everyone to digest. Stakeholders have one key question: What is the bottom line? What do the findings mean for parents? For youth? For service providers? For policymakers?

Service Inefficiencies and Inconsistencies

- Lack of consistency exists across Ontario. Different regions and centres have different age cut-offs and varied guidelines for service.
- In general, people with high needs are a priority for service and others who are deemed “less complex” receive less care.
- Do older youth know that they can still receive services from Children’s Treatment Centres (CTC)s? Services tend to be more family-centered at younger ages but as children approach school age, services become less so.
- Regular, holistic, comprehensive assessments do not appear to happen consistently and time and resources seem to be one of the biggest reasons.
 - What if we mandate these type of regular checkups and a family doesn’t want them? That isn’t being family centered, telling them what they need instead of letting them decide what they need.
- Ontario Association of Children’s Rehabilitation Services (OACRS) centres are receiving an increase in clients who are younger in age but the resources have not increased accordingly.
- Services for children with autism spectrum disorder have received new funding and resources; this is an example where policy change was driven by what families asked for.

Complexity of Policy

- There are multiple layers to policy, including governmental and organizational.
- A lot of people are currently in service in the current system so it’s not realistic to think we could stop the clock and start over. Things need to roll out slowly with internal approvals.
- There’s a need for better integration of rehabilitation services across the province, through all OACRS centres and across communities.

DELIBERATION ABOUT IDEAS TO ADDRESS THE ISSUE AND IMPLEMENTATION CONSIDERATIONS

Annual Assessments

- Is this happening already to some extent? We need a baseline of what is currently happening in OACRS centres.

- The purpose of annual assessments is to help families and youth find their way as children develop over time, keeping everyone engaged.
- How is an annual “assessment” different from an annual “review”. Calling it “annual family team meeting” puts the focus more on being more collaborative.
- Who would be at these meetings? What is the vision for who runs the assessment?
- Important to maintain choice for everyone involved.
- Potentially bring these assessments to individuals in their homes or close to home. People in the circle of care need to be mindful about the stress on the children and the adults.
- Be aware of services that are hard for families to access, as opposed to families who are hard to serve.

Suggested tools for Knowledge Translation (KT)

- *Archived Webinars*
 - Economical and can watch them on your own time (~1 hour for professionals).
 - Could be open to families and youth with a different and more engaging approach with contact opportunity to follow up and ask questions.
 - Offer through CanChild with materials posted for easy access – one stop shopping.
- *KT Summaries*
 - Design separate packages for clinicians and families but allow everyone to have access to all. Focus on the bottom line, succinct key messages.
 - Packages for youth should be much shorter – quick and entertaining. Materials that are relevant to families should be written and directed to families; clinicians and policymakers will see and hear the messages.
 - We must sufficiently impress and hook people with credible evidence. No need to dumb things down – but maintain credibility in an interesting manner.
 - Parents may need education/tips about how to evaluate credibility of evidence.
 - Outreach to pediatricians and family doctors to have access to KT summaries.
- *Research Position*
 - Each OACRS centre could hire a part time research person to support families and professionals on finding, understanding, and integrating relevant research evidence.
- *Collaborative Research*
 - Engage clinicians all over the province as participants in research, beyond the usual suspects/usual centres who participate in research.

This helps to normalize behaviours, recognize that we are all working together toward the same goal, developing relationships, champions, and a network of people who are engaged.

Strength-Based Strategies

- *Social Media and Marketing*
 - Clinically relevant Short Videos for youth depicting relatable people, images, and content (e.g. Draw my life/whiteboard videos) on YouTube or Facebook or in waiting areas with TV monitors. Videos of topic of week/month with invitation to visit an event or a website. CTCs could share these videos on their own websites. CTCs could also be encouraged to connect to social media such as Facebook and Twitter.
 - Facebook groups designed to disseminate information to parents who join the group or who join a list through short videos.
- *Culture Shift and Services*
 - Search for those (families or service providers) who have the desire and opportunity to learn. Change in perspective regarding productivity – more emphasis on doing the best, not the most.
 - More opportunities to attend conferences and time allotted to share what was learned with colleagues.
 - Revisit accreditation at OACRS – do the standards include the developmental monitoring measures we are considering? Establishing standards in performance plans so that they can be measured in some way may increase the likelihood of follow through. If we don't *need* to do something, we may not get to it.
 - Educational Outreach: train the trainer type visits – the downside of this is that typically there is peaked interest at first but then interest diminishes over time.
 - CanChild is meant to be an honest broker and they hold a unique position to offer KT services. Clinicians at OACRS centres should know that CanChild is a good place to start when they have a clinical question.
 - Researchers should remember to send executive research summaries both to the Board of Directors Chair, as well as the Chief Executive Officers of the OACRS centres. Also remember to direct new evidence to the CEO of OACRS; her role is to disseminate through many networks/pathways to get information out to all centres.
- *Engage Families and Youth*
 - Encourage children and family to create demand. Through educational guidelines regarding what to expect, regardless of geographic location, families will know what to expect from their CTCs with respect to annual assessments. Although heterogeneous, we can find some commonalities that should be occurring during rehabilitation annual assessments. We can empower families to speak up about their rights.

- Engage family advisory councils and have a separate youth advisory committee to take part in dissemination and educational strategies.
- Ensure that groups always include individuals with CP/families of individuals with CP to continue and expand the validation of the knowledge and the value parents and youth bring to the relationship. That it not be an event, give effort, and respectful attention to this so it unfolds organically until we always work together in a unified way.

RECOMMENDATIONS FOR KEY STRATEGIES TO MOVE EVIDENCE INTO PRACTICE

- *Creating educational materials to encourage KT*
 - Combined with one-on-one sessions for clinicians and families to understand the specific application of “how this applies to me”.
- *Focus on CanChild efforts*
 - Ensure that clinicians at CTCs know how to navigate CanChild website.
 - Email blast from CanChild/OACRS to highlight key items and key pieces of evidence and their potential impacts with different versions for families and clinicians.
 - Hold parent information sessions.
 - Advertise CanChild use and website in waiting rooms more.
- *Knowledge Brokering*
 - Combined with other educational efforts (mentioned above).
 - Having information formatted in lay terms would be helpful and more efficient to understand.
- *Communication efforts targeted towards young people*
 - Draw my life, whiteboard style presentations (30-60 seconds).
- *Efforts Geared to Clinicians*
 - Make time for service providers to keep up with research evidence and share information with one another. Build in time for scheduled learning blocks for clinicians for webinars.
 - Reminder to direct families to existing KT materials/CanChild
 - All regular output shared with parents should also be shared with clinicians – constant update about what is going on.
- *Explore Relationship Between Program Supervisors, Communities, and Ministries.*
- *Value the Knowledge of Children, Youth, Parents, and Families.*
- *Continue to grow and expand the relationship between OACRS and CanChild.*

NEXT STEPS

The meeting wrapped up with a description of the next steps in this process, including preparation of this summary, post-deliberative dialogue interviews with each participant, participants' reviews of their transcribed interviews, and finally, a qualitative analysis of all of the planning and documentation of the deliberative dialogue using grounded theory methods to describe the findings of this collaborative work. The results will inform the KT plan of the On Track Study (and other studies) conducted through CanChild.

The Deliberative Dialogue process addresses an issue through collective problem solving. Through this process we are able to harness information, convene stakeholders, and facilitate change by empowering participants to meet pressing health issues creatively, setting agendas, taking well-considered actions, and effectively communicating rationale.

Acknowledgements

The Deliberative Dialogue was facilitated by Dianne Russell in consultation with Jennifer Boyko. Notes were taken on the day of the dialogue by Alisiyah Daya, Tianna Deluzio and Barb Galuppi.

Citation

Daya A, Galuppi B, Bartlett D. Dialogue Summary: How can we facilitate the use of research evidence to optimize outcomes of individual children with cerebral palsy? CanChild Deliberative Dialogue: 18 November 2016.

Appendix J: Ethics Approval



Research Ethics

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: 108262
Study Title: Facilitating the uptake of research evidence in rehabilitation for children with cerebral palsy: Combining deliberative dialogue and grounded theory approaches

HSREB Initial Approval Date: October 15, 2016
HSREB Expiry Date: October 15, 2017

Documents Approved and/or Received for Information:

| Document Name | Comments | Version Date |
|---------------------------------|--|--------------|
| Western University Protocol | Received October 14, 2016 | |
| Recruitment Items | Recruitment Emails - Received September 19, 2016 | |
| Letter of Information & Consent | | 2016/10/14 |
| Instruments | Evaluation | 2016/07/05 |
| Instruments | Interview Guide - Received September 19, 2016 | |
| Instruments | Deliberative Dialogue Agenda - Received September 19, 2016 | |
| Other | Issue Brief - Received September 19, 2016 | |
| Other | Background Information on Participants - Received September 19, 2016 | |
| Other | Letter from McMaster HIREB - Received for Information Only | 2016/09/21 |
| Other | References - Received July 11, 2016 for Information | |

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. Marcelo Kremenutzky, HSREB Vice Chair

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

Curriculum Vitae

EDUCATION

- 2015-2017 **Master of Science: Health and Rehabilitation Sciences**
Western University, London, ON, CAN
Supervisor: Dr. Doreen Bartlett
- 2010-2015 **Bachelor of Health Sciences (BHSc): Honours Specialization in Health Sciences**
Western University, London, ON, CAN
Graduated with Distinction

SCHOLARSHIPS AND AWARDS

- 2017-2016 **Western Graduate Research Scholarship**
- 2015- 2011 **Dean's Honour List for the Faculty of Health Sciences**
- 2010 **Western Continuing Admission Scholarship**

ACADEMIC CONTRIBUTIONS

- 2015-2017 **Research Assistant with Dr. Bartlett**
- 2017 **Teaching Assistant in Occupational Therapy**

PRESENTATIONS & CONFERENCES

Daya, A. & Belliveau, M. Identifying the gaps in clinical documentation to improve quality of care in the OBCU at Victoria Hospital.

- Faculty of Health Sciences Research Day. London, ON. March 25 2015. Poster Presentation
- Western Student Research Conference. London, ON. March 21 2015. 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 (Work in progress)

- Faculty of Health Sciences Research Day. London, ON. March 22 2016. Poster Presentation
- CanChild Family Engagement Day Conference. Hamilton, ON. April 2 2016. Poster Presentation

Deluzio, T. Daya, A., Bartlett, D. How do families of children with cerebral palsy prefer to receive individualized evidence-based information? (Work in progress)

- Faculty of Health Sciences Research Day. London, ON. March 22 2016. Poster Presentation
- CanChild Family Engagement Day Conference. Hamilton, ON. April 2 2016. Poster Presentation

Daya, A. Using a Deliberative Dialogue to Facilitate the Uptake of Research Evidence for Children with Cerebral Palsy

- On Track Wrap Up Meeting. London, ON. June 14 2017. Power Point Presentation