

PARENT ENGAGEMENT IN DEVELOPMENTAL REHABILITATION
SERVICES

PARENTS' ATTENDANCE, PARTICIPATION AND ENGAGEMENT IN
CHILDREN'S DEVELOPMENTAL REHABILITATION SERVICES

By MICHELLE PHOENIX, B.A.Sc., M.H.Sc.

A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the
Requirements for the Degree Doctor of Philosophy

McMaster University © Copyright by Michelle Phoenix, May 2017

McMaster University DOCTOR OF PHILOSOPHY (2017) Hamilton, Ontario
(Rehabilitation Science)

TITLE: Parents' attendance, participation and engagement in children's developmental
rehabilitation services

AUTHOR: Michelle Phoenix, PhD. (McMaster University)

SUPERVISOR: Dr. P. Rosenbaum NUMBER OF PAGES:9, 161

Lay abstract

Children's developmental rehabilitation services are thought to be most effective when parents consistently attend, participate and engage in the service. When families do not consistently attend, participate or engage in services they can be labelled as 'hard-to-reach'. Little is known about why families are hard-to-reach, if there are organizational barriers to service use, and how to promote engagement. This thesis provides a foundation for understanding parent engagement by exploring the clinical application of family-centred service, Family Stress Theory, and ethical principles. A grounded theory study is presented to contextualize parent engagement and explain how parents engage in their child's developmental rehabilitation services. Service providers, organizational leadership, and policy makers can apply this theory to promote access and engagement in children's developmental rehabilitation services.

Abstract

Parent engagement in children’s developmental rehabilitation services is thought to be a fundamental component that is needed for children to reach their potential. This is especially true in the approach known as family-centre services – an approach that positions parents as partners in their child’s services. However, service providers and organizations can have difficulty engaging those parents who often miss their child’s appointments. These families are typically referred to as ‘hard-to-reach’, however this label may ascribe ‘blame’ to parents and lead service providers, researchers and policy makers to overlook the social, organizational, and economic barriers that can limit families’ use of services. Chapters 2-4, explore multiple avenues to contextualize parents’ attendance and engagement in children’s therapy services by applying family centred service tenants, Family Stress Theory, and ethical principles. These chapters lay the foundation for the grounded theory study presented in Chapter 5. This study, conducted with parents of children who use developmental rehabilitation services, describes the conditions that affect parent engagement and presents The Phoenix Theory of Parent Engagement to illustrate how parents attend, participate and engage in their child’s therapy service. These results are presented as a metaphorical *journey* through children’s developmental rehabilitation services in pursuit of *child health and happiness*. The implications of this theory are presented as they might be relevant to service providers, organizational leadership, and policy makers. These ideas are offered in an effort to inspire a coordinated effort to improve access and excellence in the provision of developmental rehabilitation services for children and families.

Acknowledgements

I humbly thank my supervisor Dr. Peter Rosenbaum, whose mentorship and friendship have changed my life. Dr. Rosenbaum inspires all his students to change the world, then positions us to do so through encouragement and selfless sharing of his knowledge and skills.

I deeply appreciate my committee member Dr. Susan Jack for pushing my thoughts and the quality of my research to new heights. Your kindness and brilliance are beyond measure.

I gratefully thank my committee member Dr. Cheryl Missiuna for always believing in me and caring about me and my future. I have treasured, and will always welcome, your advice.

I am indebted to the children, families, clinicians and organizational leadership at KidsAbility Centre for Child Development. You were the seed, the soil, the water and the sun that allowed me and this work to grow.

I have been blessed with caring and brilliant friends who have shared their ideas, resources and support throughout this journey. Sincere thanks to Dr. Briano DiRezze, who welcomed me to the program, offered advice at every stage, and reviewed my thesis materials. Warmest thanks to colleagues at *CanChild*, the School of Rehabilitation Science, and the Grounded Theory Club for joining me on this ride.

I am grateful for the funding provided to me by the Canadian Institutes of Health Research (Doctoral Award) and the Canadian Child Health Clinician Scientist Program (Career Enhancement Program Award).

Most importantly, all my love and my heart to my children, my husband, and our families. In a million ways on a thousand days, you made this possible. Thank you, Andrew, Maya, Caileigh, Owen, Freda, Allen, Ken and Sue.

Table of Contents

Chapter 1. Introduction: Setting the Stage	1-14
Context and personal assumptions that frame the issue of parent engagement in children’s developmental rehabilitation services	1-3
Background literature on parent engagement in children’s developmental rehabilitation services	3-8
Methodological and philosophical underpinnings of this work	9-10
How and why have I positioned myself within this research?	10-11
The overarching purpose and aim	11
A brief overview of the thesis components	12-14
Chapter 2. Laying the Foundation: Family-Centred Services	15-36
Introduction to Chapter 2	15-16
Letter of permission to reprint manuscript 2a	17
Letter of permission to reprint manuscript 2b	18
2a. In Press Manuscript. Establishing partnerships with parents in the provision of children’s speech-language therapy services	19-32
2b. Published Manuscript. Client-centred occupational therapy with children a critical perspective	33-36
Chapter 3. Laying the Foundation: Application of Family Stress Theory	37-54
Introduction to Chapter 3	37
Manuscript under review. Presenting the Model of risk, disability and hard-to-reach families to inform early intervention services	38-53
Figure 1. The Model of Risk, Disability and Hard-to-Reach Families	54
Chapter 4. Laying the Foundation: Application of Ethical Principles	55-65
Introduction to Chapter 4	55
Letter of permission to reprint chapter 4	56
Published book chapter. Service provision for hard-to-reach families: what are our responsibilities?	57-65
Chapter 5. Building from the Foundation: A Theory of Parent Engagement in Children’s Developmental Rehabilitation Services	66-139
Introduction to Chapter 5	66-67
5a. Manuscript prepared for submission. Contextualizing parent engagement in children’s rehabilitation services: <i>The journey to child health and happiness</i>	68-101
Figure 1. The family and service conditions that impact parents’ engagement in therapy	102
5b. Manuscript prepared for submission. A grounded theory of parent engagement in children’s developmental rehabilitation services: <i>The journey to child health and happiness</i>	103-137

Figure 1. The parents' gears of attendance, participation and engagement	138
Figure 2. The child, parent, professional or organizational grease and grit that impact gear movement	139
Chapter 6. Conclusion: Implications for practice, policy and research	140-153
Conclusion: Implications for practice, policy and research	140-141
Implications for service providers	141-143
Implications for organizational leadership	143-145
Implications for policy-makers	145-148
Implications for researchers	148-149
Summary	150-151
Parents, continue to...	151
Table 1. Implications for Service Providers, Organizational Leadership, Policy-Makers, and Researchers: An Overview of Ideas we can all Apply in Daily Practice	152-153
References	154-161

List of figures and tables

Chapter 3. Figure 1. Page 54

The Model of Risk, Disability and Hard-to-Reach Families

Chapter 5a. Figure 1. Page 102

The family and service conditions that impact parents' engagement in therapy.

Chapter 5b. Figure 1. Page 138

The parents' gears of attendance, participation and engagement

Chapter 6. Table 1. Pages 152-153

Implications for Service Providers, Organizational Leadership, Policy-Makers, and Researchers: An Overview of Ideas that can all Apply in Daily Practice.

Declaration of Academic Achievement

I was the **sole author** on the following components of this thesis and have benefited from the guidance, review, and feedback from my advisor Dr. Peter Rosenbaum, and committee members Drs. Susan Jack and Cheryl Missiuna:

Chapter 1, Chapter 2a, Chapter 4, Chapter 6

I was the **primary author** on the following components of this thesis and have benefited from the contributions of co-authors as follows:

Chapter 2b. Sandra VanderKaay was a co-author on this publication. In this role, she provided feedback on the initial ideas for the paper, contributed to writing a minor section of the paper, and reviewed the entire paper.

Chapter 3. Dr. Peter Rosenbaum was a co-author on this publication. In this role, he provided feedback on drafts of the manuscript that I wrote. I was responsible for the intellectual development of this paper and created the Model of Risk, Disability and Hard-to-Reach Families.

Chapter 5. Drs. Susan Jack, Peter Rosenbaum, and Cheryl Missiuna are co-authors on the two manuscripts presented in Chapter 5. In this role, they provided guidance and support in developing and carrying out the thesis study, analyzing the data, and preparing the manuscripts. I was responsible for development of the theory presented in these papers, but benefited from discussion and feedback from all co-authors. I was responsible for writing these manuscripts and co-authors contributed by reviewing drafts and making suggestions that enhanced the quality of the work.

Chapter 1. Introduction: Setting the Stage.

Context and Personal Assumptions that Frame the Issue of Parent Engagement in Children's Developmental Rehabilitation Services

The **United Nations (UN) Convention on the Rights of the Child** was developed to respect and protect children; it recognizes the child's family as "the natural environment for the growth and well-being" (UN Human Rights Office of the High Commissioner, 1996). According to this treaty, whenever it is possible the government should provide families with education, health, childcare and rehabilitation programs. Therefore, within a Canadian context, children have a right to publicly-funded rehabilitation services, and my work focuses on these services as offered in Ontario, Canada. These services are intended to help children develop to the best of their potential, live with dignity, experience independence and participate actively in their communities (UN Human Rights Office of the High Commissioner, 1996).

The **World Health Organization's ICF framework** highlights the importance of community participation, recognizing it as equally important to the body functions and structure and activity components that together comprise health (World Health Organization, 2001). The environment and personal factors also gain prominence in this framework and must be considered in an overall picture of an individual's health. The ICF can be used to inform clinical rehabilitation practice with respect to goal setting and therapy planning (Constand & Macdermid, 2013; Darrah, 2008; Kraus de Camargo, 2011). Conceptually, the ICF may help to shift clinical practitioners' and researchers'

thinking beyond a medical approach focussed on fixing body functions and structure, to a biopsychosocial approach that promotes and measures function in a child's real world environments (Cunningham et al., 2017; Rosenbaum & Gorter, 2012). The family is once again recognized as the child's primary natural environment, so the needs of parents must be recognized alongside those of their child (Rosenbaum, 2009; Rosenbaum & Gorter, 2012). The increased focus on the child's function reminds practitioners and researchers that children may demonstrate variation in the way that they perform a skill or participate socially (Rosenbaum, 2006). Children are in a constant state of development and therefore need opportunities to participate socially to find their place in society and prepare for their future (Rosenbaum, 2009; Rosenbaum & Gorter, 2012).

The biomedical model focuses on fixing deficits within the body functions or structure, whereas the biopsychosocial model allows for the recognition of child and parent strengths that can be nurtured and developed, even in the face of functional differences or impairments. Resulting models of care prioritize family strengths, focus on solutions, recognize resilience, and empower families to make change (Baldwin et al., 2013; McConnell et al., 2013; Patterson, 2002). A **strengths-based approach** to services naturally fits with family-centred care by respecting the knowledge and skills that parents bring to the therapeutic relationship (Baldwin et al., 2013). Integration of **Family Stress Theory** with a strengths-based model allows for detailed exploration and identification of the family's stressors in addition to their resources that, together with their perspective on each, accounts for why some families experience crisis (Patterson, 2002). Family Stress

Theory has been used to investigate how parents adjust to periods of major change and exhibit resilience when they have a child with a chronic illness or disability (Patterson 1988; Patterson 2002). For many years raising a child with a disability was considered to be a strain on parents causing stress, depression and crisis; however, this negative perspective has been criticized, and a positive lens has been applied to focus on the strength and resilience in these families (McConnell et al., 2013; Patterson 2002; Risdal & Singer, 2004).

Background Literature on Parent Engagement in Children's Developmental Rehabilitation Services

Modern pediatric rehabilitation services are designed to promote participation in real world contexts, such as home or school, and improve quality of life for children with disabilities (King et al., 2002). In the language of the World Health Organization's International Classification of Functioning, Disability and Health (ICF) these services have been shown to improve children's body structure (Novak et al., 2013), functional skills (Chen, Heinemann, Bode, Granger & Mallinson, 2004), and community participation (Law et al., 2011). These goals are addressed by many rehabilitation professionals including occupational therapists, physical therapists, speech-language pathologists and social workers. Service providers are encouraged to use a **family-centred** model of practice when providing services to young children and their families (Rosenbaum, King, Law, King & Evans, 1998) – an approach that regards parents as the experts on their child and provides parents with opportunities to direct their child's

therapy (Rosenbaum et al., 1998). Kuhlthau et al. (2011) completed a systematic review of family-centred service in medical, nursing, sociology and psychology literature and found “positive associations of FCC (family-centred care) with improvements in efficient use of services, health status, satisfaction, access to care, communication, systems of care, family functioning, and family impact/cost.” (p. 136) Even with strong evidence to support the use of family-centred care there are challenges in implementing this model in rehabilitation (Bamm & Rosenbaum, 2008; Phoenix & Vanderkaay, 2015; Sumsion & Smythe, 2000). A common challenge in pediatric health and rehabilitation services concerns how to engage families who appear to be disengaged as indicated by frequently missed or cancelled appointments (Arai, Stapley & Roberts, 2014; Ballantyne, Stevens, Guttman, Willan & Rosenbaum, 2012; Phoenix & Rosenbaum, 2014).

Although **parental engagement** is thought to be a critical component of children’s therapy, it is poorly defined and understood (King, Currie & Petersen, 2014; Staudt, 2007). Conceptualization of engagement ties directly to motivation and includes clients’ affective, cognitive, and behavioural commitments (King et al, 2014). Given that children cannot make decisions about therapy for themselves, parent motivation is key to understanding how the family will engage in services (Arrigo, Ziviani, Poulsen, Copely & King, 2016). The term ‘was not brought’ has been suggested to replace the phrase ‘did not attend’ to illustrate that parents are making decisions on behalf of their child (Arai, Stapley & Roberts, 2014). This change highlights the need to focus on the parents’ responsibility to access care for their child; indicates the potential need for safeguarding

when children are not brought to therapy; and raises ethical concerns about penalizing or discharging children if their parent does not bring them to appointments (Arai et al., 2014). Another ethical issue is the potential to discharge families who are facing the most barriers to accessing care and therefore have a history of missing appointments (Phoenix, 2016). There is a risk that this focus on the parents' motivation and responsibility to access care can overshadow the organizational, structural, economic, and social barriers that may impede parents' use of rehabilitation services.

Pediatric rehabilitation services are part of the broader system of early childhood services designed to support children's health and development. In a systematic review of the literature Boag-Munroe and Evangelou (2012) identify the diverse set of family-related and organizational barriers that limit the use of these health, education, and social services for children and families. They reported **family-related barriers** to service use that include parent mental health issues, single parent families, and drug or alcohol addiction (Boag-Munroe & Evangelou, 2012). Deeper exploration undertaken directly with parents who did not use the home visiting or community-based services that were available to them revealed that parents were often unsure about what was 'on offer' (Coe, Gibson, Spencer & Stuttaford, 2008; Winkworth, McArthur, Layton, Thomson & Wilson, 2010), or how they could benefit from the service (Barlow, Kirkpatrick, Stewart-Brown & Davis, 2005); some experienced the service as judgemental or stigmatizing (Barlow et al., 2005; Winkworth et al., 2010). When issues of attendance and parent engagement were studied in pediatric rehabilitation, similar barriers to service use were found at the

family and organizational levels, with additional considerations related to distance to the hospital, other health care providers involved with the family and illness in the family (Ballantyne et al., 2012; Phoenix & Rosenbaum, 2014). Due to a historical focus on the family factors that limit service use, families have been labelled as ‘hard-to-reach’ when they use services less than expected or are challenging for service providers to engage (Boag-Munroe & Evangelou, 2012; Cortis, 2012). This label has been contested because it can too easily lead service providers and researchers to overlook the organizational barriers that obstruct families use of services (Boag-Munroe & Evangelou, 2012; Cortis, 2012; Flanagan & Hancock, 2010).

In a systematic review of the literature, Boag-Munroe and Evanagelou (2012) identified many **organizational barriers** that limited the use of health, education and social services for children and families. They reported decreased accessibility due to poor communication, lengthy waitlists, inconsistent staffing or unwelcoming venues (Boag-Munroe & Evangelou, 2012). Children with disabilities may be underrepresented in community-based early intervention programs, such as Head Start, due to organizational barriers that include limited enrollment capacity and lack of trained staff available to meet the child’s needs (Beauchesne, Barnes, Andrea & Patsdaughter, 2004). The organizational barriers to service use within a pediatric rehabilitation facility included limited transportation support for families, hours of operation that conflicted with parents’ work schedules, waitlists and fees for private for diagnostic assessments (Phoenix & Rosenbaum, 2014). The term ‘hard-to-reach’ families is used with caution in this thesis in

order to connect with the larger body of literature on this topic and to deeply explore the family, organizational, ethical, and theoretical perspectives on attendance, participation and engagement in children's developmental rehabilitation services. However, given the significance of these organizational barriers I am personally hesitant to use the language **'hard-to-reach'** families, and critically explore this language in Chapter 3 of this thesis. All children should have **equal access** to the potential benefits of pediatric rehabilitation services, including physical and functional improvements, increased participation in society and quality of life. Family-centred services can help children to achieve these aims, but require parents to be engaged in collaborative relationships with service providers. At a minimum level parents are expected to bring their children to appointments, but this does not occur consistently for these so-called 'hard-to-reach' families. A punitive approach may be used to address this issue, whereby families are discharged from service, or child protective services may become involved. Alternately service providers, policy makers, and researchers can seek out **the family's perspectives** to understand what facilitates and impedes parental engagement in pediatric therapy services and use this information to revise and improve organization structures, processes and policies.

In **summary**, policy documents, theories and the research literature described above underlie my belief that all children and families have a right to accessible developmental rehabilitation services. These services must be sensitive to the multitude of challenges faced by families that can limit their use of services and work to support families by

minimizing barriers to care at the organizational and systems levels. When families are involved with developmental rehabilitation services, service providers and organizations should build on family strengths in order to promote child and family development, participation in society and improved quality of life. To do this effectively service providers can draw on family-centred care principles to promote engagement and partnership with families. However, service providers will be better prepared to promote engagement with all families, including so-called ‘hard-to-reach’ families, when they better understand parents’ perspectives about what constitutes, promotes, and limits parent engagement in their child’s developmental rehabilitation services.

There is little known about the topic of parent engagement in children’s developmental rehabilitation, especially from the perspective of parents. Therefore, a naturalistic **qualitative study** was done to explore parents’ experiences of engagement, from diverse parent perspectives, with consideration of the family, organizational and systems contexts that can affect the use of children’s therapy services. Qualitative research is well suited to elicit patient voices in order to improve rehabilitation services (Ohman, 2005; Vanderkaay et al., 2016) and to understand the complex political, economic and social contexts that shape the health of children and families (Jack, 2006). Qualitative research, particularly grounded theory, can be used to address ‘how’ questions (Creswell, 2013; Jack, 2006), in this case to explore the question **“How do parents participate and engage in their child’s developmental rehabilitation services?”**

Methodological and philosophical underpinnings of this work

Qualitative research is characterized by **methodology** that is inductive, grounded in participant experiences, inclusive of contextual influences, and emergent and flexible in design (Jack, 2006). Grounded theory is a specific qualitative research design, primarily used to investigate a basic social process and answer ‘how’ questions through development of a theory with practical applications that may predict or explain a situation (Glaser, 1967). **Constructivist Grounded Theory** methodology (Charmaz 2006, 2014) was used in this thesis study with methods details provided in Chapter 5. Charmaz developed this constructivist approach to contrast the objective, passive and neutral stance of the researcher present in Glaser and Strauss’ original work (Charmaz, 2014). Rather, Charmaz presents the researcher as an active contributor in the development of knowledge:

“We start with the assumption that social reality is multiple, processual, and constructed, then we must take the researcher’s position, privileges, perspective, and interactions in account as an inherent part of the research reality. It, too, is a construction.” (Charmaz, 2014, p. 13).

Strauss and Corbin also describe research as a social exchange between the researcher and the participants that changes and affects them both (Strauss & Corbin, 1994). These ideas reflect the integration of symbolic interactionism within grounded theory methodology (Health & Cowley, 2004). With these contrasting philosophical underpinnings informing grounded theory, it is imperative that researchers explore and articulate their own epistemologies, methodologies, and methods (Carter & Little, 2007).

Research practices are influenced by four **philosophical assumptions**: ontology, epistemology, axiology, and methodology (Creswell, 2013). Each of these components will be described according to the constructivist paradigm and my own beliefs as a researcher. **Ontology** concerns the nature of reality, an area in which my personal belief is well suited to a constructivist position. I believe that there is no single truth; rather, individuals experience the world in different ways, as a reality that they construct through interactions with people in their environments. The **epistemology** and **axiology** assumptions concern how reality is known and the role of values. A positivist lens would expect that truth can be objectively known by an unbiased and neutral researcher. My view is the opposite, as I see researchers and participants working together to create an understanding of a topic that respects the ideas, values, and contributions of both parties. The **methodological** beliefs in grounded theory are compatible with these philosophical underpinnings espousing methods such as theoretical sampling and constant comparison that allow for the development of questions and theory that is grounded in the participants' words and experiences. Methods that promote reflexivity, such as writing field notes and memos and peer debriefing, are common within grounded theory and necessary to identify and explain the researcher's role throughout a study (Gentles, 2014; Montgomery & Bailey, 2007).

How and why have I positioned myself within this research?

Throughout the PhD journey I have reflected on my personal, academic and clinical identities, and have become aware over time that these parts of self melded together to

become one. **Personally**, I am a wife and mother, daughter and sister, and friend. I value my family and relationships with others above all else. Therefore, it is unsurprising that I chose to work with families with young children, and that the nature of my research concerns relationships between parents, their children, and their service providers.

Professionally, I work as a speech-language pathologist at a publicly-funded children's treatment centre. I am deeply committed to this profession because I feel that communication is the way in which people connect to one another. These connections between families, friends, and society promote inclusion, a right that should be experienced by all people. My belief that all children and families should be included in society also fuels my commitment to promote inclusion in children's therapy services. Recognition that some families have better access to these services than others is what led me to pursue **PhD studies**. I purposely chose the rehabilitation science program because issues pertaining to access and engagement in children's therapy services transcend any specific disciplinary orientation. I completed this work at McMaster University and with *CanChild* because of their commitment to research that will change the everyday life and future of children with disabilities and their families.

The **overarching purpose** of this thesis is to promote accessibility and excellence in the provision of children's developmental rehabilitation services.

The **aim** of this thesis is to generate knowledge about parents' attendance, participation and engagement in children's developmental rehabilitation services.

The following paragraphs provide a brief **overview** of how the thesis components, viewed collectively, can help service providers, researchers and policy makers to better understand parents' engagement in children's developmental rehabilitation services. Their application of these ideas can promote accessibility and excellence in the provision of these services to children and families. **Chapters 1-4** present the **foundation and context** for the thesis study, **Chapter 5** presents the **thesis study** and **Chapter 6** presents **key implications** of this body of thesis work. Any overlap between the chapters with respect to background literature or methods is presented here. Author roles, publication status and copyright information are included on the page preceding each chapter.

This opening chapter (**Chapter 1**) presents an **introduction** to the general theme and objective of the thesis. The context of the thesis work is presented using literature, theory, methodological and philosophical underpinnings, and the researcher's position. Literature that appears within this section will be explored in more detail as it relates to family-centred care (Chapter 2), Family-Stress-Theory and 'hard-to-reach' families (Chapter 3), ethics and rehabilitation policies (Chapter 4), and parent engagement (Chapter 5).

Information that applies broadly to the methodology of grounded theory is presented in this introductory chapter, whereas specific methods are outlined in the Chapter 5 manuscripts.

Chapter 2, parts (a) and (b) presents two manuscripts that explore **family-centred care**, an accepted approach to the provision of children's developmental rehabilitation services.

In these manuscripts principles of family-centred care are applied to pediatric speech-language pathology services to promote therapist-parent partnerships, and are then explored critically with respect to pediatric occupational therapy services. These manuscripts are presented as a pair given that they are built on a common literature, but present alternate views and applications of family-centred service. This work informed the thesis study by identifying the practices that are already developed to promote engagement with families, and where these principles are problematic in implementation.

Chapter 3 presents a manuscript that uses **Family-Stress Theory** to define high-risk families and families of children with disabilities, describing the services that they are typically offered and barriers to service use. This work informed the thesis study by highlighting the need to use a holistic approach to studying the family's challenges and resources, and to sample interview participants who varied by level of service use.

Chapter 4 presents a book chapter that considers the **ethical responsibilities** of therapists and developmental rehabilitation organizations in service provision for 'hard-to-reach' families. This work informed the thesis by increasing the researcher's sensitivity to the ethical issues that are pertinent in the study of 'hard-to-reach' families' access and engagement in children's developmental rehabilitation services. Furthermore, this work illuminated the ethical tensions between service providers and organizations, which led to the completion of interviews with service providers and the collection of policies regarding discharge from 18 children's treatment centres in Ontario.

Chapter 5, parts (a) and (b) includes two manuscripts that together present the qualitative grounded theory thesis study investigating **how parents attend, participate and engage** in their child's therapy service. The first manuscript presents the conditions, inductively developed from parents' perspectives, that affect parent engagement in developmental rehabilitation services. The second manuscript presents the Phoenix Theory of Parent Engagement to describe how parents participate and engage throughout the *family's journey to child health and happiness*. All parts of this metaphorical journey, and the relationships among the parts, are explained. These manuscripts are presented as a pair given that they are both derived from the same study and tell different parts of a single story. The background literature and methods sections were written to complement one another and information was only used in both papers if it was necessary for understanding should the published paper be read on its own.

Chapter 6 presents the **conclusions** of this thesis, tying together themes presented in this body of work with implications for service providers, organizational leadership, policy makers, researchers and families. These implications are written to facilitate implementation of the ideas presented in this thesis to promote accessibility and excellence in the provision of children's developmental rehabilitation services.

Introduction to Chapter 2. Laying the Foundation: Family-Centred Service

Chapter 2, parts (a) and (b) present a pair of complementary manuscripts that explore the implementation of family-centred service in children's developmental rehabilitation services. Family-centre service is a well-established approach to children's services that prioritizes partnership with families and promotes goal attainment and family satisfaction. The term client-centred service is used in the second manuscript to fit with the special issue in which it was published. In clinical practice with children the concept of client-centredness is embedded in family-centred services. These manuscripts discuss the application of family-centred service in different practice environments and identify challenges in implementation. Both manuscripts support the use of family-centred services and call for advocacy to promote the use of family-centred principles at the organizational level, in research, and in policy.

Part (a) is a manuscript accepted for publication in the Speech-Language Audiology Canada blog Communiqué. Written permission was provided (May 5, 2017) to reprint the article as a part of this thesis using the following citation:

Phoenix, M. (in press) Establishing partnerships with parents in the provision of children's speech-language therapy services. *Communiqué*. In press.

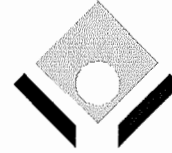
Part (b) is a manuscript published by Taylor & Francis (<http://www.tandfonline.com/>) who provided written permission to reprint the article (May 4, 2017) as a part of this thesis using the following citation:

Phoenix, M., & Vanderkaay, S. (2015). Client-centred occupational therapy with children: A critical perspective. *Scandinavian Journal of Occupational Therapy*, 22(4), 318–321. <http://doi.org/10.3109/11038128.2015.1011690>

Please note that as the first author I took a lead role in developing the concept for this article and I wrote majority of the article. My co-author discussed the concept for the article, wrote a small section of the article, reviewed the entire article, and provided feedback.



School of Rehabilitation Science
1400 Main Street West
IAHS-403
Hamilton, ON L8S 1C7
T: (905) 525-9140, ext 22867
E: rehab@mcmaster.ca
www.srs-mcmaster.ca



School of
Rehabilitation
Science
REACHING FURTHER

Julie Bourassa
Communication Specialist
Speech-Language Audiology Canada
julie@sac-oac.ca

Michelle Phoenix
School of Rehabilitation Science
michellepphoenix@gmail.com

May 3, 2017

Dear Julie Bourassa

I am completing a PhD. Thesis at McMaster University entitled "Parents' Participation and Engagement in their Child's Developmental Rehabilitation Services". I would like your **permission to reprint in full** the following chapter in my thesis:

Phoenix, M. (in press). Establishing partnerships with parents in the provisions of children's speech-language therapy services. Communiqué

I am also requesting that you **grant irrevocable, nonexclusive license to McMaster University and to the National Library of Canada** to reproduce this material as a part of the thesis. Proper acknowledgement of your copywrite of the reprinted material will be given in the thesis.

If these arrangements meet with your approval, please sign where indicated below and return this letter to me at michellepphoenix@gmail.com. Thank you very much.

Sincerely,

A handwritten signature in cursive script that reads "Michelle Phoenix".

Michelle Phoenix

PERMISSION GRANTED FOR THE USE REQUESTED ABOVE

Authorized by: JESSICA BEDFORD

Title: CHIEF OPERATING OFFICER

Date: MAY 5, 2017

Signature A handwritten signature in cursive script, appearing to be "J Bedford", written over a horizontal line.

Academic Journals Society Permissions <society.permissions@tandf.co.uk> May 4 (6 days ago)

to me

Our Ref: MD/IOCC/P17/339

4th May 2017

Dear Michelle Phoenix,

Thank you for your correspondence requesting permission to reproduce the following article published in our journal in your printed thesis and to be posted in your university's repository at McMaster University entitled 'Parents' Participation and Engagement in their Childs Development Rehabilitation Services'

'Client-centred occupational therapy with children: A critical perspective' By Michelle Phoenix & Sandra Vanderkaay Scandinavian Journal of Occupational Therapy Vol.22:4 pp.318-321

We will be pleased to grant permission on the sole condition that you acknowledge the original source of publication and insert a reference to the article on the Journals website:

This is the authors accepted manuscript of an article published as the version of record in Scandinavian Journal of Occupational Therapy 2015 <http://www.tandfonline.com/> <http://dx.doi.org/10.3109/11038128.2015.1011690>

Please note that this license does not allow you to post our content on any third party websites or repositories.

Thank you for your interest in our Journal.

Yours sincerely

Michelle Dickson – Permissions & Licensing Executive, Journals.
Routledge, Taylor & Francis Group.
4 Park Square, Milton Park, Abingdon, Oxon, OX14 4RN, UK.
Tel: [+44 \(0\)20 7017 7413](tel:+442070177413)
Fax: [+44 \(0\)20 7017 6336](tel:+442070176336)
Web: www.tandfonline.com
e-mail: Michelle.Dickson@tandf.co.uk

Taylor & Francis is a trading name of Informa UK Limited, registered in England under no. 1072954

Establishing partnerships with parents in the provisions of children's speech-language therapy services

Introduction

Parent-clinician partnership and collaboration form the foundation of family-centred service (FCS) in children's rehabilitation therapy. There is strong evidence to support the fact that implementation of FCS shows positive associations with access to care, child outcomes, family functioning and parent satisfaction with service (Bamm & Rosenbaum, 2008; Cunningham & Rosenbaum, 2014; Kuhlthau et al., 2011). FCS has been widely adopted across the world, illustrated within Canada by Accreditation Canada's (2013) use of client and family-centred care as an integral component of evaluation, the College of Audiologists and Speech-Language Pathologists of Ontario's (2014) identification of child and family-centred approach as a necessary element of children's assessment, and the Ontario Association of Children's Rehabilitation Services' ([OACRS], 2010) key values that include engaging families and collaboration with partners. Even with strong evidence and endorsement, implementation of FCS has been challenging in the children's therapy environment (Bamm & Rosenbaum, 2008; Phoenix & Vanderkaay, 2015), specifically with clinicians struggling to work collaboratively with parents (An & Palisano, 2014). Speech-language pathologists (SLP) and researchers are left asking an important question: "How can we make parents essential partners and collaborators in their children's therapy?" The answer to this question will be presented using the three central tenets of FCS, which together support parent partnerships and collaboration: (i) parents are the experts on their child; (ii) each family is unique; and (iii) children develop best in a supportive family and community context (Rosenbaum, King, Law, King & Evans, 1998). Challenges to implementing

these tenets are presented alongside opportunities to promote partnership with families that move beyond the direct therapist-parent interaction.

FCS Tenet 1. “Parents know their children best and want the best for their children” (Rosenbaum et al., 1998, p. 9)

The medical model of service views the professional as the expert on identifying and addressing the needs of the child, whereas the social model of disability views the child within their broader context and requires the expertise of parents (McLeod & Bleile, 2004). Parent involvement in goal-setting is a key element in the provision of FCS and one way parents can share their expertise and collaborate with professionals in the therapy process (Brewer, Pollock, & Wright, 2014).

Goal-setting is a common part of rehabilitation, thought to promote behavior change and improve communication between the client and the practitioner (Wade, 2009). Parent engagement in goal-setting increases collaboration between the parent and clinician based on shared observation of the child, and increased communication about priorities and achievable targets (Oein, Fallang, & Østensjø, 2010). Parents can identify goals that are meaningful to them and their family and important in the everyday life of the child (Oein et al., 2010). This is reflective of a social model of disability in which goals are more likely to target participation and social relationships than change at the body structure or function level (McLeod & Bleile, 2004). Recognizing parent expertise and including parents in goal setting is one way SLPs can foster parent collaboration.

There are of course challenges to including parents in the goal-setting process. Clinicians require time, training and organizational support to develop and use the skills needed to engage parents in collaborative goal-setting (Brewer et al, 2014; Kolehmainen et al., 2012). Parents can be overwhelmed and unprepared to set goals if they are given too much responsibility with

inadequate support (Oien et al., 2010; Phoenix & Vanderkaay, 2015). A major tenet in FCS is allowing parents to determine how they want to be involved in therapy; therefore SLPs can still promote collaboration with parents by taking the lead in goal-setting if that is the parent's desire. The key message is that SLPs should talk with families about their preferred roles in goal-setting and the therapy process, and make every effort to engage families, being mindful of the ways in which parents wish to collaborate.

FCS tenet 2. "Families are different and unique" (Rosenbaum et al., 1998, p.9)

In order to provide FCS, and thereby develop partnerships with parents, SLPs must respect individual family members and form trusting relationships that are inclusive of diversity (Rosenbaum et al., 1998). Families are dissatisfied with their professional partnerships when they feel that professionals blame them for their child's difficulties, or do not consult with them or believe them (Wodehouse & McGill, 2009). Families most frequently identified "partnerships" as being important in FCS and valued "the human qualities of professionals, such as kindness, concern, compassion, sensitivity, and approachability" over clinicians' technical competence (Bamm & Rosenbaum, 2008, p. 1621). In comparison, professionals did not identify 'partnerships' as a main component of FCS and were primarily focused on education and counselling (Bamm & Rosenbaum, 2008). SLPs need to focus on their relationship with families because families prioritize this aspect of FCS and the therapist-family relationship is a key element to achieving client goals (King, 2009; King 2016).

It can be difficult for SLPs to develop a strong relationship with families when the family is not seen to be participating in the therapy process (Littell, Alexander, & Reynolds, 2001). It may appear that parents are not participating or engaged if they disagree with the therapy approach or

do not attend regularly, and in some cases families may be discharged due to non-attendance (Arrigo, Ziviani, Poulsen, Copely, & King, 2016; Littell et al., 2001; Littell et al., 2001; Phoenix, 2016). Families who have difficulty with attendance and engagement have been labelled ‘hard-to-reach’ (Boag-Munroe & Evangelou, 2012). Researchers and service providers have viewed these families with blame and judgment, which compromises the trusting and respectful relationship required to build collaboration (Barrett; 2008). When SLPs and families have a relationship that empowers families to express differences of opinions and describe their challenges with attendance, these ‘barriers to collaboration’ may be used as discussion points in the formation of a therapy approach that fits the family’s unique goals, desires, and life context. Two models of pediatric service delivery that are flexible and responsive to families’ differences can be used by SLPs to promote collaborative work with families: the “Model of family-professional collaboration: a four step model of service delivery” (An & Palisano, 2014) and “Making Alternative Therapy Choices Happen (MATCH): a care path to promote engagement with hard-to-reach families” (Phoenix & Rosenbaum, 2015). Although these models of service delivery were developed using evidence, neither has been evaluated rigorously enough to determine effectiveness. What can be stated with confidence is that SLPs can establish a partnership with families when they are respectful, develop trust and are responsive to the uniqueness of each child and family.

FCS Tenet 3. “Optimal child functioning occurs within a supportive family and community context: The child is affected by the stress and coping of other family members”

(Rosenbaum et al., 1998, p.9)

The World Health Organization’s (2002) International Classification of Functioning, Disability and Health draws attention to the personal and environmental factors that are important in

understanding an individuals' health and participation. The family is recognized as children's natural environment, and the health and wellbeing of parents are tied to the development of their child (Rosenbaum & Gorter, 2012). Within FCS the psychosocial needs of all family members must be considered (Rosenbaum et al., 1998), especially as we place expectations on parents to partner and collaborate in the therapy process. Parents raising children with disabilities are at increased risk for experiencing long-term physical and mental health challenges (e.g., depression), which increase the likelihood that children with chronic physical illness will experience anxiety or depression (Brehaut et al., 2011; Ferro & Boyle, 2015; Lach et al., 2009).

The following ethical questions are raised by Reddihough and Davis (2016) regarding whether child health clinicians have an ethical responsibility to identify the mental health and support needs of parents: Do professionals have the expertise to identify mental health concerns and appropriate recommendations or resources? Which professional on a team is required to ask the parents about their needs? What about parent privacy and their potential unwillingness to disclose mental health issues? On the surface, it appears obvious that partnering with families includes recognizing parents' challenges related to physical and mental health, given that these are likely to impact parents' involvement in therapy and the child's development. However, there are many ethical and pragmatic complexities for SLPs to consider when engaging in this area of practice.

Although there is strong evidence to indicate that the parents with whom SLPs work are likely to experience physical and mental health issues McConnell et al. (2013) remind researchers and practitioners that parents of children with disabilities can also exhibit resilience and positive experiences of raising their children. Strengths-based approaches to intervention can help SLPs to identify the strengths within the family and community context, and use those to promote child development. The Solution-Focused Coaching model for pediatric rehabilitation practice was

developed to help practitioners implement FCS by developing a relationship with parents oriented around their child and family strengths and hopes for the future (Baldwin et al. 2013). Although there is low to moderate evidence for the use of coaching in pediatric occupational therapy practice the generalizability to SLP practice is unknown (Kessler & Graham, 2015) and the transdisciplinary Solution-Focused Coaching model has yet to be evaluated (Baldwin et al., 2013).

Organizational partnerships with families to promote collaboration in therapy services

So far this paper has focused on ways SLPs can promote partnership and collaboration in the *individual* work they do with families by implementing the central components of FCS. The *organizational* context has been considered only to the degree that it supports or restricts SLPs' attempts to implement FCS, e.g., by providing time and training to learn about and implement goal setting with families or implement models of service that support FCS. However, SLPs may also support parent collaboration at the organizational level by advocating for parent involvement in strategic planning processes or on advisory boards. Parents can be encouraged to partner in the therapy process by sharing their stories, concerns and ideas with provincial initiatives such as the OACRS (2010) Family Advisory Council or the Ministry of Health and Long-Term Care (2016) Patient and Family Advisory Council, or national initiatives such as Patients Canada (2014) that encourage patients to share information with the Ministers of Health to champion change in health care. When SLPs are informed about these avenues for parent partnership they can share information with families in order to support family empowerment and advocacy.

Research to promote partnership and collaboration with families

Finally, parent partnerships and collaboration can be strengthened by the research that SLPs do and the engagement of families as part of the research team. As one personal example, my doctoral research is a qualitative grounded theory study that aims to answer the question: “How do parents of children with disabilities participate and engage in their child’s therapy?”

Approximately half of the sample is comprised of families who are labelled as ‘hard-to-reach’ as indicated by missed appointments, frequent cancellations or declining services that are offered to them. Although this work is in progress, families have consistently said they are engaged in the therapy process when (i) they are working on skills and issues that matter to them, (ii) they trust and have a relationship with the therapist, and (iii) they feel good about the therapy. Families also report feeling overwhelmed and sometimes unable to attend given the pragmatic life barriers (e.g., travel and childcare) that can impact service use. This work will help to disentangle attendance, participation and engagement and can hopefully be used by SLPs to strengthen partnerships with families and advocate with them for services that best meet their needs.

In Canada and across the world patient and family engagement in research is gaining momentum (INVOLVE, 2015; Patient Centered Outcomes Research Institute, 2016). The Canadian Institutes of Health Research (2016) funds the Strategy for Patient-Oriented Research and states “Patient-oriented research refers to a continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes”. SLP researchers can partner with parents to develop meaningful research questions, tailor research processes or interventions, meaningfully interpret results and move these into use (Brett et al., 2014). Engaging parents in the research process has been referred to as Family-Centred Research because of the parallels with FCS that include recognizing parent expertise and collaborating with parents as equal partners (Rosenbaum 2011). Philosophical, pragmatic and regulatory arguments have been used to support

the position that family involvement, and to a lesser extent service provider involvement, are crucial in all stages of childhood disability research (Morris et al., 2011). Unfortunately, Family-Centred Research has not yet been evaluated to the same extent as FCS and this has been raised more generally as a criticism of patient and public involvement in research (Brett et al., 2014; Staniszewska et al., 2008). Given the increased cost and time needed to engage families, and the threat that families may be involved in a tokenistic manner, or that a biased sample of families may be involved, there is certainly a need for more research to inform how families are engaged and whether engagement is associated with positive outcomes.

In summary, SLPs can promote partnership with parents by applying the principles of FCS in therapy provision and by encouraging parents to collaborate with organizations, policy makers and researchers to develop services that best meet their unique child and family needs. SLPs should provide opportunities for parent involvement in goal setting and therapy planning, build trusting and respectful relationships with families, and recognize parents' own physical and mental health concerns. This can be a difficult task given organizational constraints and lack of evidence-based models to support these practices. There are also ethical considerations related to service provision for hard-to-reach families and parents with mental health concerns. Therefore, SLPs may face pragmatic and ethical challenges when trying to engage parents as partners. True partnership will require that SLPs implement the principles of FCS in their work with families and broadly encourage parents to partner with organizations and researchers to create evidence-based children's therapy programs that value and support parental-SLP collaboration.

References

- Accreditation Canada. (2013). *Client- and family- centred care*. Retrieved from <https://accreditation.ca/client-and-family-centred-care>
- An, M., & Palisano, R. J. (2014). Family-professional collaboration in pediatric rehabilitation: a practice model. *Disability and Rehabilitation*, 36(5), 434–440. <http://doi.org/10.3109/09638288.2013.797510>
- Arrigo, R. D., Ziviani, J., Poulsen, A. A., Copley, J., & King, G. (2016). Child and parent engagement in therapy : What is the key ? *Australian Occupational Therapy Journal*, 1–4. <http://doi.org/10.1111/1440-1630.12279>
- Baldwin, P., King, G., Evans, J., McDougall, S., Tucker, M. A., & Servais, M. (2013). Solution-Focused Coaching in Pediatric Rehabilitation: An Integrated Model for Practice. *Physical & Occupational Therapy in Pediatrics*, 33(May 2012), 467–483. <http://doi.org/10.3109/01942638.2013.784718>
- Bamm, E. L., & Rosenbaum, P. (2008). Family-centered theory: origins, development, barriers, and supports to implementation in rehabilitation medicine. *Archives of Physical Medicine and Rehabilitation*, 89(8), 1618–24. <http://doi.org/10.1016/j.apmr.2007.12.034>
- Barrett, H. (2008). *Hard-to-Reach Families: Engagement in the Voluntary and Community Sector*. London, UK: Family and Parenting Institute.
- Boag-Munroe, G., & Evangelou, M. (2012). From hard to reach to how to reach: A systematic review of the literature on hard-to-reach families. *Research Papers in Education*, 27(2), 209–239. <http://doi.org/10.1080/02671522.2010.509515>
- Brehaut, J. C., Garner, R. E., Miller, A. R., Lach, L. M., Klassen, A. F., Rosenbaum, P. L., & Kohen, D. E. (2011). Changes over time in the health of caregivers of children with health problems: growth-curve findings from a 10-year Canadian population-based study.

American Journal of Public Health, 101(12), 2308–16.

<http://doi.org/10.2105/AJPH.2011.300298>

Brett, J. Staniszewska, S., Mockford, C, Herron-Marx, S., Hughes, J., Tysall, C., Suleman, R.

(2014). A systematic review of the impact of patient and public involvement on service users, reserachers, and communities. *The patient-Patient-centered outcomes research*, 7(4), 387-395.

Brewer, K., Pollock, N., & Wright, F. V. (2014). Addressing the challenges of collaborative goal

setting with children and their families. *Physical & Occupational Therapy in Pediatrics*, 34(October 2012), 138–52. <http://doi.org/10.3109/01942638.2013.794187>

Canadian Institutes of Health Research (2016). *Strategy for Patient-Oriented Research*. Retrieved

from <http://www.cihr-irsc.gc.ca/e/41204.html>

Cunningham, B. J. & Rosenbaum, P. L. (2014). Measure of Processes of Care: A review of 20

years of research. *Developmental Medicine and Child Neurology*, 56(5), 445–452.

<http://doi.org/10.1111/dmcn.12347>

Ferro, M.A. & Boyle, M.H. (2015). The impact of chronic physical illness, maternal depressive

symptoms, family functioning, and self-esteem on symptoms of anxiety and depression in children. *Journal of Abnormal Child Psychology*, 43(1), 177-187.

INVOLVE (2015) *INVOLVE National Institute for Health Research*. Retrieved from

<http://www.invo.org.uk/>

Kessler, D. & Graham, F. (2015). The use of coaching in occupational therapy: an integrative

review. *Australian Occupational Therapy Journal*, 62(3), 160-176. **DOI:** 10.1111/1440-1630.12175

- King, G. (2016). The Role of the Therapist in Therapeutic Change : How Knowledge From Mental Health Can Inform Pediatric Rehabilitation. *Physical and Occupational Therapy in Pediatrics*, Early Online, 1–18. <http://doi.org/10.1080/01942638.2016.1185508>
- King, G. (2009). A relational goal-oriented model of optimal service delivery to children and families. *Physical & Occupational Therapy in Pediatrics*, 29(4), 384–408. <http://doi.org/10.3109/01942630903222118>
- Kolehmainen, N., MacLennan, G., Ternent, L., Duncan, E. A., Duncan, E. M., Ryan, S. B.,... Francis, J. J. (2012). Using shared goal setting to improve access and equity: a mixed methods study of the Good Goals intervention in children’s occupational therapy. *Implementation Science*, 7(1), 76. <http://doi.org/10.1186/1748-5908-7-76>
- Kuhlthau, K.A., Bloom, S., Van Cleave, J., Knapp, A.A., Romm, D., Klatka, K.,... Perrin, J. M. (2011). Evidence for family-centered care for children with special health care needs: a systematic review. *Academic Pediatrics*, 11(2), 136–43. <http://doi.org/10.1016/j.acap.2010.12.014>
- Lach, L.M., Kohen, D.E., Garner, R.E., Brehaut, J.C., Miller, A.R., Klassen, A.F., Rosenbaum, P.L. (2009). The health and psychosocial functioning of caregivers of children with neurodevelopmental disorders. *Disability and Rehabilitation*, 31(8), 607-618.
- Littell, J., Alexander, L., & Reynolds, W. (2001). Client Participation : Central and Underinvestigated Elements of Intervention. *Social Service Review*, 75(1), 1–28. Retrieved from <http://www.jstor.org/stable/10.1086/591880>
- McConnell, D., Breitkreuz, R., Uditsky, B., Sobsey, R., Rempel, G., Savage, A., & Parakkal, M. (2013). Children with disabilities and the fabric of everyday family life. Alberta, CA: Faculty of Rehabilitation Medicine Family and Disability Studies.

McLeod, S., & Bleile, K. (2004). The ICF: a framework for setting goals for children with speech impairment. *Child Language Teaching and Therapy*, 20(3), 199–219.

<http://doi.org/10.1191/0265659004ct272oa>

Ministry of Health and Long Term Care. (2016). *Ontario Establishing Patient and Family Advisory Council*. Retrieved from [https://news.ontario.ca/mohltc/en/2016/10/ontario-](https://news.ontario.ca/mohltc/en/2016/10/ontario-establishing-patient-and-family-advisory-council.html?utm_source=ondemand&utm_medium=email&utm_campaign=p)

[establishing-patient-and-family-advisory-council.html?utm_source=ondemand&utm_medium=email&utm_campaign=p](https://news.ontario.ca/mohltc/en/2016/10/ontario-establishing-patient-and-family-advisory-council.html?utm_source=ondemand&utm_medium=email&utm_campaign=p)

Morris, C., Shilling, V., Mchugh, C., & Wyatt, K. (2011). Why it is crucial to involve families in all stages of childhood disability research. *Developmental Medicine and Child Neurology*, 53(8), 769–771. <http://doi.org/10.1111/j.1469-8749.2011.03984.x>

Øien, I., Fallang, B., & Østensjø, S. (2010). Goal-setting in paediatric rehabilitation: Perceptions of parents and professional. *Child: Care, Health and Development*, 36(4), 558–565.

<http://doi.org/10.1111/j.1365-2214.2009.01038.x>

Ontario Association of Children’s Rehabilitation Services. (2010a). *For parents and families*.

Retrieved from <http://www.oacrs.com/en/parentsfamilies>

Ontario Association of Children’s Rehabilitation Services. (2010b). *Family advisory council*.

Retrieved from <http://www.oacrs.com/en/parentsfamilies>

Patient Centered Outcomes Research Institute (2016) *Patient Centred Outcomes Research Institute*. Retrieved from <http://www.pcori.org/>

Patients Canada (2014). *Patients Canada Make Your Experience Count*. Retrieved from

<http://www.patientscanada.ca/>

Phoenix, M. (2016). Service provision for hard-to-reach families: what are our responsibilities? In

P.L. Rosenbaum, G.M. Ronen, B. Dan, J.Johannesen & E. Racine (Eds.), *Ethics in child*

health: principles and cases in neurodisability (pp. 193-201) London, UK: Mac Keith Press.

- Phoenix, M. & Rosenbaum, P. (2015). Development and implementation of a paediatric rehabilitation care path for hard-to-reach families: a case report. *Child: Care, Health and Development*, 41(3), 494–499. <http://doi.org/10.1111/cch.12194>
- Phoenix, M. & Vanderkaay, S. (2015). Client-centred occupational therapy with children : A critical perspective. *Scandinavian Journal of Occupational Therapy*, 22(4), 318–321. <http://doi.org/10.3109/11038128.2015.1011690>
- Reddihough, D.S. & Davis, E. (2016). Paying attention to parental mental health: is this our responsibility? In P.L. Rosenbaum, G.M. Ronen, B. Dan, J.Johannesen & E. Racine (Eds.), *Ethics in child health: principles and cases in neurodisability* (pp. 223-232) London, UK: Mac Keith Press.
- Rosenbaum, P. (2011). Family-centred research : what does it mean and can we do it ? *Developmental Medicine & Child Neurology*, 53(2), 99–100.
- Rosenbaum, P. & Gorter, J. W. (2012). The “F-words” in childhood disability: I swear this is how we should think! *Child: Care, Health and Development*, 38(4), 457–63. <http://doi.org/10.1111/j.1365-2214.2011.01338.x>
- Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-Centred Service : A Conceptual Framework and Research Review. *Physical & Occupational Therapy in Pediatrics*, 86(I), 1–20.
- Speech-Language Audiology Canada. (2014). *Practice standards and guidelines for the assessment of children by speech-language pathologists*. Retrieved from http://www.caslpo.com/sites/default/uploads/files/PSG_EN_Assessment_Children_by_SLPs.pdf
- Staniszewska, S., Herron-Marx, S., & Mockford, C. (2008). Measuring the impact of patient and public involvement: the need for an evidence base. *International Journal for Quality in*

Health Care : Journal of the International Society for Quality in Health Care / ISQua, 20(6), 373–4. <http://doi.org/10.1093/intqhc/mzn044>

Wade, D.T. (2009). Goal setting in rehabilitation: an overview of what, why and how. *Clinical Rehabilitation*, 23(4), 291-395

Wodehouse, G., & McGill, P. (2009). Support for family carers of children and young people with developmental disabilities and challenging behaviour: What stops it being helpful? *Journal of Intellectual Disability Research*, 53(7), 644–653. <http://doi.org/10.1111/j.1365-2788.2009.01163.x>

World Health Organization (2002). Toward a common language for functioning, disability, and health. Geneva, World Health Organization. Retrieved from <http://www.who.int/classifications/icf/icfbeginnersguide.pdf?ua=1>

SHORT REPORT

Client-centred occupational therapy with children: A critical perspective

MICHELLE PHOENIX^{1,2,3} & SANDRA VANDERKAAY²

¹CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, Ontario, Canada,

²School of Rehabilitation Science, McMaster University, Hamilton, Ontario, Canada, and

³KidsAbility Centre for Child Development, Waterloo, Ontario, Canada

Abstract

Background: Client-centredness is a central theme within occupational therapy; however, its application within clinical practice has not been thoroughly examined within the literature. *Aim:* The aim of this practice reflection is to provide a critical perspective on client-centredness in occupational therapy practice with children. *Methods:* Two action points of the Canadian Practice Process Framework (CPPF): *Set the Stage* and *Agree on Objectives and Plan* are applied to examine the concept of client-centred practice using a common practice example. *Results:* There are multiple benefits to using a client-centred approach to goal setting and developing a therapy plan. Practical challenges to client-centred practice include a lack of time, organizational support, and professional autonomy. Therapists may exert power over clients by enforcing institutional policies that prioritize the client diagnosis and organizational processes. *Conclusion:* The authors support a client-centred approach to occupational therapy practice with children but suggest that therapists may feel conflicted in trying to apply these principles within the current context of rehabilitation for children. Occupational therapists are encouraged to identify opportunities where they can advocate for a client-centred approach to services.

Key words: *practice reflection, family-centred care, Canadian Practice Process Framework*

Introduction

Client-centredness has long been a central concept within occupational therapy (OT) (1,2). However, Hammell (2) asserted that this claim to client-centredness has yet to be thoroughly examined to ensure its application in clinical practice. She encouraged consideration of the question “is the occupational therapy profession’s espoused commitment to client-centred practice evident in its ... professional practice?” (p. 175). Within OT practice with children, the concept of client-centredness is embedded within family-centred service and its application is well supported by evidence (3,4). However, there are many challenges in truly implementing client-centred practice (3,5–7). This practice reflection provides a critical perspective on client-centredness in OT practice with

children using a common practice scenario. The reflection is centred on two action points of the Canadian Practice Process Framework (CPPF): *Set the Stage* and *Agree on Objectives and Plan* (8).

Case scenario

Priya arrived 20 minutes late for Muhammad’s assessment. She rushed her three children in as she apologized about the bus then shoved the case history form into her bag, promising to complete it later. The occupational therapist, speech language pathologist, physiotherapist, and social worker began taking turns asking Priya questions about two-year-old Muhammad’s development and trying to play with him. Muhammad was uninterested in the toys or the people. He did not speak. They asked Priya “What are

your goals for Muhammad?" and she answered "Help him get better". This response was far from the specific and measurable goals required for the care plan. Then she asked "What do you think I should do?" The therapists exchanged uneasy glances, caught between wanting to foster Priya's ability to identify priority issues versus taking the lead in recommending goals and a therapy plan as Priya seemed to want.

The therapists discussed the service pathways available based on clinical observation of "red flags" for autism spectrum disorder (ASD). This involved a referral to the Early Development Team and mandatory parent training as a first step to accessing therapy. This was offered as per the service pathway despite the facts that Priya is a single parent caring for three young children, she has moderate English skills, and she uses bus transportation. Was she really going to make it to the parent training sessions and benefit from them?

The therapists explained to Priya that a referral to a pediatrician could shed light on Muhammad's development and that a diagnosis of ASD would allow him access to additional services. This news was confusing and overwhelming and the therapists knew it. The infant was crying and the four-year-old was running out of the door. The therapists wished for more time but knew that only 1.5 hours was allotted per new assessment. They were left questioning the extent to which being client-centred was realistic in the current context of rehabilitation for children.

Critical perspectives

Action point: set the stage

Client-centred practice principles. Within a model of client-centred practice children and their parents are encouraged to identify concerns and priorities (1). The therapist's role is to provide a respectful and supportive environment in which to develop a partnership with the family and promote collaborative goal setting (1). The therapist can provide information to the family to help them make an informed choice but should be aware of the potential for discrepancies between their own values and beliefs and those of the client (1). Collaborative goal setting is a central principle in the provision of a client-centred approach and research indicates that it has positive implications for client satisfaction and goal attainment (5,9).

Challenges. Challenges to collaborative goal setting include the time needed to set goals with a family, organizations that lack goal-setting processes or use of tools, therapist education regarding collaborative goal setting, and the parents' desired level of participation in decision-making (9). For multiple reasons parents

may not be ready or choose to engage in the client-centred collaborative goal setting promoted by the Canadian Occupational Performance Measure (COPM) (2) or Goal Attainment Scaling (GAS) (9).

Scenario reflection. Like many parents Priya's goal was broad: to help her son get better. Time was not available to refine that goal via discussion or use of tools such as the COPM. Within the assessment, it was difficult for the four therapists to develop a relationship with Priya and explore how her cultural values and beliefs could impact her child's goals. Hammell (2) emphasized that being client-centred includes listening to the client and being responsive to the individual, not the "condition". However, the therapists were aware that Muhammad required a diagnosis of ASD in order to access service. They held a position of power in recommending a referral to a pediatrician, who was even more powerful as the gatekeeper of service via provision of a diagnosis. Using this case scenario it is evident why clients may view therapists as a powerful part of a bureaucratic system that prioritizes the client's diagnosis and institutional processes over client-centredness.

Action point: agree on objectives and plan

Client-centred practice principles. Within client-centred practice OTs are encouraged to consider the client context when collaborating to set occupational goals and develop a plan (1,8). A central client-centred principle is the provision of flexible and individualized planning, leading to increased access to environmentally and culturally suitable services (1,10). Interventions focused on the child's environment have demonstrated effectiveness (11,12). Furthermore, clients have identified that choice of activity and environment are essential to their satisfaction and goal attainment (5).

Challenges. Recently many health care reform strategies have been implemented in children's rehabilitation settings that are aimed at increasing efficiency and decreasing costs (13). These trends include the utilization of clinical pathways based on diagnostic categorization (14) and market-based approaches to service delivery such as the managed competition model (13). Research indicates that such reforms decrease professional autonomy in implementing a flexible and individualized client-centred approach and diminish solicitation of the client perspective (13,14).

Scenario reflection. The therapists likely experienced tension in developing a plan for this family. Planning

was primarily directed by Muhammad's assessment findings, service pathways, and access to services, thus inhibiting individualization of the plan based on Priya's language, transportation, or childcare needs. Services provided in Muhammad's natural environment (e.g. home or daycare) would potentially be more accessible and closely aligned with the family's individualized goals and culture. However, organizational policy did not allow the therapists to offer community-based services or to circumvent the clinical pathway which specified parent training as a first step in accessing service. In essence, therapists were precluded from developing and offering client-centred services. This supports the critique provided by Hammell (2) that therapists often feel more accountable to their employers than to their clients. As such, it may appear to clients that therapists are willing participants who enforce the organizational policies and practices that disempower clients (2).

Summary

Based on clinical experience and evidence-informed practice the authors believe that a client-centred approach to services would improve goal attainment (9) and family satisfaction with occupational therapy services for children (3). Within this model therapists would engage families using a respectful, collaborative, and individualized approach to goal setting and developing a plan. However, therapists are likely to face challenges to using a client-centred approach within these action points.

Therapists may feel limited in their ability to engage parents in goal setting due to a lack of time, training, or organizationally supported approach. Furthermore, therapists may be limited in their freedom to consider individual needs and preferences when building a plan. Institutional policies and procedures may determine service recommendations and place therapists in a powerful role as enforcers and gatekeepers to service.

Although the authors support a client-centred approach to rehabilitation service delivery for children, they suggest that therapists may feel conflicted when trying to apply these principles in today's service environment.

Recommendations

Therapists should consider the extent to which their organization supports a client-centred approach to OT services for children by providing the time, training, and professional autonomy required for collaborative goal setting and flexible planning. It is also important to consider and respect client preferences

regarding therapist and client responsibility and roles. Given their position of power, therapists have a responsibility to critically examine institutional practices and policies and to advocate for client-centred approaches to service.

Acknowledgements

Michelle Phoenix is currently funded by a Canadian Institutes of Health Research (CIHR) Doctoral Award and the Canadian Child Health Clinician Scientist Program (CCHCSP) Career Enhancement Program Award. The authors would like to thank their past, present, and future clients for fueling their desire to learn about client-centred practice and explore challenges to its implementation.

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

References

1. Law M, Baptiste S, Mills J. Client-centred practice: what does it mean and does it make a difference? *Can J Occup Ther* 1995;62:250-7.
2. Hammell KW. Client-centred practice in occupational therapy: critical reflections. *Scand J Occup Ther* 2013;20: 174-81.
3. Bamm EL, Rosenbaum P. Family-centered theory: origins, development, barriers, and supports to implementation in rehabilitation medicine. *Arch Phys Med Rehabil* 2008;89: 1618-24.
4. Kuhlthau KA, Bloom S, Van Cleave J, Knapp A, Romm D, Klatka K, et al. Evidence for family-centered care for children with special health care needs: a systematic review. *Acad Pediatr* 2011;11:136-43.
5. Rebeiro KL. Client perspectives on occupational therapy practice: are we truly client-centred? *Can J Occup Ther* 2000;67:7-14.
6. Sumsion T, Smythe G. Barriers to client-centredness and their resolution. *Can J Occup Ther* 2000;67:15-21.
7. Wilkins S, Pollock N, Rochon S, Law M. Implementing client-centred practice: why is it so difficult to do? *Can J Occup Ther* 2001;68:70-9.
8. Davis J, Craik J, Polatajko HJ. Using the Canadian Practice Process Framework: amplifying the process. In Townsend EA, Polatajko HJ, editors. *Enabling occupation II: advancing an occupational therapy vision for health, well-being, & justice through occupation*. Ottawa: CAOT Publications ACE; 2013. p 247-72.
9. Brewer K, Pollock N, Wright FV. Addressing the challenges of collaborative goal setting with children and their families. *Phys Occup Ther Pediatr* 2014;34:138-52.
10. King S, Teplicky R, King G, Rosenbaum P. Family-centered service for children with cerebral palsy and their families: a review of the literature. *Semin Pediatr Neurol* 2004;11: 78-86.
11. Law MC, Darrach J, Pollock N, Wilson B, Russell D, Walter SD, et al. Focus on function: a cluster, randomized

Examining client-centredness in OT practice with children

- controlled trial comparing child- versus context-focused intervention for young children with cerebral palsy. *Dev Med Child Neurol* 2011;53:621–9.
12. Novak I, Cusick A, Lannin N. Occupational therapy home programs for cerebral palsy: double-blind, randomized, controlled trial. *Pediatr* 2009;124:e606–14.
 13. Randall GE, Williams AP. Health care reform and the dimensions of professional autonomy. *Can Public Admin* 2009;52:51–69.
 14. Currie VL, Harvey G. The use of care pathways as tools to support the implementation of evidence-based practice. *J Interprof Care* 2000;14:311–24.

Introduction to Chapter 3. Laying the Foundation: Application of Family Stress

Theory

Chapter 3 presents a manuscript that draws on existing literature and Family Stress Theory to create the Model of Risk, Disability, and Hard-to-Reach families. This model is used to define high-risk families and families of children with disabilities. The chapter describes existing services that are available to those groups of families, and potential barriers to use of those services. This use of Family Stress Theory provided the groundwork for the thesis by informing the sample and interview guide with respect to the types of services that families may use and potential barriers to their use of these services.

This manuscript is currently (May 2017) under review for publication in Disability and Rehabilitation.

Phoenix, M. & Rosenbaum, P. Presenting the Model of Risk, Disability and Hard- to-Reach Families to inform early intervention services. Manuscript submitted for publication.

As lead author on this publication I reviewed the literature, and developed the Model of Risk, Disability and Hard-to-Reach Families. Dr. Rosenbaum helped to refine the model and provided feedback on the manuscript that I wrote.

**Presenting the Model of Risk, Disability and Hard-to-Reach Families
to inform Early Intervention Services**

Abstract

Introduction: Several concepts – risk, resilience, disability and hard-to-reach families in early intervention services – are talked and written about in many ways. Family Stress Theory can be usefully applied to explore these issues systematically.

Problem: The relationship between risk and disability has not been explicated, nor has the role of resilience been fully explored. The idea of ‘hard-to-reach families’ is not well defined, thus presenting challenges to service providers and policy makers.

Reflection: This paper presents the Model of Risk, Disability and Hard-to-Reach Families and uses the model to: 1. define the groups of high risk families and families of children with disabilities and explore the concept of resilience within these groups; 2. describe services offered to these groups; and 3. reflect on service use and hard-to-reach families.

Conclusion: Service providers can apply the Model of Risk, Disability and Hard-to-Reach Families to consider each family’s unique strengths and challenges, and use those individual elements to influence service recommendations and anticipate service use.

Introduction

The literatures on risk, resilience and disability highlight the importance of considering the child and family context when determining early intervention needs and outcomes; however, the relationship between risk and disability has not been explicated, nor has the role of resilience been fully explored. The concepts of ‘risk’, ‘resilience’,

'disability' and 'hard-to-reach families' must be clearly defined in order to determine what services should be offered to families, in what ways, and their likelihood of using these services. Exploring the relationships among these concepts allows for a better understanding of the demands and capabilities of families raising young children. Family Stress Theory (FST) can be used to define these concepts, identify appropriate services, and understand service use.

Family Stress Theory

Hill [1,2] explains family crisis by identifying the following major concepts: A: the stressor event, B: the crisis-meeting resources, and C: the family's definition of the event. These factors interact to promote or protect from X: Crisis, which is seen as a major change in the family's daily patterns and roles. The stressor event (demands), and the resources to meet the crisis (capabilities) should be explored at the personal, family and community levels to determine if a family is likely to experience crisis [3]. In determining family outcome, the family's definition and perception of their stressors and resources are more important than the number of each [1,2].

Risk

High risk families are typically identified using the biological, behavioural or environmental factors that increase their chances of experiencing a negative outcome. The expected outcome will depend in part on what risk factor is being explored. Environmental factors known to influence health outcomes are referred to as the social determinants of health [4,5]. Low income is thought to be the most important social determinant of health and is associated with decreased life expectancy, increased risk for suicide, increased

incidence of disease, and decreased access to health and social services [4,5,6]. Risk factors are often discussed in relation to one another, with many authors noting that the accumulation of risk factors is more predictive of stress or negative outcomes than any single risk factor [4,7].

Resilience

The concept of resilience is used to explain why some families can do surprisingly well when faced with risk [8,9]. Thus risk or adversity must be present for a family to use resilience [10]. Although professionals tend to view resilience as a personal trait, researchers view resilience as a process by which individuals use their personal and environmental resources to avoid or recover from negative outcomes [9,11].

Disability

A commonly accepted definition of health and disability is the World Health Organization's International Classification of Functioning, Disability and Health (ICF) [12,13]. This biopsychosocial model of health recognizes the complex relationship between the individual and their environment, replacing previous medically-based models that presented limitations and restrictions as the consequence of an individual's impairment [13]. The ICF framework presents bidirectional relationships among the personal and environmental factors, and an individual's body structure and function, activity and participation [12]. Accordingly, an individual may be disabled (e.g., their participation is limited) in one environment but not in another, due to a variety of environmental factors (barriers such as prejudice, social policies or physical impediments, or enhancers like

universally-designed environments to accommodate variations in functional capacity, or social policies that promote integration).

Hard-to-Reach Families:

This ill-defined term is widely used to describe families who are eligible for assistance, but for various reasons do not use the service or are difficult for service providers to identify and engage [14,15,16]. It has been suggested that no family would be hard to reach if services were well funded and able to meet each family's needs; thus the term 'hard-to-accept-services' has been suggested [14,17]. Hard-to-reach families have been identified using demographic, attitudinal, pragmatic or organizational factors [14,15,17]. The term high-risk has been used synonymously with hard-to-reach, however authors note that some high-risk families are open to receiving help and 'lap up services', while others may be distrustful of services and avoid service use [17]. Given that some high-risk families use the services available to them, and given that a variety of factors affect service use, it is inappropriate to equate high-risk families with hard-to-reach families.

Reflection

Phoenix and Rosenbaum developed The Model of Risk, Disability and Hard-to-Reach Families (Figure 1) in order to help distinguish high-risk families from other families of children with disabilities, and hard-to-reach families. FST is used to consider the role of resilience within each group. Within this reflection the Model of Risk, Disability and Hard-to-Reach Families is used to: 1. define high-risk families and families of children with disability, and consider resilience; 2. describe services typically offered to high-risk

families and families of children with disability; and 3. explore service use and hard-to-reach families.

--Insert Figure 1 here—

1. Defining high-risk families and families of children with disabilities, and exploring resilience

Group A, High-Risk Families are identified as families who have high levels of demands at the personal, family or community levels. Families may face multiple demands at any point in time, and those demands may be normative (e.g., starting school), chronic (e.g., poverty) or temporary (e.g., moving house). Multiple demands may outweigh a family's capabilities to cope, and increase the chance they will experience crisis [18,19]. However, some families who appear to have minimal hardship, and adequate resources to meet the demands, may undergo a crisis if they view the hardship as insurmountable [2]. Therefore, when determining family risk and appropriate interventions it is critical to take a holistic view of the family and assess their demands in addition to their resources, exploring how they view and experience each of these elements of their life.

Group B, Families of Children with Disabilities have most often been viewed as having a demand (e.g., child with a disability or illness) that would promote crisis or create strain in the family system [19,20]. Environmental demands related to disability, such as insufficient societal acceptance and funding, have been recognized [4,21]. More recently, FST has been used to recognize the resilience and positive meaning that families attribute to having a child with a disability [21,22,23]. Evaluating demands and supports at the

individual, family and community levels, and the meaning a family attributes to the disability, are key in understanding whether disability is likely to promote crisis in a family system [9,21].

Group C, High Risk Families of Children with Disabilities. Raising a child with a disability increases the likelihood that families will face additional risk factors related to poverty [21,24, 25,26] and reduced parental physical and mental health [27,28]. The increased risk of poverty is due to the cost for equipment and therapy, decreased availability to work due to inaccessible child care and time needed for caregiving [21,24,25,26]. Parents' physical and mental health is associated with the complexity of the child's health problem and may be linked to parental stress [29]. Using FST, poverty, parental physical and mental health issues, and childhood disability can be viewed as increased demands on the family system. Other demands reported by parents of children with disabilities include advocacy, service coordination, personal care, and transportation [21,30]. The likelihood that these demands will promote a crisis in a family will depend on how the family views their demands and the resources available to them. Therefore, when determining the most appropriate early interventions and likelihood for their use it is critical to look beyond disability at the number of additional demands and the resources available to a family, in addition to how they view these demands and resources [9,21].

2. Services offered to high risk families and families of children with disabilities

Group A, Early Intervention Service for High Risk Families. Early intervention programs are often offered to disadvantaged families. They aim to increase child outcomes (e.g., health, social and academic achievement) and parent outcomes (e.g., positive

parenting behaviors and employment). Head Start in the United States and Sure Start in the United Kingdom are two early intervention programs that have demonstrated positive outcomes [31,32].

Group B, Early Intervention Services for Families of Children with Disabilities.

Some specialized services are offered only to children with disabilities or delays, such as specialized medical services, equipment, environmental modifications, or rehabilitation services. These may be offered under the umbrella of early intervention services such as Head Start or through outside agencies [33]. In Canada, publicly-funded rehabilitation services for children can include physical therapy, speech therapy, occupational therapy, respite services, and specialty services (e.g., for children who are hearing impaired or have Autism Spectrum Disorder) [34]. These interventions may improve the child's body structure [35] or their functional skills [36], promote environmental modifications [37], or provide family respite support [21].

Group C, Early Intervention Services for High Risk Families of Children with Disabilities. Head Start and Sure Start include service provision for children with disabilities as a part of their mandate [33,38]. This is done in recognition of the fact that families raising children with disabilities often face financial hardship and other barriers to accessing services including childcare [21,26] and to promote inclusion [33]. Therefore, although services such as Head Start and Sure Start are not developed specially for children with disabilities, these families are encouraged to participate given that childcare and recreation are expected to benefit all families [21,39].

3. Service Use and Hard-to-Reach Families

Group D, High-Risk Families who are Hard-to-Reach. Concerns have been raised that the families most in need of supports offered to high-risk populations are the least likely to use them [40,41]. Families who have high demands may feel too overburdened to use services [40,42]. Additionally, parents may not use a service if they view it as stigmatizing or useless [40,41,43]. Having supportive family members might encourage some parents to use services [21] or indeed to decrease service use if parents already feel well supported [40]. Clearly the demands on the family, the family resources, and the meaning they attribute to a service should be considered when evaluating whether a high-risk family will use an early intervention program.

Group E, Families of Children with Disabilities who are Hard-to-Reach. There are individual, family and community reasons for missing health care appointments; for example, a child's lack of progress [44], illness in the family [45], and poor organizational communication [46]. Furthermore, families do not attend if they are unconcerned about the child's skills or if they don't value the service provider [46,47]. Use of FST can aid service providers and organizations that offer health and rehabilitation services to determine which families might want services for their child, and the barriers and supports to accessing those services.

Group F, High-Risk Families of Children with Disabilities who are Hard-to-Reach. Children with disabilities and their families may face barriers to accessing social, health, and education services due to social exclusion. Although a mandate exists to include children with disabilities in early intervention programs such as Head Start, research shows

that children with moderate or severe disabilities are less likely to participate in these programs due to lack of experienced or available staff or physical barriers that include transportation issues [48]. Researchers identified having a child with a disability as a potential barrier to parental involvement in Head Start Programs, however parents did not cite this as a reason for limited involvement [42]. Given the attitudinal, physical, and pragmatic barriers to inclusion in early intervention services for children with disabilities, they are likely to be seen as a hard-to-reach group.

Conclusion

This paper illustrates how the Model of Risk, Resilience, Disability and Hard-to-Reach Families can be used to identify target families, explore appropriate services, and understand service use. Service providers, organizations and policy makers who use this model must consider the demands and resources of a family, and how the family views these elements of their life. In doing so, the professional may recognize the many demands faced by a family and offer them community-based early intervention or prevention programs. If disability is also identified in a high-risk family, service providers should be attuned to the additional barriers that may impact use of community-based early intervention programs. Furthermore, these families may benefit from connections to medical and rehabilitation services. When a family has a child with a disability, but is well resourced with few additional demands, time should be spent exploring the family's level of concern and expectation of medical and rehabilitation services, given that these impact service use. It must also be recognized that families may move between categories in the model

as their needs and resources change over time. The relationship between risk, resilience, disability and service use is complex. Using the model (as illustrated in Figure 1) encourages service providers to consider not just whether a child has a disability, but the strengths and challenges of each family, in order to identify who could benefit from services, what services should be offered, and how to best support service use.

Acknowledgement

This work was supported by the Canadian Institutes of Health Research and the Canadian Child Health Clinician Scientist Program.

Declaration of Interests

The authors report no conflicts of interest.

References

1. Hill R. Families under stress: Adjustment to the crises of war separation and reunion. Westport(CT): Greenwood Press Publishers;1949.
2. Hill R. Generic features of families under stress. Soc Casework. 1958;39:139-150.
3. Patterson JM. Families Experiencing Stress. Fam Syst Med. 1988;6(2):202–237.
4. Mikkonen J, Raphael D. Social determinants of health: the Canadian facts. Toronto: York University School of Health Policy and Management;2010.
5. World Health Organization [Internet]. WHO; 2017 [cited 2017 March 8]. Available from: http://www.who.int/social_determinants/en/

6. Organization for Economic Co-Operation and Development. DAC Guidelines and Reference Series: Poverty and Health. Paris: OECD Publishing;2003.
7. Zolkoski SM, Bullock LM. Resilience in children and youth: A review. *Child and Services Rev.* 2012;34(12):2295–2303.
8. Masten AS. Resilience in children threatened by extreme adversity: Frameworks for research, practice, and translational synergy. *Dev and Psychopathol.* 2011;23(02):493–506.
9. Patterson JM. Integrating Family Resilience and Family Stress Theory. *J of Marriage and Fam.* 2002;64(May):349–360.
10. Reaching IN...Reaching OUT. Resilience: Successful navigation through significant threat. Report prepared for the Ontario Ministry of Children and Youth Services. Toronto: The Child & Family Partnership;2010.
11. Liebenberg L, Ungar M. *Researching Resilience.* Toronto: University of Toronto Press;2009.
12. World Health Organization. *International Classification of Disability Functioning and Health.* Geneva: World Health Organization;2002.
13. Masala C, Petretto DR. From disablement to enablement: conceptual models of disability in the 20th century. *Disabil and Rehabil.* 2002;30(17):1233–44.
14. Boag-Munroe G, Evangelou M. From hard to reach to how to reach: A systematic review of the literature on hard-to-reach families. *Res Pap in Educ.* 2012;27(2):209–239.

15. Brackertz N. Who is hard to reach and why? ISR Working Pap. 2007; (January): 1–7.
16. Cortis, N. Overlooked and under-served? Promoting service use and engagement among “hard-to-reach” populations. *Int J of Soc Welf.* 2012;21(4), 351–360.
17. Barrett H. ‘Hard to Reach’ Families: Engagement in the Voluntary and Community Sector. Family and Parenting Institute: London:2008.
18. McCubbin HI, Patterson JM. The Family Stress Process : The Double ABCX Model of Adjustment and Adaptation. *Marriage and Fam Rev.* 1983;6(1-2):7–37.
19. Patterson JM. Families Experiencing Stress. *Fam Syst Medicine.* 1998;6(2):202-237.
20. Patterson JM, Garwick AW. Special Section Chronic Illness and the Family Levels of Meaning in Family Stress Theory. *Fam Process.* 1994;33(3):287–304.
21. McConnell D, Breikreuz R, Uditsky B, Sobsey R, Rempel G, Savage A, Parakkal M. Children with Disabilities and the Fabric of Everyday Family Life. Faculty of Rehabilitation Medicine Family and Disability Studies Initiative: University of Alberta:2013.
22. Gallimore R, Bernheimer LP, Weisner TS. Family life is more than managing crisis: Broadening the agenda of research on families adapting to childhood disability. In: Gallimore R, Bernheimer P, MacMillan DL, Speece SL, Vaughn S. Mahway, NJ. Developmental perspectives on children with high-incidence disabilities. Mahwah (NJ): Lawrence Erlbaum Associates Publishers; 1999. P55-80.

23. King G, Baxter D, Rosenbaum P, Zwaigenbaum L, Bates A. Belief system of families of children with Autism Spectrum Disorders or Down Syndrome. Focus on Autism and Other Dev Disabil. 2009;24(1):50-64.
24. Emerson E, Hatton, C. The socio-economic circumstances of children at risk of disability in Britain. Disabil & Soc.2007;22(6):563–580.
25. Petrenchik MT. Childhood Disability in the Context of Poverty. Hamilton, ON: CanChild Centre for Childhood Disability Research:2008.
26. Wiart L, Kehler H, Rempel G, Tough S. Current state of inclusion of children with special needs in child care programmes in one Canadian province. Int J of Incl Educ.2013;(May):1–14.
27. Brehaut JC, Garner RE, Miller AR, Lach LM, Klassen AF, Rosenbaum PL, Kohen DE. Changes over time in the health of caregivers of children with health problems: growth-curve findings from a 10-year Canadian population-based study. Am J of Public Health. 2011;101(12):2308–16.
28. Lach LM, Kohen DE, Garner RE, Brehaut JC, Miller AR, Klassen AF, Rosenbaum PL. The health and psychosocial functioning of caregivers of children with neurodevelopmental disorders. Disabil and Rehabil.2009;31(8):607-618.
29. Brehaut JC, Kohen DE, Garner RE, Miller AR, Lach LM, Klassen AF, Rosenbaum PL. Health among caregivers of children with health problems. Am J of Public Health. 2009;99(7):1254-1262.
30. Hanvey L. Children with disabilities and their families in Canada (Discussion paper). Washington, DC: National Children’s Alliance:2002.

31. Deming D. Early childhood intervention and life-cycle skill formation: Evidence from Head Start. *Am Econ J: Appl Econ.*2009;1(3):111–134.
32. National Evaluation of Sure Start Research Team [Internet]. No place or publisher available; The impact of Sure Start research programs on 3 years olds and their families 2008 [cited 2016 April 26] Available from:
<http://www.ness.bbk.ac.uk/impact/documents/42.pdf>
33. US Department of Health and Human Services [Internet]. Washington,DC: Office of Human Development; The status of handicapped children in Head Start programs. 1987 [cited 2016 April 26]. Available from <http://files.eric.ed.gov/fulltext/ED297559.pdf> on April 26.
34. Ontario Ministry of Children and Youth Services [Internet]. Ontario: Special Needs. Queen’s Printer for Ontario 2010-15. 2015 [cited 2017 March 8] Available from:
<http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/index.aspx>
35. Novak I, McIntyre S, Morgan C, Campbell L, Dark L, Morton N, Stumbles E, Wilson SA, Goldsmith S. A systematic review of interventions for children with cerebral palsy: state of the evidence. *Dev Med and Child Neurol.*2013;55(10):885–910.
36. Chen CC, Heinemann AW, Bode RK, Granger CV, Mallinson T. Impact of pediatric rehabilitation services on children’s functional outcomes. *Am J of Occup Ther.*2004;58(1):44–53.

37. Darrah J, Law MC, Pollock N, Wilson B, Russell DJ, Walter SD, Rosenbaum P, Galuppi B. Context therapy: a new intervention approach for children with cerebral palsy. *Dev Med and Child Neurol.*2011;53(7):615–620.
38. Pinney A. [Internet]. London: Birkbeck College. A Better Start: Children and Families with Special Needs and Disabilities in Sure Start Local Programmes. 2007 [cited 2016 April 26]. Available from <http://www.ness.bbk.ac.uk/implementation/documents/1520.pdf>
39. Rosenbaum P, Gorter JW. The “F-words” in childhood disability: I swear this is how we should think! *Child: Care, Health and Dev.* 2012;38(4):457–463.
40. Barlow J, Kirkpatrick S, Stewart-Brown S, Davis, H. Hard-to-reach or out-of-reach? Reasons why women refuse to take part in early interventions. *Child and Soc.*2005;19(3):199–210.
41. Winkworth G, McArthur M, Layton M, Thomson L, Wilson F. Opportunities Lost—Why Some Parents of Young Children Are Not Well-Connected to the Service Systems Designed to Assist Them. *Aust Soc Work.*2010;63(4):431–444.
42. Lamb-Parker F, Piotrkowski CS, Baker AJL, Kessler-Sklar S, Clark B, Peay L. Understanding barriers to parent involvement in Head Start: A research-community partnership. *Early Child Res Q.*2001;16(1):35–51.
43. Coe C, Gibson A, Spencer N, Stuttaford M. Sure start: voices of the “hard-to-reach”. *Child: Care, Health and Dev.*2008;34(4):447–53.

44. Phoenix M, Rosenbaum P. Development and implementation of a paediatric rehabilitation care path for hard-to-reach families: a case report. *Child: Care, Health, and Dev.*2015;41(3):494-499.
45. Ballantyne M, Stevens B, Guttman A, Willan AR, Rosenbaum P. Transition to neonatal follow-up programs: is attendance a problem? *The Journal of Perinat & Neonatal Nurs.*2012;26(1):90–98.
46. Arai L, Stapley S, Roberts H. “Did not attends” in children 0-10: a scoping review. *Child: Care, Health and Dev.*2014;40(6):797–805.
47. Skeat J, Wake M., Ukouunne, O. C., Eadie, P., Bretherton, L., & Reilly, S. Who gets help for pre-school communication problems? Data from a prospective community study. *Child: Care, Health and Dev.*2014;40(2):215–222.
48. Beauchesne MA, Barnes A, Patsdaughter C. Children with disabilities need a Head Start too! *J of Learn Disabil.*2004;8(1):41–55.

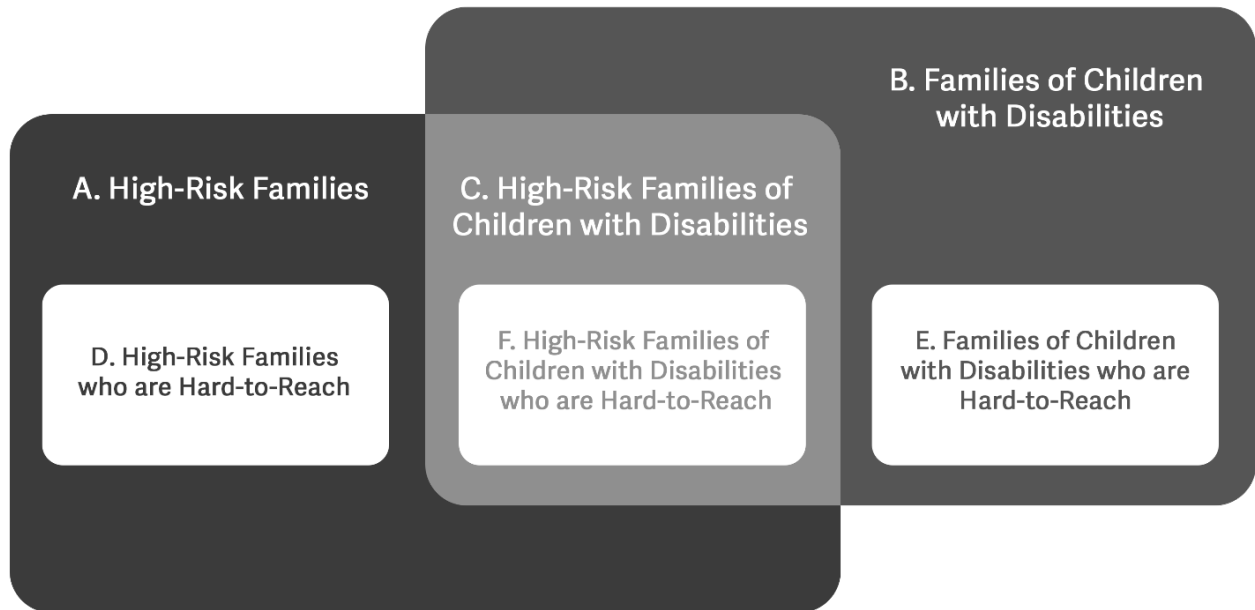


Figure 1. The Model of Risk, Disability and Hard-to-Reach Families

Introduction to Chapter 4. Laying the Foundation: Application of Ethical Principles

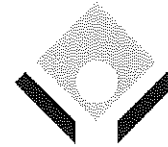
Chapter 4 presents a published text book chapter that explores the ethical implications of service provision for hard-to-reach families. A clinical case is presented to investigate thorny issues that arise when families miss their child's developmental rehabilitation appointments. Questions addressed include whether service providers can help families to avoid missed appointments and whether current policies to manage missed appointments are ethical. Ethical principles are viewed from the clinician and organizational viewpoints. This sets the foundation for Chapter 5's exploration of parents' perspectives on attendance, participation and engagement in children's developmental rehabilitation services.

The chapter was published by Mac Keith Press, who provided written permission (April 24, 2017) to reprint the chapter as a part of this thesis using the following citation:

Phoenix, M. (2016) Service provision for hard-to-reach families: What are our responsibilities? In P. Rosenbaum, G. Ronen, E. Racine, J. Johannesen, & B. Dan (Eds) *Clinical Ethics in Child Health Principles and Cases in Neurodisability* (pp. 193-201). London: Mac Keith Press.



School of Rehabilitation Science
1400 Main Street West
IAHS-403
Hamilton, ON L8S 1C7
T: (905) 525-9140, ext 22867
E: rehab@mcmaster.ca
www.srs-mcmaster.ca



School of
Rehabilitation
Science
REACHING FURTHER

Udoka Oluonu
udoka@mackeith.co.uk

Michelle Phoenix
School of Rehabilitation Science
michellepphoenix@gmail.com

April 21, 2017

Dear Udoka Oluonu

I am completing a PhD. Thesis at McMaster University entitled "Parents' Participation and Engagement in their Child's Developmental Rehabilitation Services". I would like your **permission to reprint in full** the following chapter in my thesis:

Phoenix, M. (2016) Service provision for hard-to-reach families: What are our responsibilities? In P.Rosenbaum, G. Ronen, E. Racine, J. Johannesen, & B. Dan (Eds) *Clinical Ethics in Child Health Principles and Cases in Neurodisability* (pp. 193-201). London: Mac Keith Press. Please note that I am a co-author of this work.

I am also requesting that you **grant irrevocable, nonexclusive license to McMaster University and to the National Library of Canada** to reproduce this material as a part of the thesis. Proper acknowledgement of your copyright of the reprinted material will be given in the thesis.

Here is the information that you requested to process this request

If these arrangements meet with your approval, please sign where indicated below and return this letter to me at michellepphoenix@gmail.com. Thank you very much.

Sincerely,

Michelle Phoenix

PERMISSION GRANTED FOR THE USE REQUESTED ABOVE

Authorized by: **UDOKA OLUONU**

Title: **PRODUCTION MANAGER |
COMMISSIONING EDITOR**

Date: **24th APRIL 2017**

Signature

Chapter 17

Service provision for hard-to-reach families: what are our responsibilities?

Michelle Phoenix

Cinical scenario

I was standing at my colleague's desk trying to decide whether or not to plan a treatment session for little Nicole and her family. This was not an uncommon scenario in our children's treatment center – trying to guess 30 minutes before a session whether the family would come in. The occupational therapist (OT) and I, the speech language pathologist (SLP), had scheduled a joint therapy session for this 2-year-old with cerebral palsy. Nicole typically came in with her father Jeff and they both participated enthusiastically. Our goals included increasing functional play and imitation skills, and teaching parents ways to engage Nicole in play at home to promote her development.

Things seemed to be going well until that first missed appointment. We recognized that this can happen to anyone. We called and spoke to Jeff who said the appointment had been forgotten, but he would be there next week. Next week they came in and we seemed to be

Author's note

Please note that the opinions expressed in this chapter are those of the author and not of the program in which she works.

back on track. In discussing home practice, we learned that Jeff and his wife had recently separated. He said he was coping well with the change and they were sharing custody. Sens-ing this was a chaotic time for the family, we offered to postpone therapy. We did remind him of the center's policy that if two appointments were missed without prior notice the child would be discharged from services. However, Jeff chose to continue with the appointments we had scheduled. We printed out a schedule and gave it to him ... which brings me back to my colleague's desk a week later.

It is hard to describe the premonition that warns you not to expect that family you ought to be expecting. We decided to prepare the room and materials anyway, but that day the family did not arrive. With sinking hearts my colleague and I knew this meant discharge from the center and the OT and SLP services that might be of benefit to Nicole and her family. We were still working on feeding, early sign language and accessing daycare. In accordance with the center's policy, we charted the second 'no-show', recorded the discharge due to 'declined intervention' and notified the family via a discharge report.

I continue to question whether we did everything we could to engage this family in service and also whether it is ethical to discharge families when they are having difficulty making it in for appointments.

This scenario describes a so-called 'hard-to-reach family', often defined as a family who is eligible for services but for a variety of reasons does not use them (Boag-Munroe & Evangelou 2012; Cortis 2012). Within a pediatric rehabilitation context, clinicians identified reasons at the child, parent, family and organizational levels that contribute to making a family hard-to-reach (Phoenix & Rosenbaum 2015). These reasons may occur in isolation (e.g. having a child who is medically fragile) or co-occur (e.g. having a lengthy wait list for service, no childcare for siblings and a parent with mental health impairments). The ethical dilemma explored in this chapter concerns how pediatric rehabilitation services are provided to hard-to-reach families. Specifically I examine the practice of discharging families if they miss appointments without prior notification, so-called 'no-shows'. First, this issue is discussed at the parent-therapist level to explore whether and how missed appointments could be avoided. Second, I explore the issues at a systems level to question whether discharging families after missed appointments is an ethically acceptable practice.

Can parents and therapists work together to avoid missed appointments?

The term 'hard-to-reach families' implies that problems with service use are the family's fault; therefore many authors recommend reframing the term as 'hard-to-access services' (Barrett 2008; Boag-Munroe & Evangelou 2012; Cortis 2012). This change in language suggests that organizations and therapists bear some responsibility in helping families to access their services. There is strong evidence to suggest that using the principles of family-centered services and cultural competence can help families to access care

(Kuhlthau et al. 2011; Rosenbaum et al. 1998; Tseng & Streltzer 2008). By communicating clearly with families, listening to the families' needs and priorities, and allowing families to make decisions about their care it might be possible to engage these apparently hard-to-reach families and avoid the missed appointments that result in discharge.

Therapists are responsible for providing both general and specific information to families (King et al. 2010). This may include general information about childhood development, a particular condition, or resources and services that are available. It is important that this information is presented in a way that helps parents to understand their options and to make informed decisions regarding their child's goals and services (Rosenbaum et al. 1998). In studies evaluating parents' perceptions of family-centered service in pediatric rehabilitation programs, parents consistently rate therapists poorly in their provision of general information (Dyke et al. 2006; King et al. 2010). This can have major implications for service use; for example, families are unlikely to access a service if they do not understand what is on offer (Winkworth et al. 2010).

In thinking back to my experience with Nicole and her family, I wonder how clearly we had communicated the goals of therapy. Given that we were focused on developing play and early imitation skills, perhaps it appeared that we were simply playing with the child. We may have taken for granted that parents knew that play was the way that children learn about and experience the world around them. When the family was trying to cope with a separation, it may not have seemed important to come in and play. Alternately, the family's attendance may not have been a reflection of the value they placed on therapy; rather, the missed appointments may have been due to logistical difficulties of scheduling and transportation. In this family's case we did not know the precise reason that they missed appointments. An essential skill in family-centered service is listening to and valuing parents' information about their own strengths and needs in addition to those of their child. It is possible that by improving the quality and timeliness of the information we provided to this family and by being better listeners, we could have avoided the missed appointments and resulting discharge.

When working as a pediatric therapist, it is easy to focus solely on the needs of the child; however, within a family-centered service approach we are expected to recognize the holistic needs of the family (Rosenbaum et al. 1998). This is because children develop within a family system, and the health and well-being of parents will impact the child. In hard-to-reach families, parents may have a multitude of challenges that need to be addressed (e.g. poverty, limited literacy, mental health issues, substance abuse, language or cultural barriers) (Barrett 2008; Boag-Munroe & Evangelou 2012). It is vital to ask parents about these areas of their lives and to help families to access resources and supports to address these challenges. Early intervention programs are of the most benefit to children once material security in the family is achieved (Turnbull et al. 2014).

Given the competing challenges for parents' time and energy, it is critical to encourage parents to determine the nature of intervention that would best suit their family's needs. Within a model of family-centered service, therapists should present families with options about the services that could be provided and allow families to determine how much control they want over decision-making (Rosenbaum et al. 1998). Some families may decide to ask the therapist what she would recommend for their child; other families may want total control over developing their service plan. Ideally, services would be individualized and flexible, able to adapt to the families' changing needs and strengths over time.

In the vignette described at the opening of the chapter, individual therapy was being offered in the center on a weekly basis, with the father bringing his daughter in and participating throughout the joint OT and SLP session. This therapy plan was developed with the parents to fit with Jeff's work schedule. Offering OT and SLP sessions together meant one less appointment for the family each week and also allowed for collaborative practice. At a surface level it appears that we created an individualized service plan together with the family to best fit their needs. Looking back now, I question if we could have done more. Perhaps the more pressing needs were related to the parents' relationship and social work help could have been offered. If the parents were overwhelmed by the appointments, we might have been able to dedicate more time and effort into supporting daycare enrolment and supporting the staff there. Although we offered to postpone therapy, we could have encouraged a richer dialogue about what a break in therapy might mean, or even discuss whether the family wanted to continue with therapy at all.

When parents assume responsibility for making therapy-related decisions for their child they may act in a way that is different from what the professional believes to be best. It is important for professionals to accept and respect these decisions, given that a basic assumption within family-centered care is that parents know their child best (Rosenbaum et al. 1998). This can be especially difficult in cases where the family chooses to decline therapy services. As therapists we often believe that we can help children to develop and we offer support to parents. There is evidence to indicate that participating in pediatric rehabilitation services can lead to positive outcomes for children with impairments (Chen et al. 2004). Therefore, it can be difficult to accept a parent's choice not to participate in therapy. Therapists might even overlook the option of 'discontinuing services' when discussing choices for therapy (e.g. group intervention or individual therapy). This makes it very difficult for parents to tell a therapist that they may not want to continue with services and to discuss openly the reasons for this choice. Parents may feel pressure to accept therapy and appear that they are being 'good parents' by doing what is recommended, as opposed to doing what they feel is right for themselves and their family.

There are some instances in which not following through with therapy might indicate harm or neglect and child protective services would need to be involved. These

circumstances might be clear and include, for example, unsafe feeding practices for a child with swallowing difficulties. Yet there are many circumstances when it is not clear whether a child is in need of protection. For example, what if a parent does not want to take the child out of the house because they are afraid that child will be made fun of? The term ‘child not brought’ was suggested to replace ‘did not attend’ to indicate that it is the parents’ responsibility to bring the child to appointments and that failure to do so might indicate safeguarding and welfare concerns (Arai et al. 2013). It can be challenging for therapists to decide when to trust parents as knowing the best and doing the best for the child versus making decisions that constitute harm or neglect.

In some cases, families are already involved with child protective services and attend therapy because this was recommended (or indeed ordered) by the agency as a mandatory part of retaining (or regaining) child custody. These families often attend because they have to, not because they want to. When these families miss an appointment the therapist is obliged to notify the family’s caseworker. This practice may hold families who are known to child protective agencies to a higher standard of participation than is common for most families who use pediatric rehabilitation services.

In the scenario described, the family was observed to be loving and highly supportive of Nicole. They avidly watched her develop and cheered her on enthusiastically. Nicole appeared to be safe, stimulated and well cared for. When the family missed appointments we did not consider involving the child protective agency or approaching our manager. We followed the center-based policy that indicated a discharge from service was required for this little girl and her family.

Is the practice of discharging families due to missed appointments ethically acceptable?

The center’s discharge policy directs clinicians to discharge a family following two missed appointments without prior notification. It is intended to promote equity for clients such that clinicians are consistent and unbiased in their discharge practices. However, this policy may unfairly disadvantage children whose parents did not commit to participation in therapy and families whom service providers had difficulty engaging. The policy is also intended to promote utilitarian justice, whereby resources are shared fairly among those in need of service. Thus by taking the therapy spaces from families who are not using them and offering the time, space and care to families who are awaiting service, program administrators are promoting justice. The ethical dilemma is how to balance the need to best serve each individual client (beneficence) while limiting harm (non-maleficence) with the need to use resources fairly for all (utilitarian justice) (Blackmer 2000).

In Ontario, Canada, the Ministry of Children and Youth Services funds pediatric rehabilitation services with the aim of ensuring ‘all children and youth have the best

opportunity to succeed and reach their full potential' (Ontario Ministry of Children and Youth Services 2010). Yet not all families may be served equally by the existing services. Hard-to-reach families have been described as isolated, often facing multiple challenges that impair their ability to access healthcare and early intervention programs (Barrett 2008; Boag-Munroe & Evangelou 2012). These families can be overlooked, potentially never accessing the services that are available to them (Coe et al. 2008; Winkworth et al. 2010). As in the case described here, families may try to use services but demonstrate difficulties by missing appointments. If some hard-to-reach families never access care and others are discharged because of missed appointments, organizations may be missing the opportunity to support the families – and children – who are probably most in need of support (Cortis 2012).

It is recognized that attracting and retaining hard-to-reach families takes additional time and resources (Barrett 2008; Boag-Munroe & Evangelou 2012; Cortis 2012). Time and skilled professionals are required to empower and build trust with these families (Cortis 2012). This can pose difficulties for publicly funded organizations that are often responsible for doing much more than their limited resources make possible. Organizations are concerned about their waitlists and may be evaluated on the number of children seen, the time periods spent waiting for care and positive client outcomes. 'Resource scarcity and pressure to achieve and demonstrate short-term results may lead providers to concentrate their efforts on those easiest to reach and engage, or those for whom change will be most evident' (Cortis 2012 p. 352).

At the center at which I work, the policy regarding discharge following missed appointments was developed and implemented in part due to high numbers of client 'no-shows'. Clients at this center missed over 4000 appointments in a 1-year period, 1367 of them without prior notice (Phoenix & Rosenbaum 2015). These appointments use clinician time and center resources. Retaining families on active caseloads who are not attending their appointments keeps clinicians from picking up children from the treatment program waitlist that can range from 3 months to over a year. Given the belief that services provided early in childhood provide the greatest impact on development, it can be considered unfair to increase the wait times for children while attempting to engage families that are not typically coming in for their appointments. In this service environment it is understandable that the organization would choose to implement a discharge policy based on missed appointments in an effort to promote justice via equitable sharing of resources for all clients.

This discharge policy can create tension for clinicians who want to promote justice for all clients, but also are concerned with beneficence – providing the best service for the client in front of them. This tension is increased when clinicians recognize that providing the best service for hard-to-reach families requires increased time and effort, resources that could otherwise be directed to clients awaiting care. In the case above, I was left with the unsettled feeling that there was more I could have done to engage this family

and provide services better suited to meet the family's needs. I did not feel right following the center's discharge policy, but I understood the reasons the policy exists. I could have circumvented the organization's discharge policy, but thought this created unfairness for other families discharged when clinicians have followed the policy. The struggle to achieve balance between beneficence and justice within rehabilitation medicine is an ethical dilemma that is not easily resolved (Blackmer 2000).

The resolution

In this case we notified the family of the discharge via a mailed report that clearly stated that if the family had further concerns they were welcome to re-refer for service. It felt uncomfortable discharging Nicole when we knew there was so much more we could do to support her development. It was hard to inform the parents of the discharge knowing that they were going through a difficult time. We thought about circumventing the policy – no-one would be checking to see if this child had a previous missed appointment – but felt that wouldn't be fair to other families who were discharged after two missed appointments per the center-based policy. We hoped that Nicole's family would come back – and they did initiate a re-referral and returned for service. The family had great attendance when they returned and Nicole developed many of the skills needed for successful entry into a community-based junior kindergarten program.

In retrospect it is easy to think that we could have provided better service for this family. Perhaps we could have given more information about service options and the goals we were working on in therapy. It might have helped had we been better listeners and aimed to elicit more information about the whole family and not just the child. We assumed that therapy was doing no harm, but perhaps it was adding stress to the parents' lives. Discharge should have been discussed as an acceptable choice with this family prior to the missed appointments. We could also have negotiated a different schedule that fit better with family needs and might have avoided missed appointments. Once the appointments were missed we could have ignored the policy that specified discharge as a next step. Regardless of our decision to discharge the family or keep them on case-load, we would have struggled to balance our relationships with the employer and the client while acting ethically and doing 'what's right'. Perhaps the organization should revisit the policy to determine if there is an alternate way to support families who have missed appointments. Any policy changes would need to consider not just the needs of the family who is participating in care, but also the needs of the children and families who are awaiting service.

The big picture

The case above is used to illustrate the ethical complexity of providing pediatric rehabilitation services within the context of a Canadian children's treatment center.

This environment can be considered resource-rich when contrasted with the money and services available for children with impairments once they move into school age and adulthood. We must also consider that there are countries that do not publicly fund rehabilitation services for children. Furthermore, some countries do not have the professional support, infrastructure or money to provide comparable pediatric rehabilitation services. Limited funding can heighten barriers to service accessibility, making even more families 'hard-to-reach'. In the case of limited service it becomes even more important to consider which families are able to access care and whether certain families are being marginalized and disadvantaged by rehabilitation organizations.

Themes for discussion

- Does the program in which you work have a policy regarding 'hard-to-reach' (or 'hard-to-serve') families? On what basis was such a policy developed? Was there ever an explicit discussion of the ethics of such a policy?
- Most if not all the services we offer to families of children with developmental impairments are available during 'working hours' of weekdays. Is it ethical to expect busy families to march only to our drummers, or would it be more appropriate to offer evening and weekend hours as part of being 'family-centered'?

References

- Arai L, Stapley S, Roberts H (2014) 'Did not attend' in children 0–10: A scoping review. *Child Care Health Dev* 40: 797–805.
- Barrett H (2008) *Hard-to-reach families: Engagement in the voluntary and community sector*. London: Family and Parenting Institute.
- Blackmer J (2000) Ethical issues in rehabilitation medicine. *Scand J Rehabil Med* 32: 51–55.
- Boag-Munroe G, Evangelou M (2012) From hard to reach to how to reach: A systematic review of the literature on hard-to-reach families. *Res Papers Educ* 27: 209–239.
- Chen CC, Heinemann AW, Bode RK et al. (2004) Impact of pediatric rehabilitation services on children's functional outcomes. *Am J Occup Ther* 58: 44–53.
- Coe C, Gibson A, Spencer N, Stuttaford M (2008) Sure start: Voices of the 'hard-to-reach'. *Child Care Health Dev* 34: 447–453.
- Cortis N (2012) Overlooked and under-served? Promoting service use and engagement among 'hard-to-reach' populations. *Int J Soc Welf* 21: 351–360.
- Dyke P, Buttigieg P, Blackmore AM, Ghose A (2006) Use of the measure of process of care for families (MPOC-56) and service providers (MPOC-SP) to evaluate family-centred services in a paediatric disability setting. *Child Care Health Dev* 32: 167–176.

- King S, King G, Rosenbaum P (2010) Children's health care evaluating health service delivery to children with chronic conditions and their families: Development of a refined measure of processes of care (MPOC-20). *Child Health Care* 33: 35–57.
- Kuhlthau K, Bloom S, Van Cleave J et al. (2011) Evidence for family-centered care for children with special health care needs: A systematic review. *Acad Pediatr* 11:136–143.
- Ontario Ministry of Children and Youth Services (2010) *About the Ministry* [Online]; <http://www.children.gov.on.ca/htdocs/English/about/index.aspx> (accessed 14 May 2015).
- Phoenix M, Rosenbaum P (2015). Development and implementation of a paediatric rehabilitation care path for hard-to-reach families: A case report. *Child Care Health Dev* 41: 494–499.
- Rosenbaum P, King S, Law M et al. (1998) Family-centred service: A conceptual framework and research review. *Phys Occup Ther Pediatr* 86: 1–20.
- Tseng W, Streltzer J (2008) *Cultural competence in health care*. New York, NY: Springer.
- Turnbull H, Loptson K, Muhajarine N (2014) Experiences of housing insecurity among participants of an early childhood intervention programme. *Child Care Health Dev* 40: 435–440.
- Winkworth G, McArthur M, Layton M, Thomson L, Wilson F (2010) Opportunities lost – why some parents of young children are not well-connected to the service systems designed to assist them. *Austral Soc Work* 63: 431–444.

Introduction to Chapter 5. Building from the Foundation: A theory of parent engagement in children's developmental rehabilitation services

Chapter 5 presents a pair of manuscripts prepared for journal submission that explore how parents attend, participate and engage in their child's developmental rehabilitation service. The papers report a qualitative grounded theory study with two sets of results: (a) the conditions that affect parent engagement and (b) the theory of parent engagement in children's developmental rehabilitation services. These results are illustrated using a metaphorical *journey* in pursuit of the parents' chosen destination of *child health and happiness*. The implications of this work are presented for service providers, organizational leadership, policy makers and researchers to help inform a coordinated vision and plan for accessible rehabilitation services that promote engagement with children and families.

Please acknowledge the following author contributions and roles:

Phoenix, M., Jack. S., Rosenbaum, P., Missiuna, C. Contextualizing parent engagement in children's developmental rehabilitation services: The journey to child health and happiness. Manuscript in preparation.

Phoenix, M., Jack. S., Rosenbaum, P., Missiuna, C. A grounded theory of parent engagement in children's developmental rehabilitation services: The journey to child health and happiness. Manuscript in preparation.

As lead author, I was responsible for development of the research question, the study design, carrying out the study and writing the manuscripts. I completed these tasks with the support and guidance of my advisor, Dr. Peter Rosenbaum and committee members Drs. Susan Jack and Cheryl Missiuna. In order to carry out the study I obtained ethics approval, completed the interviews, and did the coding for analysis. My advisor and committee members helped with these tasks by reviewing materials and discussing the analysis at key moments throughout the study. I wrote the manuscripts presented here, but deeply appreciate the review and feedback provided by committee members. Transcription was done by a professional transcriptionist, Caroline Phelan. The data management for the policy data was done by a student, Tessa Dickison.

Contextualizing parent engagement in children's developmental rehabilitation services: *the journey to child health and happiness*

Introduction

Parenting can be viewed as a dance led by the child, so the developmental needs of children and parents cannot be uncoupled (Rosenbaum, 2009). When children have a developmental delay and/or a diagnosis they may use a variety of developmental rehabilitation services (children's therapy) to help them to reach their full potential.

Children's therapy services include, but are not limited to, occupational therapy, physical therapy, speech-language pathology and social work services. In Ontario, Canada 65,000 children with physical, developmental and communication needs use publicly funded children's therapy services on a yearly basis (Ontario Association of Children's Rehabilitation Services, 2010). To promote child development these services aim to integrate principles of family-centred service, an approach that recognizes parents as the experts on their child and includes parents as partners in their child's therapy (Kuhlthau et al., 2011; Siebes et al., 2007). Although parental engagement is viewed as a crucial component in children's therapy, defining the nature of engagement and the strategies to promote engagement is in its infancy (Arrigo, Ziviani, Poulsen, Copley & King, 2016; King, Currie, & Petersen, 2014). Parents have been described as 'hard-to-reach' when they do not use the available services, or require extra efforts from service providers to engage (Boag-Munroe & Evangelou, 2012; Flanagan & Hancock, 2010). In order for service providers to promote engagement with all families, there is a need to understand what makes parent engagement in rehabilitation services successful or problematic.

To be eligible for rehabilitation services children must have an identified developmental delay or a medical diagnosis. This may appear obvious, but quickly becomes convoluted by complexities in the identification of a delay and the definition of a health condition or disability. Rosenbaum (2006) explores the nuance between variation and abnormality in children's development, questioning whether a slowed rate of development or an alternate way of doing a task constitutes a need for therapy. Application of the World Health Organizations (2007) International Classification of Functioning Disability and Health framework raises similar questions, by moving beyond the purely medical conceptualization of disability to include activity, participation, personal and environmental factors. The family is the child's first and most important environment, reinforcing the need to look at both child and parent health.

In order to study the relationship between child and parent health Brehaut et al. (2009) identified child health problems according to activity and functional limitations, reported health conditions, and elevated service use. They found that "caregivers of children with health problems had more than twice the odds of reporting chronic conditions, activity limitations, and elevated depressive symptoms, and had greater odds of reporting poorer general health than did caregivers of healthy children" (p. 1254). There is considerable evidence documenting the compromised physical health and increased stress and depression for parents of children with disabilities (e.g., Barlow & Ellard, 2006; Brehaut et al., 2004; Lach et al., 2009). The child's specific diagnosis and the presence of behavioural challenges have been shown to affect parents' health (Lach, 2009; Abbeduto

et al., 2004). On the other hand, the positive effects of raising a child with a disability and resilience within families have received little attention (McConnell et al., 2013; Patterson 2002; Urbano & Hodapp, 2007). Caregiver health is likely to be compromised when raising children who have multiple and complex needs and the increase in health service use for both children and parents is taxing (McConnell et al., 2013).

A family's ability to make use of the services available to them may be partially determined by family characteristics such as marital status, age, and number of children. Researchers have frequently tried to determine whether having a child with a disability increases the likelihood that parents will divorce. Results from a meta-analysis indicate that there is an average 5.97% increase in divorce for parents raising a child with a disability (Risdal & Singer, 2004). Divorce rates may vary according to the child's diagnosis with parents raising a child who has Autism Spectrum Disorder divorcing more often than a matched comparison group (Hartley et al., 2010) and parents raising a child with Down Syndrome divorcing less often than a comparison group (Urbano & Hodapp, 2007). Factors such as parents' age and level of education were found to affect divorce rates, and these may differ by diagnostic group (Hartley et al., 2010; Urbano & Hodapp, 2007). Having multiple children in a family places additional strains on parents' time, energy, and finances, especially when one or more children have an impairment (McConnell et al., 2013; Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008). In some cases, there is increased genetic risk for siblings to have a disability, and at other times siblings are thought to develop emotional and behavioural challenges due to the daily life

disruptions caused by their siblings' health condition (Barlow & Ellard, 2006). Parents also report benefits to children growing up with a sibling with an impairment (Barlow & Ellard, 2006; Mulroy et al., 2008). The complexity of the 'balance sheet' of benefits and risks to parents and siblings in families with a child with an impairment should encourage researchers and clinicians to apply a holistic family lens to their work.

Given the focus on family-centred service in pediatric rehabilitation, the complexities in child and family composition and health, and the limited understanding of parent engagement in therapy, the purpose of this study was to investigate how parents of children with a developmental delay participate and engage in their child's therapy service. The results are presented in two parts: the current paper describes the conditions under which engagement occurs with respect to family composition, health, and service complexities (Chapter 5a); the second paper presents the Phoenix Theory of Parent Engagement to show how parents attend, participate, and engage in their child's developmental rehabilitation services (Chapter 5b).

Methods

A constructivist grounded theory study (Charmaz, 2006, 2014) was conducted in order to develop a substantive theory to explain how parents participate and engage in their child's therapy services. The grounded theory methodology was first published by Glaser and Strauss (1967) as a contrast to the predominant positivistic research paradigm that prioritized quantitative methods for their objectivity. At that time theory development

consisted of grand theories without a foundation in data. Glaser and Strauss (1967) proposed a systematic process for concurrently collecting and analyzing data in order to develop a theory that describes a basic social problem and the process by which the problem is addressed. Charmaz (2014) built on these methods and describes a Constructivist Grounded Theory approach that views researchers as a “part of the world we study, the data we collect, and the analyses we produce” (p.17). From this, researchers draw from their own knowledge, feelings, and perspective generated over time through their interactions with other people. Constructivist grounded theory methods were chosen for this study because there is little known about the topic of parent engagement and the purpose of the study is to develop a theory that describes how parents experience this basic social process.

Sampling: All recruitment was done at a single publicly-funded children’s treatment centre (CTC) in Ontario, Canada. This site was chosen because the researcher was clinically employed there and her familiarity with the culture, services, and characteristics of clients promoted a rich understanding of the research topic. Sampling was initially purposeful, composed of parents who spoke English and had attended at least one therapy session at the CTC for their 0-6 year old child. When interviews with the first 4 participants were coded theoretical sampling was used to recruit participants who could provide more specific information in areas that emerged as theoretically important (Brekenridge & Jones, 2009; Gentles, Charles, Ploeg, & McKibbon, 2015), including: parents of children who had delays in more than one developmental area, parents who had

a history of missed or cancelled appointments, and fathers. Theoretical sampling also led to alterations in the interview guide such that new questions directly informed the emerging theoretical concepts. Recruitment opened in January 2016 and closed in February 2017 once the key theoretical categories were saturated. Saturation was determined when the final four participants described each category of engagement prior to being shown the theory, then agreed with all parts of the theory once it was shown, with no new components of engagement described.

A critical case sampling method was used to select service providers at the CTC who could provide information about the organizational and therapeutic context that could impact parent engagement. This sampling method involves selecting individuals who have an “important role in the scheme of things” (Patton, 2002, p143). Therefore, service providers who held the role of Clinical Advisor were selected from the Occupational Therapy, Physical Therapy, Speech-Language Pathology and Social Work disciplines were recruited and consented to participation. Within this CTC, Clinical Advisors are responsible for developing processes and practices that support clinical excellence and responsiveness to client needs.

Twenty parents (15 mothers and 5 fathers) from 18 unique families participated in the study. All families spoke English and in four cases a second language was spoken in the family home. Six participants reported being single parents and three shared custody with the child’s other parent. All families but one had more than one child. Eight participants

had not completed college (with four not completing high school) and the other 12 had college or university education. The sample was split with 11 participants staying home to care for children (notably three of these families worked from home while caring for children), nine participants working full time or part time outside of the home, and one participant being on a medical leave from work. The total family income was <19,000 for four participants and >100,000 for five, with the other families spread across the range. All parents had at least one child who used therapy services at the CTC; of these children seven had a formal medical diagnosis (e.g., Autism Spectrum Disorder or Cerebral Palsy). Six children used a single service at the CTC, whereas all other children were involved with more than one discipline. There were multiple types of therapy used within the group, including: individual therapy, group therapy, parent education, or preschool consultation. Ten families reported using community-based services in addition to the therapy used at the CTC where recruitment was conducted.

Data collection: There were three types of data collected in this study: parent and clinician semi-structured interviews, child health record data, and policy-procedure data. The primary data source was parents of children with disabilities chosen because of the potential to gather the deep rich data needed to inform a grounded theory (Charmaz, 2014). Twenty parents (15 mothers and 5 fathers) from 18 unique families participated in the study, when both parents participated, they were interviewed separately. The first author completed initial interviews at the family's home or a community location of their choice. All parents except for one allowed the interviews to be audio-recorded, these were

later professionally transcribed. The purpose of the initial interview was to gather information about the services used by the family, the ways in which parents had participated and engaged in the service, and the factors that impacted their engagement. The questions asked at these interviews changed over time as is expected within grounded theory and explained below in the data analysis section. Families also completed a child and family demographic questionnaire at the time of their initial interview, that included information such as parent's language, income and education levels, living and work situation, and descriptive information about the child's needs and therapy. Field notes were written after each initial interview and used as an additional data source (Montgomery & Bailey, 2007). Follow-up interviews were completed by the first author with all 20 participants using audio-recorded telephone calls that were later professionally transcribed. The purpose of these second interviews was to gather more information about ideas that appeared to be significant including: parent motivation and satisfaction, parent mental health, and parent age. Parents also reviewed the theoretical categories with the researcher and provided information about their level of agreement or additional ideas for improvement.

In a constructivist approach, it is important to understand the context in which a study takes place, therefore the clinician interview data, child health record data, and policy-procedure data were obtained. These data sources provided information about the organizational and therapeutic context in which children receive therapy services. There were four semi-structured clinician interviews completed by the first author. These were

done at the CTC, audio-recorded and professionally transcribed. These service providers also completed a brief questionnaire that described their level of experience and familiarity with organizational policies and service delivery models. Child health record data were obtained electronically with specific consent from all participants (n=18). Data included: history of session attendance, types of therapy, modes of communication with family and professionals involved. Policy and procedure documents (n=90) pertaining to discharge for reasons of non-contact or missed appointments were collected from 18 of 21 Ontario CTCs.

Three types of memos were written during the course of this study (Birks, Chapman & Francis, 2008): (i) audit trail memos to work through methods, decisions and timing, (ii) reflexive memos to investigate the researcher's role and influence within the study, and (iii) theoretical memos to develop the categories and their relationship to one another. Existing literature was used at the outset of the study to determine if there was need for this research, and again once the major theoretical categories were identified, to increase theoretical sensitivity and interrogate the emerging findings.

Analysis: Parent interview transcripts were reviewed by the first author while listening to the interview audio recordings to check for accuracy and de-identification prior to coding. The first author then coded each parent interview transcript using action-focussed codes to represent small units of data (e.g., 2-3 lines) (Charmaz, 2014). Categories were developed by comparing data within the focussed codes, grouping similar codes together,

and continuously exploring the boundaries and relationships between categories (additional details about these methods are included in Chapter 5b). A qualitative software program (QSR Nvivo 10) was used to store transcripts, memos, and complete coding. A fundamental method for conducting analysis within grounded theory is constant comparison (Boeije, 2002). In this study, constant comparison was used to compare data within a participant's interview, between participants, within a category and between categories. Memos were written to capture ideas generated through this method of comparison, with increasing theoretical relevance and leaps in abstraction (Birks, Chapman, & Francis, 2008; Charmaz, 2014; Montgomery & Bailey, 2007). Constant comparison and memo writing were used to define the properties and dimensions of codes and elevate specific codes to abstract theoretical categories (please see Chapter 5b for details). Child health record information was analyzed descriptively to count and itemize the professionals involved, services used, appointments attended or missed, and reasons for missed appointments. This information was triangulated with parent interview data to inform the unit of analysis. Clinician interview data were thematically coded using traditional content analysis (Hsieh & Shannon, 2005) to identify clinical and organizational factors that could impact parents' engagement, then triangulated with parent interview data to provide complementary information (Farmer, Robinson, Elliot, & Eyles, 2006). Memos were written after reading the policy documents to determine how the issue of missed appointments is being viewed by CTCs across the province. This allowed for comparison of how families and organizations view the issue of missed appointments.

Rigor: There were many efforts made to establish trustworthiness in this study according to the four criterion set forth by Lincoln and Guba (1985): credibility, transferability, dependability, and confirmability. Steps taken to ensure *credibility* included the triangulation of data sources (e.g., parent and clinician interviews) and types (e.g., interview, document and charts) (Farmer, Robinson, Elliot, & Eyles, 2006). Peer debriefing was completed with clinical and academic colleagues who discussed new hypotheses, contributed to problem solving study challenges, evaluated established ideas, and helped to identify any researcher bias or gaps in understanding (Lincoln & Guba, 1985). *Transferability* was enhanced by writing and analyzing field notes after each interview and reviewing the child's health record in order to support thick description to allow others to judge the transferability of this theory to their own setting (Lincoln & Guba, 1985; Montgomery & Bailey, 2007). *Dependability* and *confirmability* were promoted in this work by writing audit trail memos to record the actions taken throughout the projects and show the process and timing for making methods decisions (Lincoln & Guba, 1985). The first author maintained a commitment to reflexivity throughout this project, using memos to investigate and account for the researcher's influence in all phases of the process (Gentles, Jack, Nicholas, & McKibbin, 2014).

Ethics approval was provided for this study by the Hamilton Integrated Research Ethics Board (December 23, 2015) and the Research Ethics Committee at the community CTC where recruitment was completed. Participants provided consent at the time of the initial and follow-up interviews, with separate consent given for access to their child's health

record. All participants and their family members were assigned pseudonyms. The names of all clinicians and organizations have been removed to protect anonymity.

Results

When parents were asked about why they attend, participate and engage in therapy services for their child they describe the pursuit of child health and happiness. Every family's journey is unique and can only be fully understood once the conditions that affect engagement are examined, including: family composition, child and family health complexity, and the service organizations and professionals involved with a family. Each of these elements has the potential to promote or problematize the family's movement towards health and happiness. When viewed as a journey through childhood therapy we can visualize the family composition as *the family vehicle*, the child and family health complexity as *the vehicles' working condition*, and the organizations and service providers as *the road* that the family travels in pursuit of child health and happiness (Figure 1). Together these conditions set families up for a *stalled, slow, or smooth* journey in which they withdraw from services, use services inconsistently, or use services consistently.

A. Family composition: *The family vehicle*

There are structural elements to a family's composition that parents describe as promoting or limiting their attendance, participation and engagement in service. Three structural elements include whether the child's parents live together, the age of the parent, and the

number of children living in the household. When these elements are facilitatory, the family vehicle is thought of as a *car* that typically moves easily along the road. When these elements are limiting, the family vehicle is thought of as a *bike*, capable of moving along the road but likely to face more challenges in doing so.

Do the child's parents live together?

Parents who live together have increased opportunity to support each other emotionally, share financial, household, and childcare responsibilities, including attending therapy and doing therapy tasks at home. However, these tasks are not always shared in dual parent households; for example, in this study eight of the mothers who lived with their child's father attended most of the therapy appointments on their own. As a result, these mothers became responsible for sharing information with their partner and most often doing the therapy homework with the child. This created stress for parents when they wanted their partner to be more involved in therapy or when they disagreed about parenting practices. Additional stress was created when parents' tendency to 'put their child first' limited the time, energy or attention that parents directed towards each other.

Five mothers and two fathers in this study did not live with the child's other biological parent. These mothers reported that the child's other parent did not contribute to therapy by attending or working on skills when the child was in their care. Kate found doing everything by herself to be the most stressful part of attending therapy and doing therapeutic work at home. Both single fathers reported that they attended therapy

appointments with the child's mother and both parents contributed to the home practice due to shared custody. Therapists facilitated this involvement by making dual copies of resources, sending reports to both households and booking appointments when both parents could attend. Parents reported some benefits to being divorced, which included being able to make all parenting decisions, leaving an angry or unreliable partner, and getting a break from caretaking responsibilities.

Evidently, the parents' satisfaction with the support received from the child's other parent is more important than looking at single or divorced status alone as an indicator of the *family vehicle* and their ability to move through services.

How old are the parents?

Initially parents were not asked about the age at which they became parents; however, several mothers who had their child as a teenager reported significant challenges with care providers due to their age. Therefore, in follow-up interviews all parents were asked about the age at which they became a parent and about whether that had any effect on their engagement in therapy services. Four participants were teenagers when they had their first child, and all reported being negatively judged for their age and having Child Protective Services called on them. This occurred despite parents' planning and desire to have a child. Parents who were over 25 years old when they had their child reported that their age protected them from feelings of judgment and allowed them to complete educational and work experiences that helped them to understand and engage in therapy.

Positive and negative educational, vocational and therapy experiences related to parent age occurred prior to involvement with the CTC, but strongly influenced the perspective that parents brought to therapy.

How many children live in the household?

Parents talk about the “extra effort” required in the house when they are raising multiple children in addition to the child who is receiving therapy services. This includes balancing parents’ time and attention between the children, ensuring safety, and cleaning up after the kids. Significant skills are needed to coordinate the kids’ school, activity, and therapy schedules with respect to travel and childcare. Childcare is needed when parents attend therapy appointments, have hospital stays, or spend time doing the therapy practice at home. Although the child’s siblings were often described as adding stress and increased responsibility for parents, they were also thought to provide caregiving support (e.g. bringing over needed items) and emotional support for the child via play and affection. Often the child who receives therapy was more motivated to practice with a sibling than they were with a parent!

B. Child and family health complexity: *The vehicle’s working condition*

Regardless of the family composition, both *cars* and *bikes* can exist in a reliable or unreliable working condition. The *working condition* of the family vehicle, or family composition, is determined according to the child, sibling, and parent health complexity. Health complexity includes factors such as investigation for the child’s diagnosis, the

child's need for medical interventions (e.g., medications, surgeries, hospitalizations), and parents' physical or mental health challenges (e.g., chronic pain, stress, depression, anxiety). The complexities experienced by the child, siblings, or parents can be added together as an indicator of the *working condition* of the family vehicle.

Child's health complexity

Six participants described their children as having 'narrow' speech issues with no other complications related to their health or development. These children typically had difficulties with speech sound production (e.g., couldn't say the /k/ sound) or dysfluency, but never received a 'formal diagnosis' from a doctor. These children and families stood in sharp contrast to families who described traumatic birth experiences with extended stays in the Neonatal Intensive Care Unit, frequent hospitalizations due to pneumonia or need for surgeries (e.g., gastrostomy tube surgery), near-death experiences of the child, risk for seizures, prolonged investigation for a diagnosis, and ongoing daily care needs related to the child's limited self-care skills. Parents were frequently emotional when talking about these health complexities, that often took priority over the child's particular area of developmental delay (e.g., delayed expressive language) and related therapy services.

“She has been in the ICU (intensive care unit) every year since she was born in the winter because of her lungs and that is the number one concern all the time. So, sometimes that therapy was put on the burner, right? I mean, you can't spend four weeks in the ICU... I mean, she just about died the one year. It was very close.”
Victor

Parents' health complexity

Participants in this study experienced a wide variety of their own physical and mental health concerns. Physical health complexities included both temporary issues, for example those related to their birth of their child, and chronic physical and mental health conditions. These issues can be exacerbated when parents put their child's needs ahead of their self care, including not taking time for themselves and attending their own medical appointments. For example, Nicole spoke about her own chronic pain and stated:

“My health isn't that great and I have Doctors appointments but I usually don't go to them. I just make sure the kids go to theirs and I'm like, you know, adulting is only going to the Doctor when you are dying.” Nicole

Many participants shared their own diagnosis (e.g., Autism Spectrum Disorder, learning disorder, Bi-Polar Disorder, Social Anxiety, Borderline Personality Disorder, Post-Partem Depression) and/or their partner's diagnosis of a mental health condition (e.g., Tourette's Syndrome, Depression, Borderline Personality Disorder). In addition to these diagnoses parents frequently reported having stress, anxiety and depression. This could be exacerbated by the additional demands of raising a child with a delay and impact engagement in services. For example, James reported having social anxiety that kept him from going to his child's therapy appointments. When the participant identified their partner as having mental health concerns they also spoke about the need to 'be strong' and shoulder more of the responsibilities related to caretaking and therapy. Parents worried that these conditions could affect the care they provided to their child, but wanted to make it known that parents who have a diagnosis are able to fulfill their roles as parents and raise happy and well-adjusted kids: “I have also been diagnosed with

Borderline Personality Disorder... You know it's not impossible to be a mom and, you know, have some mental illness." Leila.

Siblings' health complexity

Of the 18 children whose parents participated in this study, six had at least one sibling who also received therapy service. When more than one child in a family received therapy, parents were asked to focus their discussion on a 'focal child', namely the child who was currently receiving service, or the child who had received therapy for the longer period if more than one was currently involved. Although parents were asked to focus on the therapy experiences with the 'focal child', many could not resist sharing information about the focal child's siblings and their therapy experiences. This emerged as an important finding, because parents do not separate their therapy experiences between children. Instead their therapy-related knowledge, skills, feelings and logistic considerations are influenced by experiences related to all of their children. Grace is raising three children who have a diagnosis of Autism Spectrum Disorder; she talked about knowing who to call for service and what to expect from the service when she had her third child: "Everything just went from there (assessment) and just as I expected and I think it's because we had previous experience we knew what to kind of expect." Grace stopped therapy services when one of her children was hospitalized with an illness and again when she was emotionally coping with the diagnosis of her third child. Similarly, Nicole is raising two sons who received a variety of therapy services. She reported knowing how to help her child when he was on the waitlist because of the parent training

sessions she did with her older child. However, the older child's behaviour and sensory needs made it more difficult for Nicole to attend therapy with her younger son: "Liam's had appointments that I haven't been able to take him to because Mason is being aggressive and violent". When parents are raising more than one child who requires therapy services the number of appointments can quickly become overwhelming, making attendance problematic.

"I had his appointments plus her appointments, I ended up missing appointments. He almost got kicked out of (CTC name) therapy because I kept missing the appointments. And the reason was I was just getting so overwhelmed with appointments that it was so hard for me to keep up." Patty

Clearly the health complexities of the child, siblings and parents have an additive effect that affects the *working condition* of the family unit, with lower accumulated health complexity indicating a family vehicle that is in *reliable working condition*, and higher accumulated health complexities indicating a family vehicle that is in *unreliable working condition*.

C. Organizations and service providers: *The road*

Parents were asked to focus their discussion on a single community therapy service organization, however they frequently recounted meaningful therapy experiences that occurred with other organizations (e.g., hospitals, home visiting services, child protective services). This led to the understanding that parents carry their knowledge, feelings, and the demands on their time and energy from one organization to another. This means that we must attend to all significant experiences related to multiple organizations and services professionals. Consideration of the number of organizations and service

professionals involved in the child's developmental services allows us to characterize the family's *road* to child health and happiness as a *straight road* or a *highway system*.

The straight road

Families who are on the *straight road* receive services from one organization, and most often a *single* discipline within that organization, for example, parents who only accessed speech-therapy services from the community-based organization where recruitment was completed. This was described as a simple road to travel, with a single point of entry (typically with a parent making a referral for service themselves) and few detours with respect to other professionals being sought for assessment or inquiry into different services. In general, this road was easy to navigate, with minimal *traffic jams* occurring as families waited for their initial assessment or therapy to start, and otherwise moving continuously through the service. Rose says that therapy went smoothly for her because her child has a "small focus" and doesn't need services beyond speech, however, with other children "there could be like five or six different types of therapy that a child is receiving and so you are trying to balance all of that in your life".

The highway system

When children have increased health complexity they often have involvement with more than one organization and service professional. In these cases, families illustrate a therapy route that is akin to travelling along a complex *highway system*. On this highway, families rush between appointments, with significant traffic jams in wait times for specialists, and

complex entries to and exits from the highway that include the need to advocate for referrals. For example, Freda talks about fitting 2-3 appointments into a day for her son and how exhausting that can be: “Seeing his ENT (ear nose throat doctor) or maybe the Doctor or whatever. So more just juggling, fitting that all in and allowing myself to have some downtime but there were some days where I didn’t have that really”.

Significant energy is used to coordinate appointments and share information between organizations and service providers. Additional stress is reported by families when they get conflicting advice from the people involved in their care. It is easy for families who travel this route to become lost when transitioning from one organization to another, for example moving from newborn hospital care to a community home-based provider. This point of transition can also lead to an overlap in the services offered by multiple organizations that can easily overwhelm families with the number of appointments and expectations:

“It was worse at the beginning... as we were transitioning we still had our OT and PT and Speech come to our house while we were going to (CTC name). So there was a lot of people at my house constantly like every day...And then we had a Dietician that came to our house, we had a Nurse.” Irene

Other points of transition can occur when families move from one geographic area to another as was the case for three participants, who naturally compared their service experience with one set of organizations to another.

One organization that greatly impacted families’ feelings related to therapy provision was the child protection agency. Five out of 18 of the families that participated in the study

had previous involvement with a child protection agency and these experiences often left families feeling vulnerable and angry, for being threatened with the potential loss of custody of their child. Parents resented the service providers or other individuals who called (or threatened to call) the child protective agency. After involvement with the child protective services, it took time for parents to understand that they had a say in how services were provided, determine which services they would use, and develop trust with their service providers.

In addition to having multiple agencies and service providers involved with a child, parents spoke about the changeover in therapists within an organization. This challenged relationship-building between the therapist and child, and the therapist and parent. When parents were not pleased with a previous therapist, they welcomed the change, for example Helen said: “I don’t want to hurt your feelings, but in my head I’m thinking oh please let us get somebody different in the next block”; however, the changes were typically presented as a *roadblock* towards the family’s travel towards health and happiness.

D. Parent priorities: Destination child health and happiness

Every parent who participated in the study wanted their child to be happy and healthy, a sentiment that resonated with me as a parent and with my peer debriefing groups. Often parents know that their child has a delay in one or more areas of development and when the child has a diagnosis it will be with them for life (e.g., Autism Spectrum Disorder or Cerebral Palsy); therefore, their main concern was whether their child would be healthy

and happy. Families described *health* in terms of survival, limiting pain and illness, and promoting physical growth. In times when health was limited or survival was threatened, everything else was put aside including parents' self care, care for other children, and involvement in other therapy services. *Happiness* was attributed to the enjoyment of therapy and practice activities and the attainment of skills that would allow children to play, interact with others, and experience inclusion and independence. Parents shared many examples of skills that they worked on in order to promote their child's happiness, for example by being able to climb structures at the park, join the family at skating, or make friends in school. Steve summarizes nicely by saying: "Is she going to live a happy life or not?...I know she is going to be delayed...I want to know if she is going to live... if she is going to live a happy and full life, I'm happy".

Discussion and Implications

Doesn't every parent want their child to be healthy and happy? If so, what is different about the *journey* of parents who use developmental rehabilitation services? These parents experience 'extra' contextual conditions related to *the family vehicle* (child and family health complexity) and *the road they travel* (organizations and service professionals) as they pursue child *health and happiness*. Therefore, if clinicians and researchers are truly committed to joining families as they journey through childhood therapy services we must understand these conditions and train our eyes on the same destination.

When studying or working with families *the conceptual family vehicle* must be considered with respect to whether parents live together, the parents' age, and the number of children at home. This goes beyond identification of these items on a case history or demographic form because each item can positively or negatively impact engagement. In some homes having two parents present, but only one involved in therapy, increased stress, whereas other families were comfortable with the arrangement. Some dual parent households had both parents contribute equally to their child's therapy; the same could be said for some divorced households that shared child custody. Siblings added complexity to the household due to child care and scheduling needs, however they also supported therapy efforts and contributed positively to the physical and emotional wellbeing of the child receiving therapy. Teenaged parents may require added sensitivity in therapy provision given the increased chance that they've had a negative interaction with previous health care providers based on assumptions about them and increased likelihood for previous involvement of child protective agencies. Service providers should decide whether the family composition is best represented as a *car* that is likely to move easily through service or a *bike* that is likely to face more challenges. This would require detailed conversations with parents about their family composition, asking specifically about what these structural elements mean with respect to their engagement in therapy.

Next, the clinician and researcher should investigate the *working condition of the family vehicle* as represented by the physical and mental health of the child who is receiving therapy, the child's siblings, and the parents. Although the health complexities of the

child who is receiving therapy are often investigated in detail, asking about siblings and parent health may be less common. There is overwhelming evidence to indicate that parents often have mental and physical health concerns when raising a child with a disability. However, clinicians remain unsure about their role in providing therapy to parents (Reddihough & Davis, 2016) and there are few established parent-focussed therapies that can be used as an adjunct to the therapies directed towards children with disabilities (Dykens, Fisher, Taylor, Lambert, & Miodrag, 2014). The child's clinicians may question whether parents would be comfortable disclosing their mental health issues (Reddihough & Davis, 2016). During this study many parents disclosed, during their initial interviews, that they had physical or mental health issues. However, six participants only disclosed their diagnoses during the follow-up interview when they were asked specifically if they, or their partner, had physical or mental health issues or diagnosis that they would be comfortable sharing. Asking directly, with an 'out' for parents who are not comfortable sharing, may encourage more parents to disclose mental or physical health issues that could potentially impact their engagement in services.

It would benefit clinicians and researchers to realize that not every family is travelling on *the same road* even if they share a common destination. There was a striking difference in the experiences of families who were involved only with the community-based CTC and a single discipline (the *straight road*) when compared with families who travelled the theoretical *highway system* as indicated by involvement with multiple health care organizations and professionals (e.g., hospitals, home based service providers, child

protective agencies in addition to the community based CTC). Families on the *highway system* were typically raising children with complex health care needs, who would benefit from an inter-professional approach to services that prioritizes collaboration between team members and the family (D'Amour, Ferrada-Videla, Rodriguez, & Beaulieu, 2005). Parents in this study described benefits to inter-professional collaboration when service providers shared information with each other, coordinated appointments, facilitated referrals, and developed joint treatment plans. However, parents also expressed challenges such as an overwhelming number of appointments, conflicting therapy advice, and too many recommendations being given. This begs the question of why professionals continue to face challenges relating to inter-professional practice after decades of research that support its use. Potential breakdowns can occur due to varied conceptualizations of what constitutes inter-professional practice. Healthcare professionals are trained to adopt a discipline-specific vision of their client and services, and there are organizational barriers to collaboration (D'Amour et al., 2005; Perreault & Careau, 2012). Clinicians and researchers can better support families who are travelling along the theoretical *highway system* by improving their understanding and use of inter-professional practice.

It will be difficult for clinicians and researchers to join families as they move through therapy services if they have their eyes trained on different destinations. Families consistently identified *child health and happiness* as their desired *destination* and their reason for participating and being engaged in therapy services. While medical services that follow a traditional medical model of 'assess, diagnose, treat, recover' may be

appropriate to treat the child's health concerns, happiness cannot be 'treated' in a similar manner. The revised International Classification of Functioning, Disability, and Health (ICF) expands thinking from a biomedical model to a biopsychosocial model, that includes recognition of activity, participation, the environment and personal factors (World Health Organization, 2007). Application of this model in research and practice encourages a focus on the family, functional use of skills and the child's participation in real world contexts (Cunningham et al., 2017; Darrah, 2008). Measurement of the family environment has been challenging in the field of pediatric neurodisability, however the current study supports recommendations to consider how all members of the family are experiencing their environment (Ketelaar, Bogossian, Saini, Visser-Meily, & Lach, 2016). Given parents' focus on their child's happiness it is important for service providers and researchers to consider "fun", which is linked to the personal factors component of the ICF, however items within that category not well defined (Geyh et al., 2011; Rosenbaum & Gorter, 2012). This study highlights the importance for clinicians and researchers to uncover the family factors related to family composition and health complexity (*the family vehicle and its working condition*) and the child's service complexity (*the road*) in order to understand the family's journey through therapy services to achieve the family's preferred destination of child *health and happiness*.

Strength and Limitations

A strength of this study was the qualitative methodology that allowed parents the freedom to identify the contextual elements that are most influential on their engagement. This

moves beyond consideration of the child related factors that are typically studied, for example child's diagnosis.

Due to financial and time constraints, all participants were required to speak English and this limited the cultural and linguistic diversity in the sample. Future work with refugee and immigrant populations, First Nations, Metis, and Inuit families, and rural Mennonite families could significantly expand the understanding of positive and negative experiences of parent engagement in children's therapy services.

Conclusion

To fully understand the conditions that affect parent engagement in children's therapy services service providers, organizational management, and policy makers must use a holistic family lens to consider the family composition, child-sibling-parent physical and mental health complexity, and service complexity.

References

Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M.

M. (2004). Psychological Well-Being and Coping in Mothers of Youths With Autism, Down Syndrome, or Fragile X Syndrome. *American Association on Mental Retardation*, 237(3), 237–254.

Arrigo, R. D., Ziviani, J., Poulsen, A. A., Copley, J., & King, G. (2016). Child and parent engagement in therapy : What is the key ? *Australian Occupational Therapy Journal*, 1–4.

- Barlow, J., & Ellard, D. (2006). The psychosocial well-being of children with chronic disease, their parents and siblings: An overview of the research evidence base. *Child: Care, Health and Development*, 32(1), 19–31.
- Birks, M., Chapman, Y., & Francis, K. (2008). Memoing in qualitative research: Probing data and processes. *Journal of Research in Nursing*, 13(1), 68–75.
- Boag-Munroe, G., & Evangelou, M. (2012). From hard to reach to how to reach: A systematic review of the literature on hard-to-reach families. *Research Papers in Education*, 27(2), 209–239.
- Boeije, H. (2002). A Purposeful Approach to the Constant Comparative Method in the Analysis of Qualitative Interviews. *Quality and Quantity*, 36, 391–409.
- Brehaut, J. C., Kohen, D. E., Raina, P., Walter, S. D., Russell, D. J., Swinton, M., ... Frcep, C. (2004). The Health of Primary Caregivers of Children With Cerebral Palsy : How Does It Compare With That of Other Canadian Caregivers ? *Pediatrics*, 114(2), e182–e191.
- Brehaut, J. C., Kohen, D. E., Garner, R. E., Miller, A. R., Lach, L. M., Klassen, A. F., & Rosenbaum, P. L. (2009). Health among caregivers of children with health problems: Findings from a Canadian population-based study. *American Journal of Public Health*, 99(7), 1254–1262.
- Breckenridge, J & Jones, D. (2009). Demystifying theoretical sampling in grounded theory research. *Grounded Theory Review an International Journal*, 2(8) retrieved from <http://groundedtheoryreview.com/2009/06/30/847/>

- Charmaz, K. C. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London, UK: Sage.
- Charmaz, K. C. (2014). *Constructing grounded theory (2nd ed.)*. Thousand Oaks, CA: Sage.
- Cunningham, B. J., Washington, K. N., Binns, A., Rolfe, K., Robertson, B., & Rosenbaum, P. (2017). Current Methods of Evaluating Speech-Language Outcomes for Preschoolers With Communication Disorders: A Scoping Review Using the ICF-CY. *American Journal of Speech-Language Pathology*, *60*(February), 447–464.
- D'Amour, D., Ferrada-Videla, M., Rodriguez, L. S. M., & Beaulieu, M.-D. (2005). The conceptual basis for interprofessional collaboration: Core concepts and theoretical frameworks. *Journal of Interprofessional Care*, *19*(1), 116–131.
- Darrah, J. (2008). Using the ICF as a framework for clinical decision making in pediatric physical therapy. *Advances in Physiotherapy*, *10*(3), 146–151.
- Dykens, E. M., Fisher, M. H., Taylor, J. L., Lambert, W., & Miodrag, N. (2014). Reducing distress in mothers of children with autism and other disabilities: a randomized trial. *Pediatrics*, *134*(2), e454–63.
- Farmer, T., Robinson, K., Elliott, S. J., & Eyles, J. (2006). Developing and Implementing a Triangulation Protocol for Qualitative Health Research. *Qualitative Health Research*, *16*(3), 377–394.
- Flanagan, S. M., & Hancock, B. (2010). “Reaching the hard to reach”--lessons learned from the VCS (voluntary and community Sector). A qualitative study. *BMC Health Services Research*, *10*, 92.

- Gentles, S. J., Charles, C., Ploeg, J., & McKibbin, K. A. (2015). Sampling in Qualitative Research: Insights from an Overview of the Methods Literature *The Qualitative Report*, 20(11), 1772–1789.
- Geyh, S., Peter, C., Müller, R., Bickenbach, J. E., Kostanjsek, N., Ustün, B. T., ... Cieza, A. (2011). The Personal Factors of the International Classification of Functioning, Disability and Health in the literature - a systematic review and content analysis. *Disability and Rehabilitation*, 33(13-14), 1089–102.
- Glaser, B. G., & Strauss, A. (1967). The discovery of grounded theory. Chicago, IL: Aldine.
- Hartley, S. L., Barker, E. T., Seltzer, M. M., Floyd, F., Greenberg, J., Orsmond, G., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology : JFP : Journal of the Division of Family Psychology of the American Psychological Association (Division 43)*, 24(4), 449–457.
- Hsieh, H. F., & Shannon, S. E. (2005). Three Approaches to Qualitative Content Analysis. *Qualitative Health Research*, 15(9), 1277–1288.
- Ketelaar, M., Bogossian, A., Saini, M., Visser-Meily, A., & Lach, L. (2016). Assessment of the family environment in pediatric neurodisability: a state-of-the-art review. *Developmental Medicine & Child Neurology*, 1–11.
- King, G., Currie, M., & Petersen, P. (2014). Child and parent engagement in the mental health intervention process: a motivational framework. *Child and Adolescent Mental Health*, 19(1), 2–8.

- Kuhlthau, K. a, Bloom, S., Van Cleave, J., Knapp, A. a, Romm, D., Klatka, K., ... Perrin, J. M. (2011). Evidence for family-centered care for children with special health care needs: a systematic review. *Academic Pediatrics, 11*(2), 136–43.
- Lach, L. M., Kohen, D. E., Garner, R. E., Brehaut, J. C., Miller, A. R., Klassen, A. F., & Rosenbaum, P. L. (2009). The health and psychosocial functioning of caregivers of children with neurodevelopmental disorders. *Disability & Rehabilitation, 31*(9), 741–752.
- Lincoln, S. Y. & Guba, E.G. (1985). Chapter 11. Establishing trustworthiness. *Naturalistic Inquiry*.(pp.289-331). Newbury Park, CA: Sage Publications.
- McConnell, D., Breitreuz, R., Uditsky, B., Sobsey, R., Rempel, G., Savage, A., & Parakkal, M. (2013). Children with Disabilities and the Fabric of Everyday Family Life. Retrieved from [http://www.fdsa.ualberta.ca/~media/Family and Disability Studies Initiatives/Documents/FamilyLifeReportrevised.pdf](http://www.fdsa.ualberta.ca/~media/Family%20and%20Disability%20Studies%20Initiatives/Documents/FamilyLifeReportrevised.pdf).
- Montgomery, P., Bailey, P. H., & Bailey, P. H. (2007). Field Notes and in Grounded Theory. *Western Journal of Nursing Research, 29*(1), 65–79.
- Mulroy, S., Robertson, L., Aiberti, K., Leonard, H., & Bower, C. (2008). The impact of having a sibling with an intellectual disability: Parental perspectives in two disorders. *Journal of Intellectual Disability Research, 52*(3), 216–229.
- Ontario Association of Children’s Rehabilitation Services. (2010). About OACRS: The voice of children’s rehabilitation centres. Retrieved from <http://www.oacrs.com/en/about>





- Patterson, J. M. (2002). Integrating Family Resilience and Family Stress Theory. *Journal of Marriage and Family*, 64(May), 349–360.
- Patton, M.Q. (2002). Chapter 5: Designing qualitative studies: *Qualitative Research & Evaluation Methods* (3rd ed.pp.230-247). Thousand Oaks, CA: Sage Publications.
- Perreault, K., & Careau, E. (2012). Interprofessional collaboration: One or multiple realities? *Journal of Interprofessional Care*, 26(4), 256–258.
- Risdal, D., & Singer, G. H. S. (2004). Marital adjustment in parents of children with disabilities: A historical review and meta-analysis. *Research and Practice for Persons with Severe Disabilities*, 29(2), 95–103.
- Reddihough, D. S. & Davis, E. (2016). Paying attention to parental mental health: Is this our responsibility? In P. Rosenbaum, G. Ronen, E. Racine, J. Johannesen, & B. Dan (Eds.), *Ethics in child health: Principles and cases in neurodisability* (pp. 223-232). London: Mac Keith Press.
- Rosenbaum, P. (2006). Variation and “abnormality”: Recognizing the differences. *Journal of Pediatrics*, 149(5), 593–594.
- Rosenbaum, P. (2009). Putting child development back into developmental disabilities. *Developmental Medicine & Child Neurology*, 51(4), 251.
- Rosenbaum, P., & Gorter, J. W. (2012). The “F-words” in childhood disability: I swear this is how we should think! *Child: Care, Health and Development*, 38(4), 457–63.
- Siebes, R. C., Wijnroks, L., Ketelaar, M., van Schie, P. E. M., Gorter, J. W., & Vermeer, a. (2007). Parent participation in paediatric rehabilitation treatment centres in the

Netherlands: a parents' viewpoint. *Child: Care, Health and Development*, 33(2), 196–205.

Urbano, R., & Hodapp, R. M. (2007). Divorce in families of children with Down syndrome: a population-based study. *American Journal of Mental Retardation*, 112(4), 261–274.

World Health Organization. (2007). *International Classification of Functioning, Disability and Health: Children and Youth Version*. Geneva: WHO Press.

Figure 1. The family and service conditions that impact parents' engagement in therapy.

	The road: # organizations and # of professionals	
Working Condition: child, sibling, and parent physical and mental health	 +/- ease of engagement	
	++	+ -
	- +	--

A grounded theory of parent engagement in children's developmental rehabilitation services: *The journey to child health and happiness*

Background literature

Parent attendance, participation and engagement are necessary components of children's developmental rehabilitation therapy (children's therapy), including physical therapy, occupational therapy and speech-language therapy services. Typically, these therapy services aim to integrate principles of family-centred care that require parent-service provider collaboration in order to promote child development (Kuhlthau et al., 2011; Rosenbaum, King, Law, King & Evans, 2009; Siebes et al., 2007). A systematic review examining the use of family-centred service in medical, nursing, sociology and psychology literature reported that family-centred services increase access and efficient use of services, and improve health status and satisfaction with care (Kuhlthau et al., 2011). Under-investigated elements of family-centred service include parent attendance (Arai, Stapley & Roberts, 2014), participation (Littell, Alexander & Reynolds, 2001; Siebes et al., 2007) and engagement (Arrigo, Ziviani, Poulsen, Copley & King, 2016; King, Currie & Petersen, 2014).

Non-attendance at children's health care appointments is thought to limit the efficacy and efficiency of the service and raise questions about child safety (Arai, Stapley & Roberts, 2014). Attendance has also been used to indicate participation, engagement, adherence and compliance (Littell, Alexander & Reynolds, 2011). However, non-attendance does not necessarily mean that a family is lacking participation or engagement, as various

factors may account for missed appointments, ranging from organizational barriers (e.g., poor communication with families and inadequate staffing) to family barriers (e.g., lacking means to travel to appointments, forgetting about appointments) (Arai et al., 2014; Boag- Munroe & Evangelou, 2012; Phoenix & Rosenbaum, 2014). Additional barriers concern the quality of the interaction between the family and the service provider, with families being less likely to attend if the parents feel judged or that their children are ignored during appointments (Arai et al., 2014; Winkworth, McArthur, Layton, Thomson & Wilson, 2010). Service providers who have well-developed interpersonal and therapeutic skills can help to mitigate these barriers and promote equitable access to services with improved family engagement.

Parents who participate in children's therapy services identify that therapist communication is the primary way to promote parent participation in all stages of therapy (Siebes et al., 2007). Communication skills are considered to be a key component of therapists' best practice that can improve the effectiveness of therapy interventions and increase satisfaction with services (King et al., 2017). Effective communication can help parents to negotiate their role within their child's services. For example, mothers in an infant development program clearly identified their primary role as a learner and their expectations of professionals to be knowledge translators, supporters and systems navigators (Hurtubise & Carpenter, 2011). Good communication between parents and professionals also promotes parent involvement in goal-setting, which increases parents' feelings of competence and partnership (Øien, Fallang, & Østensjø, 2010) and allows

them to focus on their priorities, namely child happiness via fulfillment and acceptance (Wiat, Ray, Darrah, & Magill-Evans, 2010). Therapists' abilities to focus on these holistic goals and provide flexible services to promote engagement depends on their level of expertise (King et al., 2007). Forsingdal et al. (2014) fully explore the factors that influence, specifically, mothers' involvement in goal-setting and more broadly, mothers' collaboration and engagement in children's therapy services, stating that "engagement itself should be a therapeutic goal" (p.588).

Although parent engagement is considered to be a central element in children's therapy services it has been poorly defined, with minimal investigation by which to understand or promote engagement (Arrigo, Ziviani, Poulsen, Copley, & King, 2016; King, Currie & Petersen, 2014; Staudt, 2007). Current conceptualizations of parent engagement, developed from the mental health literature identify affective, behavioral and cognitive components of engagement such that "engagement is an optimal state comprised of a hopeful stance, conviction with respect to the appropriateness of intervention goals and processes, and confidence in personal ability to carry out the intervention plan" (King et al., 2014, p.6). Researchers have started to use this conceptualization of engagement within rehabilitation therapy (Arrigo et al., 2016), but have yet to describe the full range of parents' participation and engagement in the therapy process with consideration for the work parents do prior to entering service (e.g., being concerned about the child) and between sessions (e.g., fitting practice into everyday life).

The **purpose** of this grounded theory study was to develop a substantive theory to explain how parents participate and engage in their children's developmental rehabilitation therapy service. The goal of this work is to provide a theory that service providers, parents, organizational management and policy makers can all apply to promote attendance, participation and engagement in children's therapy services, ideally to increase accessibility, efficiency, effectiveness and satisfaction within children's therapy services.

Methods

An exploratory qualitative study was undertaken in order to inductively derive a theory of how parents participate and engage in their child's therapy service. Constructivist grounded theory (Charmaz 2006, 2014) methodology was used to inform sampling, data collection, data analysis and the steps undertaken to promote rigor. For a full description of these methods please see Chapter 5a of this thesis.

In brief, ethics approval for this study was obtained from the Hamilton Integrated Research Ethics Board (December 23, 2015) and the Children's Therapy Centre (CTC) ethics committee. Recruitment was done at one community-based CTC where occupational therapy, physical therapy, speech-language therapy and social work services are provided to children who have a developmental delay or disability. Twenty parents and four clinicians consented to participation and completed semi-structured interviews that were conducted by the first author, audio-recorded and transcribed. All participants

and their family members have been assigned pseudonyms, and organizations and professionals' names have been removed.

Fifteen mothers and 5 fathers participated; each parent had attended at least one therapy session at the CTC, and all parents spoke English. Parents completed initial interview at their home or in the community and follow up interviews were completed by phone. A total of forty parent interviews and 4 clinician interviews were completed. Chapter 5a provides more details about the sample. In order to understand the therapeutic and organizational context, child health records (n=18) were obtained from the CTC and policy and procedure documents (n=90) were obtained from 18 of the 21 CTCs in Ontario.

All data were stored and coded using a qualitative software program, NVivo 10. Methods of constant comparison, memo writing, abduction and triangulation were used to move from narrow coding of specific segments of data to theoretical and abstract categories.

These methods of analysis are described below, given their critical function in developing the theory as presented in these results. An audit trail, member checking and peer debriefing were used to support rigor.

To begin analysis all authors separately reviewed the first transcript, then met with the first author individually to discuss overarching themes, participant language and specific codes to be aware of in subsequent interviews. From that point onwards the first author

completed all coding by comparing subsequent transcripts to one another using short, active, descriptive labels to code the small segments of data (Charmaz, 2014). After four interviews, these small ‘child codes’ were fit into larger ‘parent codes’ developed using thematic groups that the first author defined in NVivo. The method of constant comparison, central to grounded theory, was used to compare data to data within an transcript, between transcripts using codes, between codes to build thematic groups, and within and across thematic groups to build categories (Boeije, 2002; Bradley, Curry & Devers, 2007; Glaser & Strauss, 1967).

Over time the total number of codes being pursued was reduced in a process described by Glaser and Strauss (1967) as ‘delimiting the theory’, with attention given to focussed codes that showed potential for theoretical reach, direction and centrality (Charmaz, 2014). The properties and dimensions of each focussed code, as well as the relationships between codes, were developed by writing theoretical memos (Birks, Chapman & Francis, 2008; Charmaz, 2014). Memo writing encourages the researcher to enter an ambiguous space where concepts can be explored and refined, and new analytic leaps are welcome through the process of abduction (Charmaz, 2014; Timmermans & Tavory, 2012). In addition to memo writing the first author was able to deepen the theoretical nature of the analysis by discussing emerging ideas with committee members, academic and clinical colleagues; printing and reanalyzing transcripts once the central problem and core categories were identified; and loosely diagramming the categories to discover the relationships they held with one another.

Theoretical sampling is central to grounded theory methodology and includes seeking out information specific to the emerging theoretical categories, with the intention of defining the properties of each category and the relationships between them (Gentles, Charles, Ploeg & McKibbin, 2015). This was done when specific participants were recruited who could talk about their experiences with multiple services as opposed to a single discipline, and when fathers were recruited to provide an alternate perspective to that provided by the mothers who had been interviewed. Theoretical sampling was also done by going back to existing transcripts to look specifically for information that was relevant to the emerging theory, for example samples of parents' values and beliefs. Finally, theoretical sampling and theoretical saturation were done concurrently by continuously developing the interview guide to gather information needed to fully define each of the core theoretical categories and the relationships between them with consistency among participants (Charmaz, 2014; Gentles et al., 2015). Theoretical saturation was thought to be achieved when the final four initial interview participants identified each part of the theory without previously having seen it and all participants agreed with the major theoretical categories during their follow up interviews.

Results

Parents' experiences of attendance, participation and engagement in their child's therapy services can be viewed metaphorically as *a journey towards child health and happiness*. The conditions that affect families' journeys are presented in Chapter 5a and include the family composition (*the family vehicle*), the family health complexity (*the vehicle's*

working condition) and the service complexity (*the road*). No matter how straightforward or complex the family journey might be, the family vehicle is moved along *the road* via their attendance, participation and engagement in therapy services, represented metaphorically as the *parent gears* (Figure 1). There are six *parent gears* including: logistics, knowledge, skills, feelings, relationship with the professional, and values and beliefs. Movement of these *gears* can be facilitated or inhibited by *grease* or *grit* concerning the child, parent, professional or organizational with respect to: expectations, motivation, communication, resources, and timing (Figure 2). When the *gears are moving well* or there is adequate *grease* to facilitate movement the family's journey is *smooth*, characterized by good attendance, participation and engagement. However, if there is significant difficulty with at least one gear, or if the gear movement is limited by *grit* in the system, the family's journey may be *slowed* or *stalled*, where parents may attend inconsistently or withdraw from service. Every *gear* has the potential to help families move through therapy or limit their movement, and the *grease and grit* also have the ability to facilitate or limit families' attendance, participation and engagement. This theoretical conceptualization of parents' attendance, participation and engagement in children's developmental rehabilitation services is presented here as The Phoenix Theory of Parent Engagement.

- Insert Figure 1 approximately here -

A: Parent Gears

Logistics

The most significant logistic hurdle for families was **travelling** to therapy sessions. This was extremely challenging for families that did not have a vehicle or a licence, especially when they lacked money for the bus or taxi, or someone that could drive them to therapy. In some cases, families discussed these challenges with their service providers and were able to get volunteer drivers, or paid bus or taxi support. However, this support was not available for out-of-town appointments and some families were not comfortable discussing their needs with service providers. One mother (of two children who both used multiple services at the CTC) further explained that limited access to transportation ultimately ends in her cancelling the session and providing an alternate reason to the agency:

“Well yeah, I mean, if I didn’t have bus fare, I don’t drive, so if I don’t have bus fare I’m not going to be like yeah, I’m too poor to get there. I’m going to just be like I’m sick.” Nicole.

The child’s disability could also make travel challenging, with some behavioural or sensory needs limiting families’ ability to take the bus and children with physical needs experiencing pain in a car seat if the family did not have a wheelchair-accessible vehicle. All parents talked about the time needed to travel to and from appointments, with additional time needed for travel to work, school, childcare or additional health care appointments. Freda was exhausted from consistently attending appointments with multiple disciplines and specialized services (e.g., Augmentative Communication Clinic) at the CTC and with other community partners:

“It’d be racing from one appointment...it felt like ahhh, another appointment. But you know, I just did it because it was important for Joe. And then once I got there it was okay. It was just the actual physical commuting that would feel overwhelming sometimes and really tiring.” Freda

In families where parents worked full time, taking **time off work** to attend appointments was a significant barrier. In some cases, parents changed their job or quit their job in order to attend hospital or therapy appointments with their child, as described by Quinton:

“Yeah, sometimes I used to miss my work, you know, but I also work at (Company Name), then I used to work two weeks afternoon, two weeks morning. Then I quit that job because of my son’s appointments. I don’t want to miss his appointments. It’s very important to us.” Quinton

Parents’ ability to maintain employment while attending their child’s therapy appointments often depended on the flexibility of the employer and the service providers. For example, Helen is a teacher and she squeezed her daughter’s therapy into her ‘planning time’ with family and friends driving the child to and from appointments; Daria and Evan would negotiate their workplace meetings so that they didn’t conflict with their son’s therapy schedule. Victor describes using his sick days and family illness days, combined with flexible scheduling by his therapist in order to continue working while attending his daughter’s appointments:

“We are really lucky that our therapists have been flexible in times. I think too, they are a little sensitive of the fact that we spent so much time in hospitals... we spend so much time at (Hospital Name) and in other areas just in follow-up appointments and appointments and appointments throughout the day that this is really hurting our um... sick days, our family illness days, to the point where we are not getting paid some days to do these things, right, and that’s frustrating.” Victor

In addition to missing work, parents were also frustrated by having to pull children out of

school or daycare to attend appointments. When there was more than one child in the home, parents often had challenges finding **childcare** while they were in hospital or attending therapy appointments.

Parent knowledge

The parents' knowledge that affected their attendance, participation and engagement in their child's therapy was broken into three main areas: **general knowledge of child development, knowledge specific to their child's disability, and knowledge regarding services**. Parents gained **knowledge of child development** from their experiences raising other children, and from their educational or work experiences. For example, several participants were teachers, one was a therapist who worked with children with Autism and two studied to be special education resource-consultants. These parents used their knowledge to identify their child's difficulty, set goals, develop practice ideas, and access services. Parents were least confident in their knowledge when this was their first child, or if their other children had not used services and they had no prior educational or vocational experiences with children's therapy. They generally did not know what to expect from services and were appreciative of the information given to them by therapists, as described by Kate:

“There were pretty good with giving information. Like I didn't really know what to ask 'cause I've never really been through this kind of thing before. My other son was really, really good with his speech so I didn't ... I have no idea, but like they were just really, really good at giving the information I needed.” Kate

Parents often talked about learning alongside their children and **developing knowledge that was specific to their child's needs**, for example learning how to fix a wheel-chair, interpret non-verbal communication or reading about neuroplasticity. This knowledge allowed parents to understand their children and to help them at home. Parents reported positive experiences of therapy when they viewed services as a means for them to learn how to support their child, as described by Steve:

“It can be a nuisance having to go into appointments and stuff and everybody agrees but it’s like I feel good because I can go and I can learn. So, I’m basically on the same path that she’s taking, so I mean, for me as a parent it’s a learning curve. I got to learn with her, right? So what she is learning, I’m learning and then I can use that to help her at home, right?” Steve

Parents were most confident in their knowledge when they had other children who had been through developmental rehabilitation **services**. This helped parents to identify developmental issues sooner, know what services were available and how to access them, and know how to help their child. Grace had many insights to share from her experiences raising three children who have a diagnosis of Autism Spectrum Disorder:

“I’m just going to say that you have to be a squeaky wheel and you got to know the system... not the system, you have to know the facility, you have to know the needs of your child and you have to fight... being educated helped me and they all get services.” Grace

Parent skills

There are two main therapy-related skill sets that parents developed throughout the family’s journey through services. The first skill set is **case management** for their child and the second is **therapeutic skills**. **Case management skills** often related to scheduling appointments and included: timing/spacing appointments, remembering appointments,

coordinating appointments, being organized and multi-tasking. This became more difficult for families like Nicole's, when there were multiple children at home who used therapy services and had many organizations and professional involved.

“I'm pretty organized with staggering appointments. Mason has always had like ... when he was Liam's age he had six, seven appointments a week so we were, you know, like I learned how to make sure that I had enough travel time and stuff like that and making an appointment with somebody on the phone for me takes like five minutes because I'm like actually no, we have to move it here and well what about your day and ... so like, you know, I'm a stay at home mom but I got a schedule like them. So it's really hard to collaborate sometimes but we ... I always fit it in where it's possible, right?” Nicole

Parents often identified doing **therapy practice** at home as one of the main ways that they participated and were engaged in their child's therapy service. In order to carry out therapy at home most parents watched the therapist during their child's session so that they could copy them, learned about the child's goals and what to focus on, and picked up structured or unstructured practice ideas from the therapist. Sometimes parents attended groups in which they were taught specific skills they could use to help their child. As parents of preschool aged children, participants often identified the skills they developed to work therapy into their everyday life and make it fun for their child. Several parents noted that once they had developed the skills they needed to help their child, they no longer felt the need to attend therapy. For example, Barb talks about being empowered through knowledge: “Once I had the information I needed to know how to teach those specific skills that he needed, I was empowered and able to do that on my own.”

Parent feelings

Parents expressed intense feelings that served to promote or limit their attendance, participation or engagement in therapy. Initially, parents often felt **worried** and anxious about their child's survival, development, and happiness. This was especially true for children who underwent extensive diagnostic testing or had life-threatening conditions. Parents' worries were often related to the child's future, for example school entry and the potential for their children to experience bullying or fall behind academically. Mothers in particular often worried and felt **guilty** that they were not doing enough to help their children. This guilt could be externally driven by family or care providers when parents felt blamed or judged for their child's difficulties, their parenting decisions, or the amount they were doing to help their child. Often mothers who were very engaged in their child's therapy spoke about self-driven guilt, vividly illustrated by Freda as the tension between wanting to do more and being tired:

“And as parents, particularly moms, you know, are for the most part naturally inclined to feel that sense of guilt all the time. Are we doing enough? But then when you have that background information too, you know, it's I find for me it ... I'm constantly feeling like I'm not doing enough and ... but then I'm so tired. So it's almost like a paradox because there is a sense of not doing enough but then also this I'm so tired, I don't really want to do anything.” Freda

In comparison, the fathers who participated in this study felt compelled to **'be strong'** and support their children and partner, as illustrated below by Quinton. Although typically seen as 'negative feelings' parents described worry, guilt and the need to be strong as feelings that increased their attendance, participation and engagement in their child's therapy service:

“I have to be strong, you know, like uh ... she was always crying then I used to say it's okay, God give us and we have to take care of him. We have to be strong.

If we're... if we be like sick who is going to take care of ... you know, crying and worrying doesn't help you, we have to be strong especially for your son." Quinton

There were also **positive feelings** that parents associated with therapy. Parents felt relieved to get information that would help them to understand and support their children. They were proud, excited and hopeful when they saw their child grasp a new skill in therapy or at home. Parents often spoke about how they felt when leaving a therapy session, which included positive descriptions of relief and feeling "buoyed up". Service providers contributed to parents' positive feelings during therapy when they recognized the efforts that parents make to help their children and pointed out the child's improvements:

"And she does it and then they are like, you did, that's so great. I'm proud of you. You know, like that kind of thing makes a difference to how she feels when she is there and how I feel... That's pretty amazing...I do really like that part." Helen

"I loved the fact that they could say 'yeah, I am seeing progress' because sometimes when [parents are] in this vacuum of all this stuff coming at you sometimes all you see is the negative and I think [parents] miss key moments to celebrate." Clinician 3

Parents also expressed strong **negative feelings** associated with therapy that led to decreased attendance, participation and engagement. Some parents experienced "anger, upset, disillusionment and disengagement" when leaving a therapy session, especially if their expectations were not met or they disagreed with the service providers' approach or information. Anger, upset and fear were also elicited when parents were involved with a child protective agency. Most parents associated therapy with feeling frustrated and

overwhelmed, which often coincided with exhaustion, stress and depression and could lead to decreased engagement, as was experienced by Irene:

“Um, sometimes I used to just lock the door and not let [the rehabilitation service providers] in and I would just go and lay in bed with Sadie all day. But, now I feel like [the new rehabilitation service providers] hear me more and that they understand that she’s my kid ’cause the other ones used to just be like oh, this is how you do it and you are going to do it like this, this and this, then I want you to do it for ten hours and then the next therapist would be like the same thing and there’s not that many hours in the day so I could never do it all. And I felt like I was failing her, but she is progressing now and I don’t feel like a failure anymore.”
Irene

Parent professional relationship

The relationship between the parent and the therapist was identified as a critical component of engagement. Their relationship can be described according to the connection between the parent and the service provider, their level of agreement and how much the parent trusts the service provider. The **connection** refers to the personal aspects of the relationship and parents who have a strong connection often referred to their service provider as a “friend”, “buddy” or “extended family”. In these cases, the parents felt like the service provider knew them and their child well. Often these service providers would pay personal attention to the family, for example by staying to have coffee. Here are how Patty, Nicole and Helen describe positive connections with their service providers, whereas Grace describes a negative one.

“[Hospital nurses] were like extended family...extremely supportive, helpful, anything I had, any questions, any of my worries...they made it all better.” Patty

“Yeah, [child protection services worker] comes in here, kicks her feet up on my couch and has coffee with me, like she is ... like she is a worker and I mean she would never let me get away with anything bad but I consider her a buddy. Like, she comes and chats with me and like she is an inexpressible like support system.”
Nicole

“I really love going to the physio and the occupational therapy and the speech sessions. So all of those ones I look forward to going to partially because they are kind of fun and I love like the therapists so much that they are like friends now.”

Helen

“I just find that that particular individual treats us like a number and doesn't look out for our best interests. And that persists today, she is still our case worker. I just don't call. I'll go every other means before calling this woman.” Grace

When parents experience the personal connection with the service provider they are also more likely to **trust** that person. Sometimes it takes time for that trust to develop and may be dependent on child progress. When parents do not trust the service provider they are more likely to discontinue a service or change service providers. It was also important that parents felt that the service provider trusted and believed the information they shared about their child. When there is a positive connection and trusting relationship between parents and professionals, they will be more likely to reach **agreement** about the child's skills, needs, and how to move forward, often described by parents as “being on the same page”, as illustrated by Claire: “You kind of want your therapist to, you know, remember you and know you and be on the same page as you about your child's need or your family need;” and Victor: “Our physio...we're on the same page when it comes to...just trying whatever, just pushing, going forward and not setting limitations.” Progression through therapy was disrupted when parents and service providers did not reach agreement about the child's skills or an approach to therapy, as was the situation for Julie: “I think I would tune out because I thought that her advice did not apply to us. And I didn't think she was gauging Sally's real level of skills appropriately”.

Parents' values and beliefs

Parents often identified their values and beliefs as the most important *gear* affecting their engagement in their child's therapy because these (values) underlie everything else:

“I'd have to say values because that's the root of it all, right? That's the fire that ignites me into going. If I didn't believe it I wouldn't do it, right? And go through all of the logistics and all those things, so I'm going to have to say my values... my values and how much I value the effectiveness and the practice of going to therapy, how important it is for his development.” Freda

Engagement was promoted when parents valued inclusion, independence, education, and therapy. The beliefs that led to attendance, participation and engagement include: the belief that it is a parent's responsibility to help their child to reach their full potential, that we should be optimistic about what children can achieve, and that children will improve with consistent practice and this takes time.

B: Grease and Grit

Five factors affect movement of the *parent gears*; these are viewed as *grease* that promotes gear movement or *grit* that inhibits gear movement. The *grease and grit* exist at the child, parent, therapist and organizational levels. The five factors include: motivation, communication, expectations, timing, and resources, and each will be presented with the most compelling examples of how they can affect the *parent gear* system.

- Insert Figure 2 approximately here -

Motivation

Motivation is closely aligned with the *parent feelings gear* described above. Initially parents are motivated by their worry about their child experiencing hardships and hope

for their child's future. However, they are strongly influenced throughout their therapy journey by the child's motivation and progress. When children resist practice, or are unhappy during therapy it is challenging for parents to stay motivated. But when children enjoy going to therapy and have a good relationship with the service provider parents report that therapy can be fun and highly motivating. In particular, parents are motivated when their service provider appears to be committed, genuinely excited and concerned about the child, prepared and willing to try new things. When children make improvements, their progress increases parents' motivation until a point where parents report backing off because they feel the child is doing well and catching up, as noted by Daria: "I'd say (my motivation) it's getting lower because he is getting better but when he was struggling the most it was pretty high." In situations where the parent does not feel like the therapy is effective they may lose all motivation and stop attending:

"I attended mostly however I have to admit that I would call in sick when Sally was not sick. It's just that I was so angry with the level of service that I couldn't sometimes deal with it because it was depressing 'cause at times I felt like I was being blamed. So I have the skillset to attend but I didn't like what was happening in the um... sessions. And the quality of speech-language pathology was really, really bad." Julie

Expectations

The therapy journey is heaped with expectations:

- the expectations that parents and therapists have of the child
- the expectations that parents have of themselves
- the expectations that children develop regarding therapy or medical appointments
- the expectations that therapists and organizations have of parents, and

- the expectations that organizations have of service providers

When expectations match their lived experiences, parents reported more satisfaction with therapy services. Sometimes **parents or therapists** changed their expectations as they gained more information about the child, family or service. Some parents never changed their expectations and were unhappy when expectations were never met. Expectations were closely related to the *knowledge gear*, with many parents stating that initially they didn't know what to expect of therapy and they believed it would be a quick fix for their child. However, most parents described changing those expectations as they gained knowledge about their role in therapy and the amount of time and work required to make changes. Daria spoke explicitly about her initial expectation that there would be a quick fix for her son's articulation challenges, and how she quickly adjusted her expectations once therapy began:

“There's no magic to making it happen right? It's just work. When we first went you know I kind of and in fact I know other parents, you just kind of think you just go and they're going to fix your kid. Right? like that's what I had in my head. We're going to go to a few things and they're going to fix it and we're going to be good. You get there and you're like oh it's daily homework this isn't this isn't fixed overnight.” Daria

Expectations were also related to the *values gear*, for example some parents were frustrated by **service providers** who limited their expectations of the child based on their diagnosis, and instead parents valued optimism and limitless views about what to expect the child could achieve. Finally, expectations were related to the *feeling gear*, for example some families learned about their child's disability in utero and were able to prepare

themselves, whereas others did not expect to have a child with a disability and expressed grief and fear during their adjustment period.

Organizational expectations of parents were often expressed through policies regarding attendance and cancellation. For example 16 of the 18 CTCs that provided data have a policy or procedure whereby families are discharged if they miss a pre-specified number of appointments without prior notice, which typically happens if the family does not respond to communication from the CTC following an absence. At the recruitment site service providers were inconsistent in enforcing these organizational policies, however they consistently shared expectations regarding the work parents could do at home to support their child. This was appreciated by parents when it was aligned with their own expectations about what they could do at home, but created feelings of guilt or being overwhelmed when it was beyond what parents felt they could do. Irene's exasperation at the number of expectations from her service providers was palpable during her interview:

“Yeah and then we had other people for OT and Speech and they got us to do the Nook Brush and oh you got to do it like seven times a day, for this long but then PT wants you to do this for this many times a day for this long and this person wants you to do this for this many times and for this long...And then they'd show up and be like oh well I can tell you haven't been doing it for this much. Well how am I supposed to do this and this and this and this.” Irene

Service providers often felt overwhelmed with organizational expectations regarding number of clients to be seen, amount of time spent on client work versus non-client related work (e.g., meetings), and direct client work vs indirect client work (e.g., documentation). The tensions between organizational expectations of service providers and their own expectations of themselves arose frequently, for example, a clinician

stated: “you are working really hard at capacity all the time to meet those standards and I’m a person not a machine” and another clinician commented: “I think in a place like this, quota shouldn’t be as important as quality of care for the children, right?” Administrative expectations about having calendars booked with clients in advance meant that service providers had limited flexibility with client scheduling, causing tension when service providers and their clients expected timely responses to address client needs:

“We are working with families not just with little kids whose own little crazy schedules are all over the place and things happen, but because these are kids with disabilities and special needs. So, like their family lives are not following nice schedules, I mean, their whole lives are around meeting their kid’s needs. So yeah, like if we can’t accommodate to that like who else in the system does?” Clinician 1

Resources

Parents’ resources, their willingness to use their available resources, or their lack of resources are critical in determining how the *gears* function, especially in conditions that are likely to challenge gear movement, such as single parent families with multiple children or families who are using many different services. Resources are only described briefly here due to space constraints, but can be grouped in the following categories: people, faith, services or funding, information, and organizational support. Participants described varied levels of support from their partner, parents, and friends. Supportive partners helped with the *skills gear* by helping to keep track of appointments and the *logistics gear* by watching siblings or driving to appointments. Grandparents helped with the *knowledge gear* especially for young parents who relied on grandparents for general childhood and medical advice; they also helped with the *logistics gear* by paying for devices or private therapy, helping with travel and attending appointments with the child.

Notably partners and grandparents negatively impacted the *feelings gear* when they blamed the parent for the child's difficulties. Faith groups and a belief in God helped some parents to find the emotional strength they needed to participate and stay engaged in therapy.

Tangible support described by parents included funding for services such as respite, home cleaning, or childcare. Resources that families used were not always specific to the child's disability, such as mental health counselling services for parents, drug addiction programs, and income support programs. Informational resources that parents accessed including web-based searches, diagnostic-specific online or in person support groups, and library books. These resources could impact the parents' *skills, knowledge or feelings gears*. The *logistics gear* was most impacted by organizational support, including:

- travel support such as volunteer drivers, paid bus tickets or taxi support
- therapy services provided at home or daycare
- services provided outside of traditional working hours for families that work full time
- offering joint appointments with more than one discipline present or limiting the number of disciplines directly involved to decrease the overall number of appointments for a family.

These resources, offered by the organization, could make the difference between a family who was able to use services and one that was not.

Timing

Families often pointed out that therapy happens in the context of their lives, and some phases of life are more conducive to therapy than others. Kate spoke about these ‘phases’ as days in her life that affected her motivation:

“Like I have my own issues in life so I’m ... I’m going through my own things depending on, like I said, it depends on the day. Everybody is either highly motivated some days or you know, they could be least motivated on really bad days, right? If they have to deal with their own personal life, so unfortunately that affects those around you and what you are supposed to be doing in day to day life, right?” Kate

Other parents spoke about specific phases in life marked by significant events. James became a parent as a teenager and spoke about his challenges related to moving out of his parents’ home, getting engaged, and learning to live independently and raise a child with significant medical needs, all at the same time. Another parent talked about overcoming drug addiction and now that her children are old enough for childcare, she is finishing her high school diploma and feeling optimistic about her life. Normative life events, such as having another child, could increase engagement when mothers were home on maternity leave and had more time for attending appointments or decrease therapy engagement if mothers were tired by a pregnancy. Parents also faced significant legal battles, changed jobs, moved across cities or provinces, got divorced, and got married. These periods of major change taxed families’ time and emotional resources, leaving limited capacity for engagement in therapy.

Communication

Parents and service providers both identified communication as one of the most important factors in determining whether a parent would be engaged in therapy or not. Parents needed to feel that service providers were listening to them, were understanding, and that they valued parents' input:

“CTC (name) is more understanding and they listen when I talk, as the other places they just wanted it their way. And um, it was right after we got out of the hospital so then I was worried about (the child protective agency) cause like they were involved my whole life and my sister was taken away for foster care for a little bit. So um, yeah I didn't want that in my kids' life.” Irene

“[Parents] don't need to hear that everything is going to be okay and they don't want to hear just wait. They want to hear, no your concerns are valid, we are seeing this stuff, but we are here with you and we are going to support you and we are going to journey this with you”. Clinician 3

When these safe and supportive communicative relationships were developed, parents were willing to share information, ask questions, and raise concerns. When parents felt that service providers were dismissive or unresponsive they were unlikely to share their ideas or challenges. The way in which service providers shared information with parents critically affected the *skills, feeling, and knowledge gears*. Parents reported that they understood the information and were confident about knowing what to do if service providers broke things down, took time to answer questions, and avoided use of jargon. However, care providers should be aware of whether they are condescending in their attempts to share information with families as this was received negatively by parents. For example, Irene says: “well I like it when the Doctors don't talk to you like you're

stupid because like yes, it's a new thing and it's scary but like the way they talk to you is like oh they are better than you." Irene

It was helpful for parents when service providers communicated with one another and avoided giving parents conflicting information. Communication was further supported when therapists wrote things down, gave websites or pamphlets for additional information, and made dual sets of information for divorced parents. For parents who spoke English as a second language, having written information allowed them to share it with friends or family members who could help to translate and promote understanding.

Discussion

The Phoenix Theory of Parent Engagement shows that parent attendance, participation and engagement in children's developmental rehabilitation services should be viewed as an interconnected, multifaceted and complex processes. The components of these processes can be viewed metaphorically as the *parents' gears* that move the family along the children's therapy road to child health and happiness (Figure 1). These gears include parents' values and beliefs, knowledge, skills, feelings, relationship with the professional, and logistics. Notably these gears will function differently for every parent, and from one time to another, with some families experiencing *smooth* movement through therapy services, and others facing challenges that will *slow or stall* their movement to limit attendance, participation and engagement. The *grease and grit* are child, parent, service provider or organizational factors that can promote or inhibit movement of the *parent*

gears (Figure 2). These factors include motivation, expectations, communication, resources and timing. The *parent gears* and the *grease and grit* experienced by a family should both be considered with respect to the conditions that affect parent engagement. These conditions are fully described in Chapter 5a, and include the family composition, child-sibling-family health complexity, and service complexity. Full consideration of the conditions that affect parent engagement, *the parent gears*, and the *grease and grit* described within this theory of parent engagement will undoubtedly reveal a personal journey through childhood therapy services.

Although this is a novel holistic conceptualization of parent engagement that is specific to parents' experiences of children's developmental rehabilitation services, not all components of the theory are new. The logistic barriers to use of children's public health, social, and educational services use are well described in a systematic review (Boag-Munroe & Evangelou, 2012). The parents' knowledge, skills, and feelings presented here align well with the conceptualization of parent engagement within a therapy session as developed by King, Currie, and Petersen (2014) using mental health literature. These authors also identify parent beliefs, motivation and trust as factors that impact engagement. The fact that these engagement factors were inductively derived from the parent interview data in this work suggests that there are similarities between the children's mental health environment and that of children's developmental rehabilitation services, and that in-session engagement and out-of-session engagement have similar components for parents. The parent-professional relationship has been studied more than

any other ‘gear’, including bodies of work on the therapeutic relationship (King, 2009, 2016), collaborative goal setting (Forsingdal, St John, Miller, Harvey, & Wearne, 2014), and negotiated roles (Hessell, 2014; Hurtubise & Carpenter, 2011).

In addition to negotiating roles with parents, service providers should discuss their expectations of parents, and parents’ expectations of therapy, given that this can lead to improved client outcome and satisfaction (Coyne, 2015; Hessell, 2004). Parents in the study presented here echoed the experiences of other parents who used pediatric occupational therapy (Andrew, Griffiths, Harrison & Stagnitti, 2013) and speech therapy services (Carroll, 2010; Lyons, O’Malley, O’Connor & Monaghan, 2010). Typically, parents experience early uncertainty about services and expect therapists will ‘fix’ the child’s difficulty, they may also expect a particular kind of therapy. These expectations may be adjusted based on child progress, parent satisfaction and increased knowledge about the service.

Conversely, organizational expectations of parent attendance and participation as indicated through CTC policies and procedures have received minimal attention in the literature. Parent values and beliefs are also rarely studied; however, authors have described the potential discrepancy between child, parent, therapist and researcher values and assumptions that specifically impact goal-setting and measurement (Forsingdal, St John, Miller, Harvey & Wearne, 2014; Gibson et al., 2012) and rehabilitation as a field more generally (Gibson et al., 2009, Gibson, 2016). This is an area that deserves further attention, given that parents often place their values and beliefs at the heart of their

engagement in services. Many of the individual factors that impact engagement have previously been identified in the literature; this is the first study to identify inductively - from the perspective of parents who vary by their level of attendance, participation and engagement – the collective factors that account for how parents participate and engage in their child’s therapy services.

Strengths and Limitations

A strength of this study was the inclusion of participants who would traditionally be seen as ‘hard-to-reach’ due to multiple missed appointments and parents who consistently attend their appointment. These participants provided diverse perspectives that allowed for a comprehensive understanding of properties and dimensions of the major categories that comprise parental engagement in their children’s therapy services.

A limitation of this work is that all parents were recruited from a single developmental rehabilitation organization. Therefore, the transferability of this theory may be limited given that parents in other geographic regions or those accessing other models of care (e.g., school-based services) may require other considerations.

Conclusion

Based on the voices of parents, and the inductive analyses used within this grounded theory study, parents’ attendance, participation and engagement in children’s therapy service can be improved if service providers, organizational management, policy makers and researchers do three things:

1. inquire about the conditions that affect parent engagement, including family composition, child-sibling-parent physical and mental health complexity, and service complexity;
2. attend to each of the six *parent gears* to determine whether any are problematic, given that one problematic *gear* can slow or stall family movement through services; and
3. promote positive experiences (*grease*) within each of the five factors that impact movement of the *parent gears* to create smooth movement along the journey to child health and happiness.

References

- Andrews, F., Griffiths, N., Harrison, L., & Stagnitti, K. (2013). Expectations of parents on low incomes and therapists who work with parents on low incomes of the first therapy session. *Australian Occupational Therapy Journal*, *60*(6), 436–444.
<http://doi.org/10.1111/1440-1630.12044>
- Arai, L., Stapley, S., & Roberts, H. (2014). “Did not attends” in children 0-10: a scoping review. *Child: Care, Health and Development*, *40*(6), 797–805.
<http://doi.org/10.1111/cch.12111>
- Arrigo, R. D., Ziviani, J., Poulsen, A. A., Copley, J., & King, G. (2016). Child and parent engagement in therapy : What is the key ? *Australian Occupational Therapy Journal*, 1–4. <http://doi.org/10.1111/1440-1630.12279>
- Birks, M., Chapman, Y., & Francis, K. (2008). Memoing in qualitative research: Probing data and processes. *Journal of Research in Nursing*, *13*(1), 68–75.

- Boag-Munroe, G., & Evangelou, M. (2012). From hard to reach to how to reach: A systematic review of the literature on hard-to-reach families. *Research Papers in Education*, 27(2), 209–239. <http://doi.org/10.1080/02671522.2010.509515>
- Boeije, H. (2002). A Purposeful Approach to the Constant Comparative Method in the Analysis of Qualitative Interviews. *Quality and Quantity*, 36, 391–409.
- Bradley, E.H., Curry, L. A., & Devers, K.J. (2007). Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health Services Research*, 42(4), 1758-1772.
- Charmaz, K. C. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London, UK: Sage.
- Charmaz, K. C. (2014). *Constructing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage.
- Carroll, C. (2010). “It’s not everyday that parents get a chance to talk like this”: Exploring parents’ perceptions and expectations of speech-language pathology services for children with intellectual disability. *International Journal of Speech-Language Pathology*, 12(4), 352–361. <http://doi.org/10.3109/17549500903312107>
- Coyne, I. (2015). Families and health-care professionals’ perspectives and expectations of family-centred care: Hidden expectations and unclear roles. *Health Expectations*, 18(5), 796–808. <http://doi.org/10.1111/hex.12104>
- Forsingdal, S., St John, W., Miller, V., Harvey, A., & Wearne, P. (2014). Goal setting with mothers in child development services. *Child: Care, Health and Development*, 40(4), 587–596. <http://doi.org/10.1111/cch.12075>

- Gentles, S. J., Charles, C., Ploeg, J., & McKibbin, K. A. (2015). Sampling in Qualitative Research: Insights from an Overview of the Methods Literature *The Qualitative Report*, 20(11), 1772–1789.
- Glaser, B. G., & Strauss, A. (1967). *The discovery of grounded theory*. Chicago, IL: Aldine.
- Gibson, B.E. (2016). *Rehabilitation: A post-critical approach*. Boca Raton: CRC Press.
- Gibson, B. E., Darrah, J., Cameron, D., Hashemi, G., Kingsnorth, S., Lepage, C., ... Menna-Dack, D. (2009). Revisiting therapy assumptions in children’s rehabilitation: clinical and research implications. *Disability and Rehabilitation*, 31(17), 1446–53. <http://doi.org/10.1080/09638280802621390>
- Gibson, B. E., Teachman, G., Wright, V., Fehlings, D., Young, N. L., & McKeever, P. (2012). Children’s and parents' beliefs regarding the value of walking: Rehabilitation implications for children with cerebral palsy. *Child: Care, Health and Development*, 38(1), 61–69. <http://doi.org/10.1111/j.1365-2214.2011.01271.x>
- Hessell, S. (2004). “Entering the unknown?” Identifying potential expectations of paediatric occupational therapy held by families. *New Zealand Journal of Occupational Therapy*, 51(2), 5–11.
- Hurtubise, K., & Carpenter, C. (2011). Parents’ Experiences in Role Negotiation Within an Infant Services Program. *Infants & Young Children*, 24(1), 75–86. <http://doi.org/10.1097/IYC.0b013e3182008b39>

- King, G. (2009). A relational goal-oriented model of optimal service delivery to children and families. *Physical & Occupational Therapy in Pediatrics*, 29(4), 384–408.
<http://doi.org/10.3109/01942630903222118>
- King, G. (2016). The Role of the Therapist in Therapeutic Change : How Knowledge From Mental Health Can Inform Pediatric Rehabilitation. *Physical and Occupational Therapy in Pediatrics*, (Early Online), 1–18.
<http://doi.org/10.1080/01942638.2016.1185508>
- King, G., Currie, M., Bartlett, D. J., Gilpin, M., Willoughby, C., Tucker, M. A., ... Baxter, D. (2007). The development of expertise in pediatric rehabilitation therapists: changes in approach, self-knowledge, and use of enabling and customizing strategies. *Developmental Neurorehabilitation*, 10(3), 223–240.
<http://doi.org/10.1080/17518420701302670>
- King, G., Currie, M., & Petersen, P. (2014). Child and parent engagement in the mental health intervention process: a motivational framework. *Child and Adolescent Mental Health*, 19(1), 2–8. <http://doi.org/10.1111/camh.12015>
- King, G., Servais, M., Shepherd, T. A., Willoughby, C., Moodie, S., Baldwin, P., ... Mcnaughton, N. (2017). A listening skill educational intervention for pediatric rehabilitation clinicians: A mixed-methods pilot study. *Developmental Neurorehabilitation*, 20(1). <http://doi.org/10.3109/17518423.2015.1063731>
- Kuhlthau, K. a, Bloom, S., Van Cleave, J., Knapp, A. a, Romm, D., Klatka, K., ... Perrin, J. M. (2011). Evidence for family-centered care for children with special health care

needs: a systematic review. *Academic Pediatrics*, 11(2), 136–43.

<http://doi.org/10.1016/j.acap.2010.12.014>

Littell, J., Alexander, L., & Reynolds, W. (2001). Client Participation : Central and Underinvestigated Elements of Intervention. *Social Service Review*, 75(1), 1–28.

Retrieved from <http://www.jstor.org/stable/10.1086/591880>

Lyons, R., O'Malley, M. P., O'Connor, P., & Monaghan, U. (2010). “It’s just so lovely to hear him talking”: Exploring the early-intervention expectations and experiences of parents. *Child Language Teaching and Therapy*, 26, 61–76.

<http://doi.org/10.1177/0265659009349975>

Øien, I., Fallang, B., & Østensjø, S. (2010). Goal-setting in paediatric rehabilitation: Perceptions of parents and professional. *Child: Care, Health and Development*,

36(4), 558–565. <http://doi.org/10.1111/j.1365-2214.2009.01038.x>

Phoenix, M., & Rosenbaum, P. (2014). Development and implementation of a paediatric rehabilitation care path for hard-to-reach families: a case report. *Child: Care, Health and Development*, 41(3), 494–499. <http://doi.org/10.1111/cch.12194>

Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-Centred Service: A Conceptual Framework and Research Review. *Physical & Occupational Therapy in Pediatrics*, 86(I), 1–20.

Siebes, R. C., Wijnroks, L., Ketelaar, M., van Schie, P. E. M., Gorter, J. W., & Vermeer, a. (2007). Parent participation in paediatric rehabilitation treatment centres in the Netherlands: a parents’ viewpoint. *Child: Care, Health and Development*, 33(2),

196–205. <http://doi.org/10.1111/j.1365-2214.2006.00636.x>

Staudt, M. (2007). Treatment Engagement with Caregivers of At-risk Children : Gaps in Research and Conceptualization. *Journal of Child and Family Studies*, 183–196.

<http://doi.org/10.1007/s10826-006-9077-2>

Timmermans, S. & Tavory, I. (2012). Theory construction in qualitative research: From grounded theory to abductive analysis. *Sociological Theory*, 30(3), 167-186.

Wuart, L., Ray, L., Darrah, J., & Magill-Evans, J. (2010). Parents' perspectives on occupational therapy and physical therapy goals for children with cerebral palsy.

Disability and Rehabilitation, 32(3), 248–258.

<http://doi.org/10.3109/09638280903095890>

Winkworth, G., McArthur, M., Layton, M., Thomson, L., & Wilson, F. (2010).

Opportunities Lost—Why Some Parents of Young Children Are Not Well-

Connected to the Service Systems Designed to Assist Them. *Australian Social Work*,

63(4), 431–444. <http://doi.org/10.1080/0312407X.2010.508170>

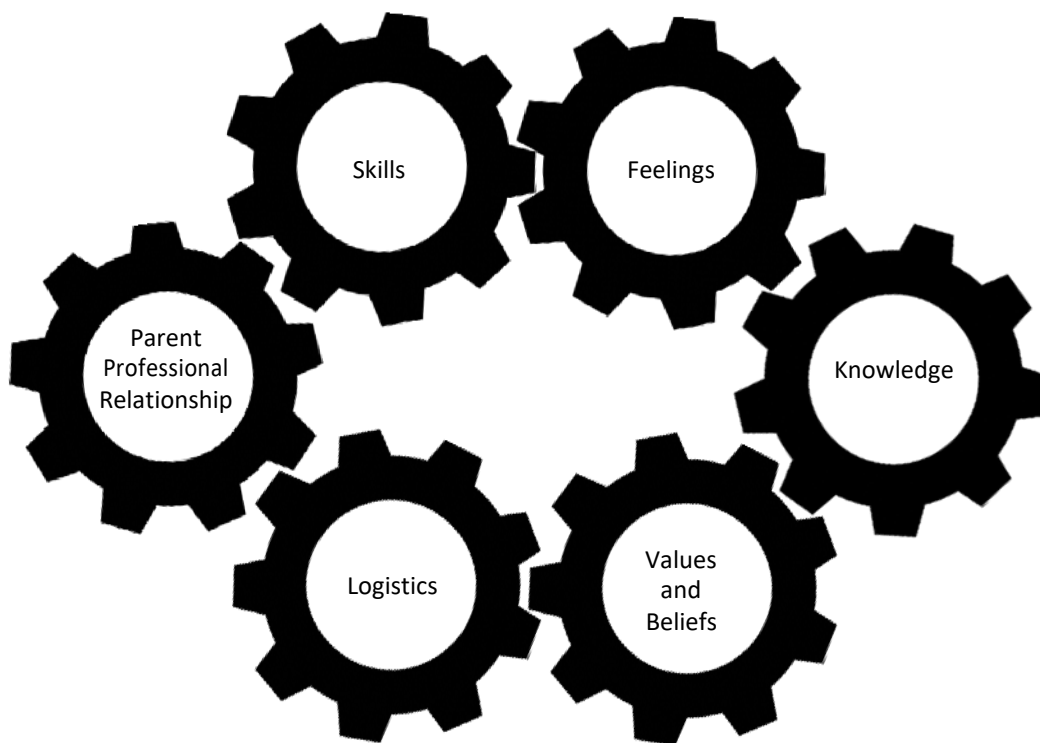


Figure 1. The parents' gears of attendance, participation and engagement



Figure 2. The child, parent, professional or organization grease and grit that impact gear movement.

Chapter 6. Implications for Practice, Policy and Research

It is my sincere hope that this thesis will illustrate the power of research to inform the everyday work – done by service providers, organizational leadership and policy makers – that affects the lives of children with disabilities and their families. Researchers can expand thinking on a clinical topic by sharing applications of an approach to service delivery (e.g., Chapter 2), using and developing theory (e.g., Chapter 3), exploring the ethical dimensions of practice-based issues (e.g., Chapter 4), and conducting research that is grounded in the experiences of children and families who live with disability (e.g., Chapter 5). Political agendas affect laws and funding for research and programs. Therefore, I encourage policy makers to adopt worldviews that promote social inclusion, access and equity in health and education services. Qualitative research is particularly well suited to address research questions in these areas because of the value placed on contextual understanding of issues that are meaningful to research participants. In the work presented in this thesis, use of qualitative methodology allowed for the deep exploration needed to understand holistically how parents participate and engage in their child's developmental rehabilitation services.

Parent engagement is widely considered to be a necessary component of effective children's developmental rehabilitation services. Yet little is known about how to define or promote parents' engagement in these services. Often limited or sporadic engagement is viewed as problematic when families do not use the services for which they are eligible, or when they frequently miss their child's appointments; families who fit this

description are typically referred to as ‘hard-to-reach’ (Boag-Munroe & Evangelou, 2012). Missed appointments raise many concerns in healthcare (Arai, Stapley, & Roberts, 2014) and rehabilitation programs (Ballantyne, Stevens, Guttman, Willan & Rosenbaum, 2012; Phoenix & Rosenbaum, 2015). The two primary concerns are the missed opportunity to promote child health and development (Ballantyne et al., 2012; Phoenix, 2015) and the inefficient use of resources (Arai et al., 2014). Families’ perspectives and concerns related to attendance, participation and engagement are largely absent in the literature evaluating the use of early childhood service (Winkworth, McArthur, Layton, Thomson, & Wilson, 2010); this is especially true for so-called ‘hard-to-reach’ families, as no previous studies have explored the experiences of these families in a developmental rehabilitation context. This gap in the literature leaves service providers, organizational leadership, policy makers and researchers struggling to determine how to engage parents, including hard-to-reach parents, in their child’s developmental rehabilitation services. Ideas that we can apply in daily practice to promote engagement with parents are detailed below and summarized in Table 1.

- Insert Table1 approximately here -

Implications for Service Providers

For many years, pediatric rehabilitation therapists have been encouraged to apply principles of family-centred service in their work with children and families (Rosenbaum, King, Law, King, & Evans, 1998). Chapters 2a and 2b present the ways in which therapists can use family-centred services to promote partnership with families, and the

challenges they may face when attempting to use family-centred principles in the current children's therapy context. Given the organizational demands faced by service providers, and the tension we can feel when attempting to use family-centred care in our practice, it is easy to wonder, 'Is it worth it?' The thesis work presented here exclaims, 'Yes, it is worth it!' Presented below are specific strategies that build on family-centred service that we can use to promote parents' attendance, participation and engagement in developmental rehabilitation services.

1. *Ask about who is a part of the family.* Remember, this can include parents, grandparents, siblings and friends. We should request details about the kinds of support offered by these people and parents' feelings about this involvement. If there are one or more siblings at home, talk about childcare and whether the siblings have any developmental challenges, and determine if parents have used therapy services before. Previous or ongoing therapy experiences with siblings can shape parents' knowledge and skills, and present logistic challenges for scheduling. We must consider our roles in asking parents about their own physical and mental health, because parents are likely to have challenges in these areas that often affect their attendance, participation and engagement in services.

2. *Listen to the family with empathy, responsiveness, and respect.* This is necessary for the deep exploration of families' values and beliefs that are central to their experience of engagement. Listening will help us to gauge parental expectations and reach agreement on goals and therapy plans. When charting the course of therapy consider the number of organizations and service professionals that are involved. Even when families are able to

attend all of these appointments they can feel pressured to do so and become overwhelmed and exhausted. When families feel that they are being heard they are more likely to discuss these negative feelings and their barriers to attendance. If it is possible, help families to mitigate these barriers (e.g., offering later appointments, or postponing therapy). When sharing information with families break it down, make it practical, and include written resources. When we have consent, we should share information with others who are involved with the child's care to avoid a burden on families and to promote the consistent messages and coordinated services that are appreciated by families.

3. Build relationships with families by celebrating their strengths and accomplishments.

Help parents to see children's progress and take time to recognize their efforts. Aim for children and parents to enjoy coming to therapy by taking time to connect with the child and keeping it fun, sharing in parents' joys and frustrations, and demonstrating our investment through small acts of caring (e.g., providing toys for a sibling who attends the session). We should keep the child's health and happiness at the forefront of our work: these are parents' central reasons for attending, participating and engaging in their child's therapy services. Families are more likely to stay engaged in services when we have an optimistic approach and a 'limitless view' of what children and families can achieve.

Implications for Organizational Leadership.

Organizational leadership can shape the culture and vision within an organization, with management often being responsible for the supervision and professional development of

therapists within children's treatment centres. Tensions between organizational expectations of therapists and the expectations that therapists hold of themselves arose frequently and various perspectives on this topic are presented in Chapter 2b, Chapter 4, and Chapter 5b. These tensions have an ethical dimension, with organizations tending to focus on the equal sharing of resources among all clients, and therapists placing more priority on doing the best they can for a particular client. An important ethical concern is the existence of policies that can lead to clients' discharge when they are struggling with attendance, participation and engagement. The following strategies may help to address the tensions that can be felt between service providers and organizational leadership, and address the ethical concerns related to discharge.

1. When organizations set strategic plans and goals for quality improvement they should place equal value on efficiency and quality of their services. Targets should move beyond the number of clients served and wait-times to consider the experiences of care received by these clients. This may lessen the pressures felt by therapists to meet quotas and fill schedules in advance with direct client work, and thereby increase therapists' flexibility to respond to clients' needs as they arise. Internal program evaluation of a service's quality can be done quantitatively using the Measure of Processes of Care that captures parents' or service providers' perceived level of experience of family-centred care (Cunningham & Rosenbaum, 2014; Dyke, Buttigieg, Blackmore, & Ghose, 2006; King, Rosenbaum, & King, 1997). I also advocate for the use of qualitative interviews with families, given that in this study interviews were responsive to multiple viewpoints and contextual factors that affect engagement. This methodology can be particularly useful for

providing 'hard-to-reach' families with opportunities to provide feedback to organizations and contribute to program development.

2. Organizations should consider the barriers to services that may be affecting the children and families that they aim to support. These barriers may include inconvenient bus routes, limited service hours, high turnover in staff, long waitlists, or poor communication about existing services and the expectations of parents. Whenever possible organizations should help families to overcome these barriers through tangible support such as providing bus or taxi fare, scheduling appointments outside of parents' (daytime) work hours, offering home visits and providing written information to families. Having options to support families at home or in the community (e.g., at daycare) may allow more families to access care. When services are difficult to navigate, the organizations require parents to be skilled in finding out what services are available, completing referral processes, and coordinating appointments with other family life responsibilities (e.g., work and childcare). These skills can take time to develop, and organizational policies that discharge families after 1-3 missed appointments may discontinue services before parents have had a chance to develop these skills.

Implications for Policy-Makers

Provincial, national, and international governmental and non-governmental bodies have the ability to influence how developmental rehabilitation services are offered to families through their financial and political decisions.

In the **province** of Ontario, the Ministry of Children and Youth Services is currently redesigning how children and youth with special needs receive services, with the goal of providing earlier identification and access to seamless and coordinated services (Ontario Ministry of Children and Youth Services, 2016). These goals align well with the need to support families in early childhood, especially (as discussed in Chapter 3) when they are identified as high-risk, and will help to address the challenges of families who are using a complex array of services as presented in Chapter 5a. Provincial decisions regarding funding and eligibility for services can impact access to care in important ways. This is made clear in Ontario's Autism Services, where major redesign of services and an investment of \$500 million dollars in funding (2016) are being used to create new diagnostic hubs to increase therapy spaces and options for direct funding models (Ontario Ministry of Children and Youth Services, 2017). This leads me to question the equity in these services, given the host of therapy-related needs and barriers shared by parents in this study (Chapter 5a, b) who are raising children with diagnoses other than Autism Spectrum Disorder (ASD) (e.g., Down syndrome, Cerebral Palsy and rare genetic conditions) and those who have no formal diagnosis (e.g., children who have severe dysfluency or speech sound disorders) – all of whose needs are just as real and compelling as those of the parents of children with ASD.

The lives of people with disabilities are affected by **national** decisions about funding and legal issues. In Canada, there are existing financial supports for parents raising a child with a disability, such as the Child Disability Benefit (Canada Revenue Agency, 2016a)

and the Registered Disability Savings Plan (Canada Revenue Agency, 2016b). This type of support can help families to offset the costs of raising children who have a disability; however, Chapter 5b details the intense workforce challenges faced by parents who are raising children with delays or disabilities, and how these require increased recognition and accommodation. Government standards, such as the US's Americans with Disabilities Act (1990), are influential in determining the rights and accommodations of individuals with disabilities to access employment, commercial facilities, and transportation without discrimination (United States Department of Labor, n.d.). Locally, the Accessibility for Ontarians with Disabilities Act became law in 2005 and requires all levels of government, non-profits, and private businesses in Ontario to identify, remove and prevent barriers for people with disabilities (Accessibility Ontario, n.d.). Provincial and national funding and laws can enhance the inclusion in society of children and parents that study participants highly valued (Chapter 5a, b).

International organizations such as the World Health Organization and the United Nations have shaped world-views on children's rights, individual and population health, disability and inclusion. These organizations helped to frame access to children's health and education services as a right. They have also shifted thinking beyond an individual's body function and structure to see the bigger contextual and social factors that determine health and wellbeing. This big-picture approach to disability services is clearly supported by this thesis that investigates the child's natural environment of family and considers the

societal issues that impact parent attendance, participation and engagement in developmental rehabilitation services including:

- the role of parents in their child's therapy (Chapter 2)
- social determinants of health with respect to disability and service use (Chapter 3)
- ethical dimensions to service accessibility (Chapter 4)
- families' contextual life factors that impact their use of developmental rehabilitation service (Chapter 5a)
- parent's use of services that support child and family development and participation in society (Chapter 5b)

Use of worldviews that promote accessibility, equity, and inclusion can promote parents' attendance, participation and engagement in children's developmental rehabilitation services.

Implications for Researchers

At the outset of this PhD program engagement had not been well defined in the literature and there were no previous studies that had investigated the perspectives of 'hard-to-reach' families in children's developmental rehabilitation services. For these reasons this work was naturalistic and exploratory. The thesis work presented here offers a strong foundation upon which to build future research on parents' attendance, participation and engagement in these services. It is recommended that future research explore the intersectoral vectors between research and public health prevention and intervention programs with consideration of ethics and policy. Developmental rehabilitation and early

childhood education services that apply public health frameworks have been recommended to improve access to services for ‘hard-to-reach’ families, who are often adversely affected by the social determinants of health (Evangelou, Coxon, Sylva, Smith, & Chan, 2013; Law, Reilly, & Snow, 2013). However, these frameworks have yet to be adopted and evaluated in developmental rehabilitation.

Researchers and service providers presume that parents’ engagement in their child’s therapy service will (i) increase attendance and (ii) increase child outcomes; however neither of these hypotheses has been tested. This thesis work identifies a variety of factors that can limit attendance, beyond a lack of engagement from the family. Therefore, the relationship between attendance and engagement remains unknown and further research in this area is recommended. The parents in this thesis study often spoke about the positive relationship between their motivation and their child’s progress, and higher motivation helped them to stay engaged in services. However, they also spoke about decreased concern and motivation when they felt their child was doing really well, leading to less engagement in the service. Therefore, there is an uncertain relationship between engagement and child outcomes (e.g., goal attainment and functional participation in real world contexts) that should be quantitatively studied using measures of parent engagement and children’s therapy outcomes.

This thesis work provides many recommendations that we, as service providers, organizational leadership, policy makers, and researchers can implement to promote

accessibility and parent engagement in children's developmental services. Through coordinated efforts to achieve a shared vision, we can create programs to support parents' and children's physical and mental health needs and promote family development and social inclusion. These interventions should recognize parent needs in addition to child needs and work to align the expectations of parents, service providers, organizational leadership, policy makers and researchers, so that we can journey together towards the destination of *child (and family) health and happiness*.

In summary, the overarching purpose of this thesis, as presented in Chapter 1, was to promote accessibility and excellence in the provision of children's developmental rehabilitation services. In order to do this, I used existing literature, theories, models of practice and contemporary lenses to explore the topic of parental engagement and participation in children's developmental rehabilitation services (Chapters 1-4). I built upon this existing knowledge by eliciting parents' perspectives to discover the conditions that affect parents' engagement in developmental rehabilitation services (Chapter 5a) and develop The Phoenix Theory of Parent Engagement (Chapter 5b). Although this knowledge was constructed with parents, the suggestions that can promote attendance, participation and engagement were developed for service providers, organizational leadership, policy makers and researchers (Chapter 6). That is because we are the individuals responsible for implementing the ideas presented in this thesis to achieve the works' purpose: to promote accessibility and excellence in service provision. Attendance, participation and engagement have typically been viewed as the responsibility of the

family. This thesis shows that a more complex and nuanced view is needed, given the interaction between children, parents, service providers, and organizations that together influence parent engagement. Therefore, the only recommendations I offer to parents are built upon the strengths and incredible efforts shared by every participant in this study.

Parents, continue to...

Celebrate your children. Celebrate their efforts, their achievements, their potential. Invite your service providers to celebrate with you.

Care for yourself. Remember that you are a person too. You are deserving of physical and mental health. Decide what are reasonable expectations for your time, energy and resources. Discuss these expectations with service providers and tell them if you feel that they are judging or blaming you.

Advocate. Advocate for services and societal opportunities that meet your needs and the needs of your child. Expect understanding, respect, and responsiveness in all arenas.

Acknowledge your efforts and those of your service providers, organizations, politicians and researchers. Be proud and uplifted; you are helping your child to achieve their potential by learning, developing skills, and overcoming logistic hurdles. You don't have to do it alone; partner with people who are willing to help and celebrate your collective efforts and achievements. I hope to be included as one of those people.

Table 1. Implications for Service Providers, Organizational Leadership, Policy-Makers, and Researchers: An Overview of Ideas we can all Apply in Daily Practice

Implications for Service Providers
<p>1. Ask about who is a part of the family</p> <ul style="list-style-type: none"> • This can include a parents, grandparents, siblings and friends. Ask about the kinds of supports offered by these individuals and listen for indications that parents can feel (or are being) blamed for their child’s issues by the people in their life. • Inquire about the child’s siblings – how are they doing and do they have any developmental challenges? • Ask if parents have used therapy services before. This can impact logistics, skills and knowledge. • Determine our roles in asking about parents’ own physical and mental health; they may easily face challenges in these areas that affect their attendance, participation and engagement.
<p>2. Listen to the family with empathy, responsiveness and respect</p> <ul style="list-style-type: none"> • By listening to families, we can reach agreement on values, expectations, goals and a therapy plan. Consider how many services and professionals are involved with the family. • Explore barriers to attendance with the family and provide help to mitigate these barriers. • Break down information and share written resources with families. Also share information with and request information from other service providers when families provide consent.
<p>3. Build relationships with families by celebrating their strengths and accomplishments</p> <ul style="list-style-type: none"> • Share in parents’ joys and frustrations and help them to see their child’s progress. Apply an optimistic and limitless approach in our work with families. • Take time to: connect with the child and keep therapy fun, recognize parents’ efforts, and show small acts of caring (e.g., providing toys for a child’s sibling during therapy).
Implications for Organizational Leadership
<p>1. Value efficiency and quality in service provision</p> <ul style="list-style-type: none"> • Balance targets for efficiency and quality when creating strategic plans and goals for continuous quality improvement projects. • In program evaluation, quality can be measured using developed tools (e.g., the Measure of Process of Care) or qualitative interviews. Interviews can provide opportunities for ‘hard-to-reach’ families to provide organizational feedback and contribute to program development.
<p>2. Consider the barriers to accessing our services</p> <ul style="list-style-type: none"> • Barriers to service accessibility can be highly contextual. Determine what barrier are affecting the clients that we aim to serve (e.g., inconvenient bus

<p>routes, limited service hours, high staff turnover, poor communication about existing services).</p> <ul style="list-style-type: none">• Provide tangible support to overcome barriers (e.g., bus or taxi fare, extended hours, home visits, written information to families).• Evaluate whether the centre's policies place families at risk for discharge when they are struggling with attendance, participation and engagement.
<p>Implications for Policy-Makers</p> <p>Policy-makers at provincial, national and international levels should adopt worldviews that prioritize access, equity, and social inclusion.</p> <ul style="list-style-type: none">• When funding services for children and youth, consider who can access these services and whether there is equity when services are based on the child's diagnostic category• Consider the supports that families require to engage fully in society when raising a child with a disability e.g., workplace accommodations or respite for parents.• Frame child health and education services and children's social inclusion as human rights, with exploration of ethical and political implications of service organization.
<p>Implications for Researchers</p> <ul style="list-style-type: none">• Develop interventions using a public health frameworks for the provision of children's developmental rehabilitation services and evaluate their use.• Test the relationships between parent engagement and (i) children's therapy outcomes using their goal attainment and social participation, and (ii) parents' attendance at developmental rehabilitation appointments.• Develop, implement and evaluate interventions that focus on parent needs in addition to the needs of the child.

References

Accessibility Ontario. (n.d.). *About the AODA*. Retrieved from

<https://accessontario.com/aoda/>

Arai, L., Stapley, S., & Roberts, H. (2014). “Did not attends” in children 0-10: a scoping review. *Child: Care, Health and Development*, 40(6), 797–805.

Arrigo, R. D., Ziviani, J., Poulsen, A. A., Copley, J., & King, G. (2016). Child and parent engagement in therapy : What is the key ? *Australian Occupational Therapy Journal*, 1–4.

Baldwin, P., King, G., Evans, J., McDougall, S., Tucker, M. A., & Servais, M. (2013). Solution-Focused Coaching in Pediatric Rehabilitation: An Integrated Model for Practice. *Physical & Occupational Therapy in Pediatrics*, 33(May 2012), 467–483.

Ballantyne, M., Stevens, B., Guttman, A., Willan, A. R., & Rosenbaum, P. (2012). Transition to neonatal follow-up programs: is attendance a problem? *The Journal of Perinatal & Neonatal Nursing*, 26(1), 90–8.

Bamm, E. L., & Rosenbaum, P. (2008). Family-centered theory: origins, development, barriers, and supports to implementation in rehabilitation medicine. *Archives of Physical Medicine and Rehabilitation*, 89(8), 1618–24.

Barlow, J., Kirkpatrick, S., Stewart-Brown, S., & Davis, H. (2005). Hard-to-reach or out-of-reach? Reasons why women refuse to take part in early interventions. *Children and Society*, 19(3), 199–210.

Beauchesne, M., Barnes, A., & Patsdaughter, C. (2004). Children with disabilities need a Head Start too! *Journal of Learning Disabilities*, 8(1), 41–55.

- Boag-Munroe, G., & Evangelou, M. (2012). From hard to reach to how to reach: A systematic review of the literature on hard-to-reach families. *Research Papers in Education, 27*(2), 209–239.
- Canada Revenue Agency. (2016a). *Child Disability Benefit*. Retrieved from <http://www.cra-arc.gc.ca/cdb/>
- Canada Revenue Agency. (2016b). *Registered Disability Savings Plan (RDSP)*. Retrieved from <http://www.cra-arc.gc.ca/rdsp/>
- Carter, S. M., & Little, M. (2007). Justifying Knowledge, Justifying Method, Taking Action: Epistemologies, Methodologies, and Methods in Qualitative Research. *Qualitative Health Research, 17*(10), 1316–1328.
- Charmaz, K. C. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London, UK: Sage.
- Charmaz, K. C. (2014). *Constructing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage.
- Chen, C. C., Heinemann, a. W., Bode, R. K., Granger, C. V., & Mallinson, T. (2004). Impact of Pediatric Rehabilitation Services on Children’s Functional Outcomes. *American Journal of Occupational Therapy, 58*(1), 44–53.
- Coe, C., Gibson, a, Spencer, N., & Stuttaford, M. (2008). Sure start: voices of the “hard-to-reach”. *Child: Care, Health and Development, 34*(4), 447–53.
- Constand, M. K., & Macdermid, J. C. (2013). Applications of the International Classification of Functioning, Disability and Health in goal-setting practices in healthcare. *Disability and Rehabilitation, 1*–10.

- Cortis, N. (2012). Overlooked and under-served? Promoting service use and engagement among “hard-to-reach” populations. *International Journal of Social Welfare*, 21(4), 351–360.
- Creswell, J.W. (2013). *Qualitative inquiry & research design: Choosing among five approaches*. Thousand Oaks, California: Sage.
- Cunningham, B. J., & Rosenbaum, P. L. (2014). Measure of Processes of Care: A review of 20 years of research. *Developmental Medicine and Child Neurology*, 56(5), 445–452.
- Cunningham, B. J., Washington, K. N., Binns, A., Rolfe, K., Robertson, B., & Rosenbaum, P. (2017). Current Methods of Evaluating Speech-Language Outcomes for Preschoolers With Communication Disorders: A Scoping Review Using the ICF-CY. *American Journal of Speech-Language Pathology*, 25(February), 447–464.
- Darrah, J. (2008). Using the ICF as a framework for clinical decision making in pediatric physical therapy. *Advances in Physiotherapy*, 10(3), 146–151.
- Dyke, P., Buttigieg, P., Blackmore, A. M., & Ghose, A. (2006). Use of the Measure of Process of Care for families (MPOC-56) and service providers (MPOC-SP) to evaluate family-centred services in a paediatric disability setting. *Child: Care, Health and Development*, 32(2), 167–176.
- Evangelou, M., Coxon, K., Sylva, K., Smith, S., & Chan, L. L. S. (2013). Seeking to Engage “Hard-to-Reach” Families: Towards a Transferable Model of Intervention. *Children & Society*, 27(2), 127–138.

- Flanagan, S. M., & Hancock, B. (2010). “Reaching the hard to reach”--lessons learned from the VCS (voluntary and community Sector). A qualitative study. *BMC Health Services Research, 10*, 92.
- Gentles, S. J., Jack, S. M., Nicholas, D. B., & McKibbin, K. A. (2014). Critical Approach to Reflexivity in Grounded Theory Critical Approach to Reflexivity in Grounded Theory. *The Qualitative Report, 19*(44), 1–14.
- Glaser B.G. & Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.
- Heath, H., & Cowley, S. (2004). Developing a grounded theory approach: a comparison of Glaser and Strauss. *International Journal of Nursing Studies, 41*(2), 141–150.
- Jack, S. M. (2006). Utility of qualitative research findings in evidence-based public health practice. *Public Health Nursing, 23*(3), 277–283.
- King, G., Currie, M., & Petersen, P. (2014). Child and parent engagement in the mental health intervention process: a motivational framework. *Child and Adolescent Mental Health, 19*(1), 2–8.
- King, G., Tucker, M. A., Baldwin, P., Lowry, K., LaPorta, J., & Martens, L. (2002). A life needs model of pediatric service delivery: services to support community participation and quality of life for children and youth with disabilities. *Physical & Occupational Therapy in Pediatrics, 22*(2), 53–77.
- King, G. A, Rosenbaum, P. L., & King, S. M. (1997). Evaluating family-centred service using a measure of parents’ perceptions. *Child: Care, Health and Development, 23*, 47–62.

- Kraus de Camargo, O. (2011). Systems of care: transition from the bio-psycho-social perspective of the International Classification of Functioning, Disability and Health. *Child: Care, Health and Development*, 37(6), 792–9.
- Kuhlthau, K. a, Bloom, S., Van Cleave, J., Knapp, A. a, Romm, D., Klatka, K., ... Perrin, J. M. (2011). Evidence for family-centered care for children with special health care needs: a systematic review. *Academic Pediatrics*, 11(2), 136–43.
- Law, M. C., Darrah, J., Pollock, N., Wilson, B., Dianne, J., Walter, S. D., ... Galuppi, B. (2011). NIH Public Access. *Developmental Medicine & Child Neurology*, 53(7), 621–629.
- Law, J., Reilly, S., & Snow, P. C. (2013). Child speech, language and communication need re-examined in a public health context: A new direction for the speech and language therapy profession. *International Journal of Language and Communication Disorders*, 48(5), 486–496.
- Novak, I., McIntyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., ... Goldsmith, S. (2013). A systematic review of interventions for children with cerebral palsy: state of the evidence. *Developmental Medicine and Child Neurology*, 55(10), 885–910.
- McConnell, D., Breitkreuz, R., Uditsky, B., Sobsey, R., Rempel, G., Savage, A., & Parakkal, M. (2013). Children with Disabilities and the Fabric of Everyday Family Life. Retrieved from [http://www.fdsa.ualberta.ca/~media/Family and Disability Studies Initiatives/Documents/FamilyLifeReportrevised.pdf](http://www.fdsa.ualberta.ca/~media/Family%20and%20Disability%20Studies%20Initiatives/Documents/FamilyLifeReportrevised.pdf).
- Montgomery, P., & Bailey, P. H. (2007). Field Notes and in Grounded Theory. *Western Journal of Nursing Research*, 29(1), 65–79.

- Öhman, A. (2005). Qualitative methodology for rehabilitation research1. *Journal of Rehabilitation Medicine*, 37(5), 273–280.
- Ontario Ministry of Children and Youth Services. (2016). *Ontario's Special Needs Strategy*. Retrieved from <http://www.children.gov.on.ca/htdocs/English/professionals/specialneeds/strategy.aspx>
- Ontario Ministry of Children and Youth Services. (2017). *Letter to Parents with Children and Youth with Autism from Minister Coteau*. Retrieved from <http://www.children.gov.on.ca/htdocs/English/specialneeds/autism/letter-to-parents.aspx>
- Patterson, J. M. (1988). Families Experiencing Stress. *Family Systems Medicine*, 6(2), 202–237.
- Patterson, J. M. (2002). Integrating Family Resilience and Family Stress Theory, 64(May), 349–360.
- Phoenix, M. (2016) Service provision for hard-to-reach families: What are our responsibilities? In P. Rosenbaum, G. Ronen, E. Racine, J. Johannesen, & B. Dan (Eds) *Clinical Ethics in Child Health Principles and Cases in Neurodisability* (pp. 193-201). London: Mac Keith Press
- Phoenix, M., & Rosenbaum, P. (2014). Development and implementation of a paediatric rehabilitation care path for hard-to-reach families: a case report. *Child: Care, Health and Development*, 41(3), 494–499.

- Phoenix, M., & Vanderkaay, S. (2015). Client-centred occupational therapy with children : A critical perspective. *Scandinavian Journal of Occupational Therapy*, 22(4), 318–321.
- Risdal, D., & Singer, G. H. S. (2004). Marital adjustment in parents of children with disabilities: A historical review and meta-analysis. *Research and Practice for Persons with Severe Disabilities*, 29(2), 95–103.
- Rosenbaum, P. (2006). Variation and “abnormality”: Recognizing the differences. *Journal of Pediatrics*, 149(5), 593–594.
- Rosenbaum, P. (2009). Putting child development back into developmental disabilities. *Developmental Medicine & Child Neurology*, 51(4), 251.
- Rosenbaum, P., & Gorter, J. W. (2012). The “F-words” in childhood disability: I swear this is how we should think! *Child: Care, Health and Development*, 38(4), 457–63.
- Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-Centred Service : A Conceptual Framework and Research Review. *Physical & Occupational Therapy in Pediatrics*, 86(I), 1–20.
- Staudt, M. (2007). Treatment Engagement with Caregivers of At-risk Children : Gaps in Research and Conceptualization. *Journal of Child and Family Studies*, 183–196.
- Strauss, A & Corbin, J. (1994). Grounded Theory Methodology. In N.K.Denzin & Y.S. Lincoln (Eds) *Handbook of Qualitative Research* (pp.273-285). Thousand Oaks, CA: Sage.
- Sumsion, T., & Smythe, G. (2000). Barriers to client-centredness and their resolution. *Canadian Journal of Occupational Therapy*, 67(1), 15–21.

United Nations Human Rights Office of the High Commissioner. (1996). *Convention on the Rights of the Child*. Retrieved from

<http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>

United States Department of Labor. (n.d.). *Americans with Disabilities Act*. Retrieved from <https://www.dol.gov/general/topic/disability/ada>

Vanderkaay, S., Moll, S., Gewurtz, R., Jindal, P., Loyola-Sanchez, A., Packham, T., & Lim, C. (2016). Qualitative research in rehabilitation science: opportunities, challenges, and future directions. *Disability and Rehabilitation*, Early Online View. <http://doi.org/10.1080/09638288.2016.1261414>

Winkworth, G., McArthur, M., Layton, M., Thomson, L., & Wilson, F. (2010). Opportunities Lost—Why Some Parents of Young Children Are Not Well-Connected to the Service Systems Designed to Assist Them. *Australian Social Work*, 63(4), 431–444.

World Health Organization. (2001). *International Classification of Functioning, Disability and Health (ICF)*. Geneva, Switzerland: World Health Organization.