The Journey of Ladders and Snakes: Help-Seeking Among Mothers and Fathers of Children with Neurodisabilities (ND)

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List of Abbreviations

ACTA	Approche Constructiviste de la Théorie Ancrée (ConGT)
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
BSW	Bachelor of Social Work
CHSLD	Centres d'hébergement de soins de longue durée (Residential and long term care facilities)
CIHR	Canadian Institutes of Health Research
CLSC	Centre Local des Services Sociaux (Local Centres for Community Services)
CISSS	Centre Intégré de Santé et de Services Sociaux (Integrated Heath and Social Service Centres)
CIUSSS	Centre Intégré Universitaire de Santé et de Services Sociaux (Integrated University Heath and Social Service Centres)
ConGT	Constructivist grounded theory
CP	Cerebral Palsy
CPJE	Centres de protection de l'enfance et de la jeunesse (Centres for the protection of children and youth)
CPMHS	Cyclical Process Model of Help-Seeking
CRSSS	Health and Social Service Council
CSSS	Centre de santé et de services sociaux (Health and Social Services Centre)
GT	Grounded Theory
HCP	Health Care Professional(s)
ICIDH	International Classification of Impairments, Disabilities, and Handicaps
ICF	International Classification of Functioning of Functioning, Disability, and Health
ICF-CY	ICF-Children and Youth
ID	Intellectual Disability
JLS	Journey of Ladders and Snakes
LSN	Local Service Network
MSSS	Ministère de la Santé et des Services Sociaux (Minister of Health and Social Services)
MSW	Master of Social Work
ND	Neurodisability: Brain-based diagnoses such as autism spectrum disorders, cerebral palsy, intellectual disabilities, epilepsy
PALS	Participation and Activity Limitation Survey
PPH	Processus de production du handicap (the handicap creation process)
QC	Québec
SI	Symbolic Interactionism
TD	Troubles Neurodéveloppementaux (Neurodisability)
WHO	World Health Organization

Dedication

This dissertation is dedicated to the mothers and fathers who gave of their time so generously, and who shared their very personal experiences so graciously.

Thank you.

Acknowledgement

"Knowledge is, in the end, based on acknowledgement." - Ludwig Wittgenstein

I am immensely grateful and thankful for the amazing gift of knowledge that has been imparted to me through this incredible doctoral journey. It has come to me in so many ways, none the least of which is the loving support that has fed my soul.

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May I, in turn, be the support to others that you have all been to me.

Abstract

Help-seeking is an ongoing endeavour for mothers and fathers of children with neurodisabilities (ND), yet little is known about what their seeking process entails: the mechanisms, structures, and interpersonal engagements that coincide during their quest to seek help. Further, current knowledge about ‘parents’ of children with ND, stems from research conducted with samples composed largely of mothers, thus what is known about parents is more precisely about mothers, lacking the perspectives and experiences of fathers. This manuscript-based social work doctoral dissertation was designed to explore how mothers and fathers of children with ND seek help, for their child and for themselves, within both informal (e.g., family, friends, neighbours), and formal (e.g., pediatric hospitals and rehabilitation centers, health and social service organizations) networks of support. It is composed of six chapters, two of which are manuscripts that report findings related to the Constructivist Grounded Theory study on help-seeking, being prepared for submission in journals of qualitative social work research, and disability.

The first article describes the *Journey of Ladders and Snakes*, the substantive theory that emerged from the analysis of interviews conducted with 6 mothers and 6 fathers (representing 6 co-parenting dyads) of children between the ages of 8 and 15 years. The theory characterises help-seeking as an ongoing journey that is focused primarily on mothers and fathers seeking for their child, through complimentary roles that reflect their personalities, personal preferences, and skillsets. The article describes elements that facilitate seeking (parental transformation, privilege, complementarity, relationships), as well as those that render seeking more challenging (negative encounters with professional helpers, difficulty navigating formal support networks, and gendered support availability).

The second article describes a *Cyclical Process Model of Help-Seeking*, a practical representation of the substantive theoretical knowledge that emerged from the study. The model depicts help-seeking as a reoccurring process that involves three elements: (1) mothers and fathers identifying that a situation is one they are unable to deal with themselves (one that is current, in the near future or anticipated later), (2) a process of active seeking (within informal and formal networks, online, social media), and (3) a period of settling back into family life (adjusting and moving on). Help-seeking is identified as a cyclical process that is unique to each need, that reoccurs along a continuum of time during which needs change, and that is characterized by improvement in parent knowledge and familiarity with the seeking process given their relatively fixed roles.

Implications for practice, policy, and future research are presented in the final chapter followed by a general conclusion.

Résumé

La recherche d'aide est un effort continuel pour les mères et pères d'enfants atteints de troubles neurodéveloppementaux (TN), pourtant, très peu est connu de ce que comporte leur processus de recherche: les mécanismes, structures et engagements interpersonnels qui coïncident lors de leur recherche d'aide. De plus, les connaissances courantes sur les « parents » d'enfants atteints de TN proviennent principalement d'études portant sur des échantillons de recherche composés majoritairement de mères. Par conséquent, ces connaissances sur les parents sont essentiellement des connaissances sur les mères, occultant ainsi les perspectives et les expériences des pères. Cette thèse de doctorat en travail social composée d'articles vise à explorer de quelle façon les mères et pères d'enfants atteints de TN cherchent de l'aide pour leur enfant et pour eux-mêmes, tant dans des réseaux de soutien informels (p. ex. les familles, les amis et amies, les voisins et voisines) que formels (p. ex. les hôpitaux pédiatriques et les centres de réadaptation, les organismes de la santé et des services sociaux). La thèse compte six chapitres, deux d'entre eux font état des conclusions d'une étude sur la recherche d'aide axée sur l'approche constructiviste de la théorie ancrée (ACTA). Ces chapitres sont préparés aux fins de publication dans des revues de recherche qualitative en travail social.

Le premier article présente la recherche de doctorat empirique et décrit le *Parcours des échelles et des serpents,* une théorie concrète dégagée de l'analyse des données d'entrevues réalisées avec six mères et six pères (correspondant à six dyades co-parentales) d'enfants âgés entre huit et quinze ans. Cette théorie caractérise la recherche d'aide comme un parcours continu axé essentiellement sur la recherche d'aide par les mères et les pères pour leur enfant, par une complémentarité de rôles qui reflètent leur personnalité, leurs préférences personnelles et l'ensemble de leurs compétences. L'article définit des éléments

qui facilitent la recherche d'aide (la transformation parentale, les privilèges, la complémentarité, les relations), ainsi que d'autres qui rendent la recherche plus difficile (des rencontres négatives avec des aidants professionnels, la navigation difficile des réseaux de soutien formels et la disponibilité du soutien sexospécifique).

Le deuxième article présente et décrit le *Modèle de processus cyclique de la recherche d'aide*, une représentation pratique de la connaissance théorique dégagée de l'étude. Le modèle définit la recherche d'aide comme un processus récurrent qui comprend trois éléments : 1) une reconnaissance par les mères et pères qu'une situation donnée les dépasse (une situation courante, imminente, ou anticipée), 2) un processus de recherche active (au sein de réseaux informels et formels, en ligne, sur les médias sociaux) et 3) une période de reprise de la vie de famille (ajustement et « tourner la page»'). La recherche d'aide est définie comme un processus cyclique unique à chaque situation, qui se répète sur un continuum de temps au cours duquel les besoins changent et qui se caractérise par une augmentation des connaissances des parents et de leur familiarité avec le processus de recherche en fonction des rôles qui demeurent relativement fixes.

Les implications pour la pratique, les politiques et les projets de recherche à venir sont résumées dans le dernier chapitre, suivi d'une conclusion général.

Author Contributions and Originality

This doctoral dissertation comprises original material produced by myself, Gina Glidden, in the course of my doctoral research project entitled: *The Journey of Ladders and Snakes: Help-seeking among mothers and fathers of children with neurodisabilities*. I designed the study, recruited and interviewed participants, analyzed the data, and wrote each chapter presented herein. Dr. Lucyna Lach, my doctoral supervisor, and Drs. Sylvie Tétreault, and Tara Flanagan, members of my doctoral committee, are co-authors on the two manuscripts included in this dissertation. They provided guidance and mentorship throughout the research proposal and ethics application process, and they read, reviewed and provided feedback on each component of the dissertation.

The initial sample for this study was partially recruited through the database from a study entitled *CIHR Team in Parenting Matters! The Biopsychosocial Context of Parenting Children with Neurodevelopmental Disorders in Canada*. Prior to beginning my doctoral work, I worked as a research assistant on the policy sub-study of this project: I conducted a pan-Canadian environmental scan of income support, respite services and case management models available to parents of children with neurodevelopmental disorders across Canada, and I recruited and interviewed key informant policy makers, program managers from three provinces about policy and programs creation. During the course of my doctoral research, I also provided some qualitative data analysis of interviews previously conducted with parents within the clinical sub-study of the project.

I acknowledge that no material presented in this dissertation has been published elsewhere, except for cited material that has been referenced as such. Manuscript one, the *Journey of Ladders and Snakes*, is being prepared for publication in the Journal of Qualitative Social Work. Manuscript two, the *Cyclical Process Model of Help-Seeking* is being prepared for publication in the Journal of Research and Practice in Intellectual & Developmental Disabilities.

Chapter 1: Introduction

Introduction to Thesis Topic

This dissertation is about help-seeking as it pertains specifically to mothers and fathers who co-parent a child with a neurodisability (ND). Mothers and fathers whose child has a diagnosis of ND (e.g., autism spectrum disorders, cerebral palsy, intellectual disabilities, epilepsy) face challenges, demands, and responsibilities related to the impact the diagnosis has on their child's health, functional capacities, and participation in every day activities. These challenges extend to their own mental and physical health, their relationship as a couple and/or co-parents, and on and the daily functioning of the family. For decades, scholars have investigated these impacts, revealing the extreme psychological and physical strain that parenting children with ND places on parents (Kenny & McGilloway, 2007; Lach et al., 2009; Leonard, Johnson, & Brust, 1993; McCann, 2017; Trivette, Deal, & Dunst, 1986). Scholars have also identified that quality help, when perceived as helpful, counters these negative impacts (Al-Gamal & Long, 2013; Hassall, Rose, & McDonald, 2005; Kilic, Gencdogan, Bag, & Arican, 2013; Wang et al., 2013). Thus, for parents of children with ND, receiving the appropriate type of help is an important contributor to their and their child's quality of life.

Help-seeking is a natural necessity of human life. At some point in our lives, we will all have encountered situations that have challenged our abilities, that have been trying and difficult, and that have left us feeling overwhelmed. In response to these challenges, we may each have created our own relationship to help and help-seeking: What do I need? Who can help me? Where do I go? We may all have experienced the vulnerability of *needing* help, the trepidation of *asking* for help, and the uncertainty of *waiting* for help, *wondering* if we would get it, from *where* it might come, and *what* it might look like. We may recall the sense of relief we felt from *receiving* help when it came, the dismay that came crashing when we were unable to get it, and what adjusting to either of these scenarios meant to us and our well-being as we participated in the world around us.

For some parents of children with ND, help-seeking starts before the birth of their child, or immediately following the birth, when something atypical in their child is detected. For other parents it stems from observations they have made themselves, or from someone in their social network who has identified that something seems to be different about their child. For most parents, the starting point of help-seeking triggers a journey that will be lifelong (Thomson, Glasson, Roberts, & Bittles, 2017). What distinguishes the help-seeking of parents whose child has ND from parents whose child is developing according to typical norms, is that the help-seeking represents an added layer of complexity. While parents of children without ND encounter the challenges associated with their child meeting developmental milestones, parents of children with ND experience the added concerns associated with their child perhaps not meeting those developmental milestones at all. Typical transition periods associated with children aging and developing (e.g., starting kindergarten, entering primary and high school, post-secondary education and career planning), may look very different for children with ND, who may require specialised assistance. While parents of children without ND may wonder about their child's post secondary education, and about their future career plans and personal life as they enter adulthood, parents of children with ND wonder about whether or not their child will be able to live independently, where their child will live, and who will take care of them when they, themselves, are no longer around to do so. Thus, while parents of children with ND may go through similar life transition periods with their child, as do parents of a neuro-typical child, what these transition periods look like, and how they are experienced is different, and as such their help-seeking journey is also different.

It is this help-seeking journey that is unique to parents seeking help for their child with a ND, and for themselves, within both informal and formal networks of support that is the focus of this doctoral dissertation.

Research Rationale

Current inquiries about help-seeking have contributed to a literature base that describes personal, societal, and environmental factors that contribute to individuals' decision-making process about engaging in help-seeking or not. These areas of research include: health conditions and perceptions about severity (Fenn, 2016), personal attitudes (Morawska & Sultan, 2016), motivations and intentions (Cohen, 1999; White, Clough, & Casey, 2018), age and gender (Eagly & Crowley, 1986; O'Mahony & Hegarty, 2009), culture and immigration (Ben-Cheikh & Rousseau, 2013; Kang-Yi et al., 2018; Lau & Takeuchi, 2001). While these factors are important in shaping the understanding about pre-seeking, little research has been undertaken to understand the actual seeking process, or what that process is like for parents of children with ND. Existing literature provides insights about what 'being' a parent of a child with ND is like, and about how 'parenting' these children is experienced (Johnson, O'Reilly, & Vostanis, 2006; Lach et al., 2009; McCann, 2017; Thullen & Bonsall, 2017). While this literature has added to the knowledge about the positives and negatives of how parents experience the help they receive, little research has focused on the actual help-seeking process they undertook. Some scholars have investigated parenting relationships, co-parenting styles, and the manner in which parenting roles are established between parents (McNeill et al., 2014; Saini et al., 2015; Sim, Cordier, Vaz, & Falkmer, 2016).

However, inquiries about what these look like in a help-seeking context are scarce. In addition, most existing literature about parents and parenting emerges from studies that engaged mostly with mothers (Meadan, Stoner, & Angell, 2015; Willingham-Storr, 2014). Therefore what is actually known about parents and parenting, is more accurately knowledge about mothers and mothering.

Thus, while existing scholarship elucidates crucial elements about parenting a child with ND, and about parents' experiences of the supports they receive (or don't receive), what is missing is knowledge about how parents seek the help they need.

Research Objectives

To bridge this gap in knowledge, the objective of this doctoral research was to develop a theoretical understanding of help-seeking that stemmed from the experiences of both mothers and fathers of children with ND, that would highlight not only the *process* of help-seeking but also the introspective nature of decision-making around help-seeking: how mothers and fathers determine *who* will seek, for *what* type of help, and under what circumstances (*when*). To do so, my research was guided by the following research question:

How do mothers and fathers who co-parent their child with ND seek help for their child and for themselves from within their informal and formal networks?

Organization of Thesis

This manuscript-based dissertation in the field of social work combines all the elements required from a traditional dissertation, organized around two manuscripts that are being prepared for submission to qualitative journals. The dissertation is organized follows:

Chapter 1 is the introductory chapter to the dissertation and serves to introduce help-seeking, the topic of the doctoral research, and to describe the rational and objectives of the research. As well, details about how the dissertation is organized are presented.

Chapter 2 entitled *Background: Help-seeking in context*, presents some of the background information deemed necessary for readers to understand the context in which help-seeking takes place. This chapter is divided into two sections. In *Section I: Conceptualizing help-seeking*, the rational for using the term help-seeking, and the utilization of a non-categorical approach to the research study are explained. Shifting perspectives about health and disability, and legislation about disability and human rights are presented, and the prevalence of disability in Canada is provided. In *Section II: Locating help-seeking,* empirical literature about parents of children with ND that elucidates some of the reasons why parents seek help is introduced, a buffering and main effect model of social support is presented, and the ABC-X model of stress appraisal is introduced. Then, three networks of support from which parents seek help: informal, formal, and community are presented within the context of a brief history of health and social services in the province of Québec. Finally, empirical research about help, and some help-seeking models that inform our understanding about help-seeking, are presented and critiqued.

Chapter 3, *Methods*, describes constructivist grounded theory, the methodological approach utilized in this study, and some of the theoretical frameworks that underpin it. In addition, the chapter describes the methods that were used in the study: ethical considerations, sampling, recruitment, data collection, and data analysis. As well, it presents rigor in qualitative research, and some elements about how qualitative research is evaluated.

Chapter 4, *The journey of Ladders and Snakes: Help-Seeking Among Mothers and Fathers of Children with ND*, is the first manuscript of this dissertation. It describes the empirical study about how parents of children with ND seek help, and presents the experiential elements of the substantive theory that was constructed. Recommendations for practice and for research are made, and limitations of the study are presented.

Chapter 5, *The Cyclical Process Model of Help-Seeking*, is the second manuscript of this dissertation, and describes the stages that mothers and fathers of children with ND undertake in their process of seeking help. Recommendations for practice and for research are made, and limitations of the model are presented.

Chapter 6, is the final chapter of the dissertation. It presents a general discussion that ties points of the dissertation together. It also summarizes the general implications for social work practice and for policy, and the recommendations for future research that were presented in chapters 4 and 5. A general conclusion brings closure to the dissertation.

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Chapter 2: Background: Help-Seeking in Context

> *Ok. So, for me, it was really, un cri du coeur. Je sais plus quoi faire, j'ai besoin d'aide, je ne sais pas ou aller, ou commencer, comment m'y prendre. Il y a, à la fois trop de, de, d'intervenants et pas assez, dans le sens qu'on ne sait pas où ils sont. So for me, seeking help is like, yes, I can't do it alone.* (Simone[i])
>
> (*Ok. So, for me, it was really a cry from the heart. I no longer know what to do, I need help, I don't know where to go, where to start, how to go about it. There is, on the one hand, too many, many interveners, and not enough, in the sense that we don't know where they are. So for me, seeking help is like, yes, I can't do it alone.)*

This dissertation is about help, and how mothers and fathers of children with ND seek it. As the opening quote exemplifies, help-seeking stems from one's very core. It emanates from being challenged beyond one's own capabilities and through recognizing the impossibility of moving forward unattended. It comes from yearning for direction and guidance, and from a visceral acknowledgment that one's attempts to do what is needed are not enough. The purpose of this chapter is to situate the help-seeking of mothers and fathers of children with ND within the context in which it unfolds in the province of Québec. It provides a theoretical and empirical overview of the literature about help-seeking, thereby situating the dissertation in the context of what is already known. This chapter is divided into 2 sections. The first section, *Conceptualizing help-seeking*, will begin with a brief explanation about how the term 'help-seeking' was adopted in this doctoral research. Next,

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[i] Pseudonym

the term neurodisability and the non-categorical approach of this dissertation will be described, and an overview of select theoretical frameworks related to health and disability that have paved the way for help-seeking as it is experienced by parents of children with ND will be presented. Disability will be located within a human rights lens, and some statistics about the prevalence of ND will be provided. In section 2, *Locating help-seeking*, some empirical literature about parenting children with ND that illuminates some of the reasons why parents seek help and how they experience seeking will be described, help-seeking will be located within a Buffering and Main Effect Models of Social Support, and the ABC-X model of stress appraisal will be introduced. Next, the informal, formal, and community networks of support in which parents located and experienced help-seeking will be described. Finally, empirical literature about help and help-seeking will be presented and critiqued.

Section I: Conceptualizing Help-Seeking

Deciding on the Term

The decision to utilize the term *help-seeking* for this doctoral research stems from a consultation that was had with parents of an advisory committee who were invited to guide and offer insight on the preliminary development of an interview guide for a study on support needs of parents who had children with ND[ii] (all mothers of children who were post diagnosis). The study was being developed through the School of Social Work at McGill University. Part of the discussion was about the situations related to their child with an ND that they had experienced as challenging/difficult. This evolved into a discussion about whether, in response to these situations, they thought they needed ‘support’ or ‘help’. The question addressed to them was whether these terms were synonymous and interchangeable,

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[ii] *Support Matters: transitions and on-line support*

or if they were in fact, two different things. If they were different, how might each term be more accurately used? The consensus was that they differed, but were related. *Help*, they concluded, is what parents were requesting (or seeking) e.g., "Please *help* me". *Support* is what parents hoped they would receive once they sought *help* (types of help).

Words are important. As a doctoral researcher who is not a parent (of a child with ND), ensuring that the terminology being utilized was significant and meaningful to parents was imperative. Thus, in this doctoral research, their term, *help-seeking*, was adopted, with the understanding that it had significance for them, parents who were hoping for the relief that various types of support would offer.

Non-Categorical Approach

My dissertation was designed using a constructivist grounded theory (ConGT) approach to develop a theoretical understanding of how mothers and fathers who co-parent a child with a neurodisability experience seeking help for their child and for themselves within formal and informal networks of support. The term neurodisability refers to:

> ... a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour (Morris, Janssens, Tomlinson, Williams, & Logan, 2013, pp. 1105-1106).

I chose a non-categorical approach to my research partly based on recent findings in the field of disability that emphasize functionality as a greater indicator of child and family well being over diagnosis (Miller, Shen, & Mâsse, 2016; Ritzema, Lach, Rosenbaum, & Nicholas, 2016). A non-categorical approach suggests that there are commonalities in the functional capacities of individuals regardless of their diagnosis (Miller et al., 2016). For example, while a child with cerebral palsy or autism spectrum disorder may differ in terms of diagnoses and the physiological expression of their diagnosis, a non-categorical view suggests they may share similar functional challenges despite the particularities of their physiological condition. This approach aligns with the International Classification of Functioning of Functioning, Disability, and Health (ICF) (World Health Organization, 2007) in which disability is understood through its interrelated personal, environmental and structural factors that exist within a larger socio-environmental context. This also aligns with the underlying reasons why help is often sought for children with ND; helping them gain and/or maintain capacities that will open up the greatest inclusive participation as possible. In addition, a non-categorical approach allowed for the inclusion of parents whose children had not received a diagnosis and who would otherwise be excluded from participating and sharing their experiences. As such, rather than focus on specific diagnoses, the theory developed through my research emerged from parents of children with diverse brain-based developmental diagnoses, analyzed together, in order to gain insight about *help-seeking* based on common experiences rather than diagnosis-specific experiences. In the writing of this dissertation, it was important to me to remain true to the full concept of a non-categorical approach. As such, I have decided to not reveal the specific diagnoses of each parent's child. While I am aware of the children's diagnoses through my discussions with parents and through data provided by parents in a demographic questionnaire, herein I provide, instead and when pertinent, details about the functional capacities of the parent's children.

Health and disability

The contexts surrounding the 'action' that mothers and fathers engage in through their help-seeking have evolved through time as the definitions, constructions, and societal perceptions of disability have changed. Until the mid-1970s, understandings of health and disability were firmly embedded within the predominant ontological stance of a medical model that pathologized difference, and focused on the treatment and cure of human conditions that departed from the accepted norm (Berghs, Atkin, Graham, Hatton, & Thomas, 2016). Herein, the attention was on managing the individual who embodied the undesirable conditions, and the aim of intervention (help) was diagnosing, (determining what was wrong), rehabilitating and fixing (the individual), and preventing (further/future) impairment. A biospychosocial model emerged out of a criticism of the medical model that "...leaves no room within its framework for the social, psychological, and behavioural dimensions of illness..."(Engel, 1977, p. 394). It shifted the focus away from the individualization of disability by recognizing the important interactions that existed between physical health and other equally important facets of an individual's total health: attributes of the individual himself, characteristics of his social environment, and aspects of the support networks available to him (Wade & Halligan, 2017). It is important to note that a biopsychosocial approach to understanding disability does not negate the physiological component of health. On the contrary, the biology behind illness is crucial to recognize and address. The important piece to keep in mind is that the biological occurs within a context that includes personal, environmental and societal aspects (Wade & Halligan, 2017).

International Classification of Functioning, Disability and Health

Perhaps the most recognized model that has addressed the intersections of health and disability is the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001). It offers a holistic perspective that recognizes the importance of an individual's physicality (medical model) within an integrated approach that also accounts for the individual's social and environmental location. The WHO defines disability as "... an umbrella term for impairments, activity limitations and participation restrictions" (World Health Organization, 2007, p. 3). The interaction between an individual's health condition and their personal and environmental factors (e.g., societal attitudes, accessibility of transportation and public buildings, and quality of social supports) is shown in figure 1(World Health Organization, 2001). More specific to the elements of well-being for children and youth, the ICF-Children and Youth (ICF-CY) (World Health Organization, 2007), encompasses elements of the ICF that may influence children's participation in the social world and their life experiences as they evolve from infancy to childhood to adolescence to young adulthood.

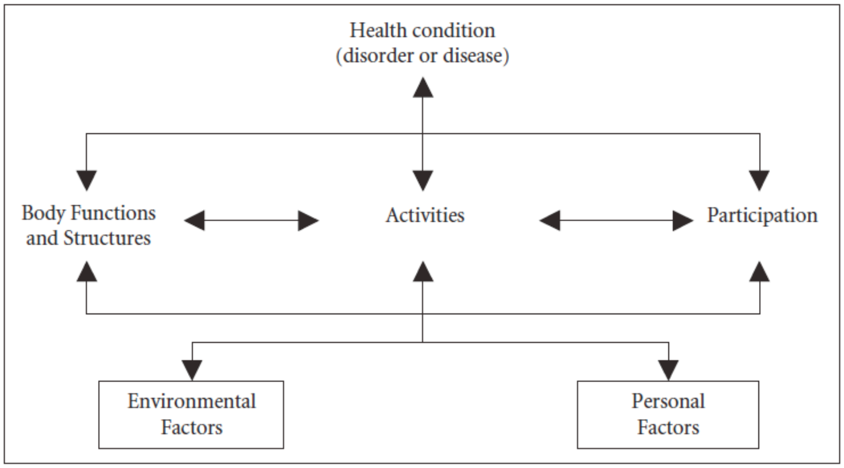

Figure 1: Interactions Between ICF Components (World Health Organization, 2001)

Processus de production du handicap (PPH)[iii]

In the province of Québec, a social-environmental model emerged in the 1990's that shifted the medical concept of disability into one that included environmental and social factors. The preliminary framework for the PPH, based on concepts held in the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (WHO, 1980), was piloted within physical rehabilitation centres that offered support to individuals with disabilities in that province. The PPH introduced a fresh, holistic nomenclature highlighting a vast spectrum of 'life habits' related to function: nutrition, fitness, personal care, communication, residence, mobility, responsibility, family relations, interpersonal relations, community, education, employment, recreational, and other habits, to rehabilitation centres. Added to these were environmental factors: social, cultural and physical dimensions (Fougeyrollas, 1995, p. 147). These informed the focus of an individual's rehabilitation process, thereby concentrating on areas of function that were relevant to them. Based on the success of the Québec model, representative members of the Office des personnes handicapées du Québec, a Québec-mandated organization that oversaw the social integration of individuals with disabilities in Québec (a brief description of the OPHQ is presented on page 49), were invited to consult with WHO among other world experts in the redefining of the section of the ICIDH related to handicap. While less known outside of the province of Québec, the PPH is currently at the heart of functional evaluations for individuals in Québec, and is utilised, in collaboration with them and based on their priorities, in the production of their intervention plans.

The help-seeking experience of mothers and fathers of a child with ND would have been significantly different through a strictly medical model where the emphasis would have

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[iii] Translation: the handicap creation process (Fougeyrollas, 1995, p. 147)

centered on help-seeking engagements with medical and rehabilitation specialists whose work and interaction with the child would have been geared toward diagnosis, deciding how to fix the physical problem and implementing actions to rehabilitate them into as "normal" a healthy body as possible. While the physicality of ND remains important, the ICF-CY and the PPH have shifted the focus of the readaptation process. Parents seeking help for their child with ND and for themselves continue to seek information and knowledge about the diagnosis of their child, and the impact they can expect the diagnosis to have of their child's function. However, the shift in perspective implies an added psychosocial component to help-seeking that focuses on increasing functionality by examining how the environment could be changed to increase the participation of their child within his environment, at the juncture of his diagnosis.

Disability and Human Rights

The fundamental human rights of individuals with disabilities in Canada are clearly stipulated in chapter 15 of the *Canadian Charter of Human Rights and Freedoms* (Government of Canada, 2018a), and in chapter 10 of the *Charte des droits et libertés de la personne* (Publication Québec, 2018), for the province of Québec. For children from First Nations communities, *Jordan's Principle* (Government of Canada, 2018b), ensures that jurisdictional disputes between federal, provincial, and territorial governments do not prevent a child from obtaining needed services, stating that whichever government is first contacted about the care needs of a child is required to pay for the necessary treatment and services without delay or interruption. Federal, provincial, and territorial governments will settle the accounts after services have been delivered (Government of Canada, 2018b). Further, Canada has also acknowledged the rights of children with disabilities to the assistance that will promote their individual developmental health in its ratification of two significant Conventions brought forth by the United Nations:

1) Article 23.3 of the *UN Convention on the Rights of the Child* (United Nations, 2018), ratified in 1991, pays particular attention to the rights of children with disabilities:

> ...assistance … shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development (2018, p. 7)

2) The *UN Convention on the Rights of Persons with Disability* (United Nations, n.d.) ratified by Canada in 2010, stipulates the importance of non-discriminatory access to equitable health services and to:

> Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons (United Nations, n.d., Article 25 (b)

> States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programs, particularly in the areas of health, employment, education and social services, in such a way that these services and programs:
>
> (a) Begin at the earliest possible stage...,
>
> (b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas (United Nations, n.d., Article 26.1 (a & b))

These documents set the standard that Canada should aspire and adhere to. There is no 'legal' obligation for Canada per se. However, individuals can appeal to human rights tribunals if they feel that the rights have been violated.

Prevalence of Children with ND

Determining the number of Canadian children with ND is challenging, due in part to varying conceptualizations of disability and ND, and to different methods of locating these children in the general population (Miller, Mâsse, Shen, Schiariti, & Roxborough, 2013). The 2012 Canadian Survey on Disability (Arim, 2015) reports that of the approximate 3.8 million (13.7%) Canadians aged 15 years and over who reported having a disability, 195,720 (4%) were children and youth between the ages of 15-24 years, with 0.6% reported having a developmental disability. While this survey provides a general picture of disability and developmental disability in Canada, it does not include children younger than 15 years of age, an age range in which neurodisabilities are typically located. Based on data from the Participation and Activity Limitation Survey (PALS), a post-census self-report survey that contains data on children and adults with disabilities, Miller et al. (2013) estimate that of the 174,810 Canadian children aged 5-14 with a disability, 128,530 (73.5%) report a ND. Arim et al. (2017) report on findings from a population-based healthcare utilization study conducted in British Columbia in 2006, and state that from n=183,041 children between the ages of 6-10 years, n=15,219 (8.3%) have a diagnosis of ND. In a study, *l'Enquête québécoise sur l'expérience des parents d'enfants de 0 à 5 ans*, a study conducted by l'Institut de la statistique du Québec (Québec), in 2015, data was collected from n=14, 905 (65.7%) mothers and fathers of (N=23,693) children between the ages of 0-5 years in sixteen regions in the province of Québec. 4.5 % had a child with a diagnosis of global developmental delay and 12.2% had a child with a developmental diagnosis (ADHD, ASD, pervasive developmental disorders) (Lavoie, 2017).

These prevalence rates suggest that the proportion of children with ND in Canada is consistent to that reported in a review conducted by Miller et al. (2016). Variability in prevalence rates makes it difficult to know what proportion of the child or general population is seeking help and needing support at any particular point in time. Ideally, allocation of budgets should be based on some understanding of the scope of the need. However, in Canada, this has not yet been unequivocally established.

Section II: Locating Help-Seeking

To attend to the research question, *How do mothers and fathers who co-parent their child with ND seek help for their child and for themselves from within informal and formal networks?* it is important to understand why they seek, what they seek for, and where they seek. In this section empirical studies that explore parents' emotional, psychological and physical responses to caring for their child with ND will be described, and they will help to frame a discussion about *why* parent seek support, *what* types of support they seek to assist them, and *where* they locate that support.

Parents and parenting a child with ND

A substantial empirical scholarship exists regarding parents of children with ND that sheds light vis-à-vis why, what, and where they might seek help, and about how they experience the support sought, in terms of access, availability and fit. Numerous reasons and circumstances exist that may drive parents of children with ND to seek help. Caring for a child with ND is a long term endeavour (Thomson, Glasson, Roberts, & Bittles, 2017) that places extreme psychological and physical strain on parents who often rely on assistance from formal and informal networks to meet their child's daily caregiving needs (Brehaut et al., 2004; Garner et al., 2013; Lach et al., 2009; Lee et al., 2009; Thurston et al., 2011). Compared to parents of typically developing children, parents of children with ND experience higher levels of depression (Blankenship, 2010; Grant et al., 2013; Kilic, Gencdogan, Bag, & Arican, 2013; Singh, Ghosh, & Nandi, 2017), anxiety (Grant et al., 2013; Kilic et al., 2013), and stress (Grant et al., 2013; Theule, Wiener, Rogers, & Marton, 2011; Wang et al., 2013), related to parenting their child. As well, they experience compromised physical health (Bella, Garcia, & Spadari-Bratfisch, 2011; Cantwell, Muldoon, & Gallagher, 2014; Gallagher & Whiteley, 2013; Garner et al., 2013; Lach et al., 2009), increased family tension and dysfunction (Chen, Clark, Chang, Liu, & Chang, 2014; Hsiao, 2014) and decreased marital satisfaction (Garner et al., 2013; Kilic et al., 2013; Lach et al., 2009; Sim, Cordier, Vaz, & Falkmer, 2016).

Many parents experience the time of diagnosis as very stressful (Croot, Grant, Mathers, & Cooper, 2012), a time that is accompanied, for some, by feelings of grief related to their sense of loss about the child they expected and did not receive (Garner et al., 2013; Thomson et al., 2017), which is sometimes accompanied by guilt for having those thoughts in the first place (Thomson et al., 2017). Raising a child with a ND can cost three times more than raising a typically developing child (Harris, 2008) and parents of children with a ND experience more difficulty acquiring paid employment and may be more likely to be living in poverty (Anderson, Dumont, Jacobs, & Azzaria, 2007; Stabile & Allin, 2012). Contributing to the personal reasons that may lead a parent to seek help is the shift in service delivery models from one that was previously medical to one that is family-centred (Brehaut et al., 2004; Trute & Hiebert-Murphy, 2013). This shift has recognized parents as vital contributors to their child's health and development care plans. Although empowering, this approach may also elevate demands on parents as they are increasingly expected to be involved in advocacy, service and treatment schedule coordination, and must liaise with various service provision professionals and organizations involved in their child's care (Brehaut et al., 2004; Drummond, McDonald, MacKenzie-Keating, & Fleming, 2004; Mullins, Aniol, Boyd, Page, & Chaney, 2002).

Despite the impact of having a child with ND on parents' emotional, physical and financial well-being, empirical literature points overwhelmingly to parents' help-seeking for their child as something that is first and foremost, often foregoing their own needs (Eapen et al., 2017; Thomson et al., 2017). Parents seek a variety of help that will not only assist them to understand their child's developmental condition but also assist them in increasing and maintaining their child's functional capacities. Parents report needing accurate information that will help them understand their child's condition (Gilmore, 2018), and the impacts a diagnosis may have on the child and family (Kirk, Fallon, Fraser, Robinson, & Vassallo, 2015). In seeking resources, therapies and interventions for their child, parents hope for information that is tailored to the specifics of their own child (Gibson, Kaplan, & Vardell, 2017). They report needing to feel they are listened to and cared for by help-providers (Doig, McLennan, & Urichuk, 2009; Strunk, Pickler, McCain, Ameringer, & Myers, 2014), and that their opinions about, and experiences with their child are validated and valued (Prezant & Marshak, 2006). Parents also report the need for coordination between help-providing sources (e.g., health and mental health) (Strunk et al., 2014; Whitehurst, 2012) so they run seamlessly and without repetition (Prezant & Marshak, 2006).

In general, parents of children with ND do not experience the support offered by formal networks favourably, reporting instead that the existing support is both lacking in quantity, meaning the support exists but not in sufficient quantity to meet the needs of all eligible individuals (Gibson et al., 2017; Thomson et al., 2017; Vohra, Madhavan, Sambamoorthi, & St Peter, 2014), and in quality (Nowak, Broberg, & Starke, 2013; Vohra et al., 2014), meaning the support that exists might not always adequately fulfill their needs. This translates to parents and children waiting for their turn to come up on a waiting list, for support they are eligible for but for which there is more demand than supply (Connolly & Gersch, 2013). Waiting is experienced as lengthy and difficult (Connolly & Gersch, 2013). It also results in parents and children utilizing support that is available to them, despite the lack of 'fit' with what they actually require (Boulter & Rickwood, 2013; Connolly & Gersch, 2013). In addition, access to support often lacks coordination (Strunk et al., 2014; Vohra et al., 2014; Whitehurst, 2012), is reported as laborious and demanding (Nowak et al., 2013), and as difficult not only in terms of locating it (Doig et al., 2009; Eapen et al., 2017; Thomson et al., 2017), but also in terms of meeting eligibility criteria that are stringent and thus limiting (Doig et al., 2009; Vohra et al., 2014).

When support is located and accessed, some parents describe difficulties associated with the time required to manage and coordinate the support (e.g., respite schedules) between the support provider and parents' schedules (Doig et al., 2009; Thomson et al., 2017). Thus, in cases where a support requested to help reduce stress is available to a parent, parents report an increase in stress associated with the amount of time related to organizing and scheduling (Doig et al., 2009; Thomson et al., 2017). When support is perceived as needed but also as unavailable, parents report frustration (Doig et al., 2009), a sense of diminished quality of life for their child, themselves, as well as for their families (Gibson et al., 2017), and a sense of vulnerability for having disclosed their need (Doig et al., 2009; Vogel & Wester, 2003) and of having been refused the requested support (Doig et al., 2009).

Buffering and Main Effect Models of Social Support

One of the main areas of inquiry regarding social support stems from an interest in understanding how it could either *buffer* stressful situations, or as act as a *main effect* between stress and well-being outcomes (House, Umberson, & Landis, 1988). Studies today continue to measure social support as a coping mechanism in terms of its relationship to stress and other negative health outcomes. In this section, the *Buffering* and the *Main Effect Models* of social support will be introduced and how each relates to social support for parents of children with ND will be presented. The ABC-X (Hill, 1958), and the double ABC-X

(McCubbin & Patterson, 1983) models of stress appraisal will also be presented within the buffering model.

Buffering Model

The *buffering model* posits that social support will have an impact on health and wellbeing primarily in situations in which individuals are facing stress or adverse life events (Cohen & Wills, 1985). As a buffer, social support decreases the effect of a stressor on an individual's outcome, behaving as a moderator between the stressor and the outcome (Baron & Kenny, 1986). A basic premise of the stress-buffer model is that an individual has appraised a situation or life event as stressful, one for which an immediate response on their part is necessary, yet unavailable, due to their own individual personal factors. While the appraisal of an individual event as stressful may not be enough to seriously impact health, the accumulation of such events and the incapacity of an individual to resolve them may (Cohen & Wills, 1985). Some individuals have the intellectual and behavioural aptitudes and resources that allow them to manage situations that they have appraised as challenging but for others, the inability to cope can lead to negative psychological outcomes (Lazarus, 1993).

For parents of children with ND, the stressor can arise from a variety of circumstances that stem from having a child with an ND, while social support is one of the resources that impacts their ability to cope by buffering the effects of the stressor. For some parents, the time of diagnosis is a stressor, a time during which they consider informational social support from professionals to accept the diagnosis (Lin et al., 2009; Croot et al., 2012), and to increase their understanding of the diagnosis and facilitate their coping with expectations for the future (Samadi et al., 2012). Difficult child behaviours are also described as a source of stress that not only impact parents' well-being (Plant, 2007; Woodman et al., 2014), but also their family functioning (Moen et al., 2015). For these families, greater social support serves as a buffer between the appraised stress resulting from the child's difficult behaviours, and the negative personal and familial outcomes. Stress also increases for parents during times of transition when responsibilities for the care of their child increase (e.g., when children transition out of pediatric care into adult care (Kirk et al., 2015). For these parents, emotional and information support are considered to be beneficial (Kirk et al., 2015). While the help mothers and fathers seek may help buffer the effect of situations they have appraised as stressful, why is it that one situation seems overwhelming for one parent, and thus is deemed unmanageable, and not to another? How do parents determine when a situation has surpassed their own coping capacities?

Stress Appraisal

As we have seen, the appraisal of a situation as stressful is often the starting point of the help-seeking process, and a fundamental component of the buffering model. Individuals appraise life events through a process of *cognitive appraisal* (Lazarus, 1999) during which meaning is ascribed to the event (*primary appraisal*) (e.g., is it harmful, will it impact my health, is it risky?), and during which an individual assesses what he can (or cannot) do about it (*secondary appraisal*) (Lazarus, 1999). One of the most referred to models of stress appraisal, the *Double ABC-X Model of Stress Appraisal* (McCubbin and Patterson, 1983), is based on stress appraisal within families, and originated from Hill's (1958) ABC-X Model of stress appraisal that, at its basis, examines the interaction between 3 factors that culminate in a situation being appraised as stressful or not stressful: a= stressor/life event (i.e.: the birth of a child with ND), b= family's resources (i.e.: social support), c= the appraisal the family attributes to event (the impact the birth may have on the family unit), and x= the ensuing crisis.

McCubbin and Patterson (1983) elaborated on Hill's Model (1958) in an effort to address the evolutionary aspect of coping with a crisis, as the authors believed that families continue to change and adapt following the passage of a crisis. Thus, their model took the *post-crisis* factors into account (see figure 2).

Whereas the *A* in Hill's (1958) model represented a stressor, the *aA Factor* (*The Pile Up*) in McCubbin and Patterson's model accounted for the accumulation of stressors that resulted from the passage of time (the original stressor, stressors related to life transitions, previous stressors, accumulated coping resources). The notion here is that each stressor will be experienced in a manner that incorporates one's internalized experience of previous stressors. So, while a stressor may be 'new', one's interpretation of its amplitude is determined in combination with that of older ones. A family may have experienced the time of original diagnosis of their child as a stressor (a), and every subsequent situation related to their child in terms of diagnosis, etc. will be felt in a way that accounts for their level of stress from previous such situations.

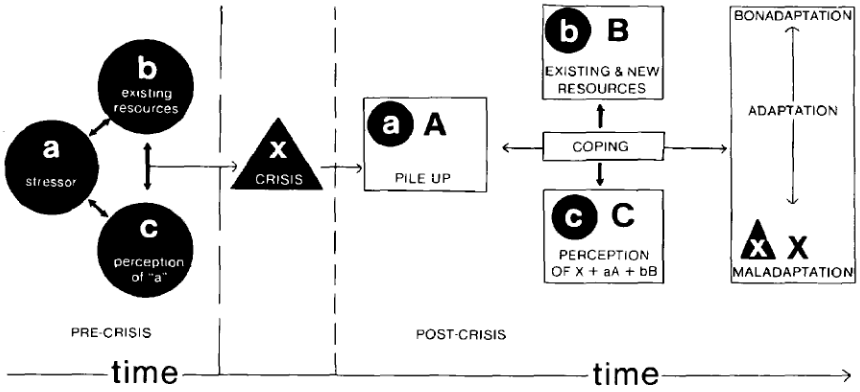

Figure 2: The Double ABC-X Model (McCubbin & Patterson, 1983: p. 12)

The *bB Factor* (*Existing and New Resources)* in the model represents the accumulation of capabilities that a family has with which to respond to a crisis; those that were part of the family's initial repertoire, as well as those that resulted from the family having coped with a crisis situation in the past. One of the main resources found within the *bB Factor* is social support (McCubbin and Patterson, 1983). Mothers and fathers of children with ND who have established supportive links within formal and informal networks are more impervious to the effects of crisis and more proficient at adapting to and moving on following a crisis. The *cC Factor* (*Perception of X + aA + bB*) represents the family's appraisal of the entire crisis, including the original stressor and any new stressor(s), the availability of previous and new coping resources, as well as the family's strategies for restoring a sense of balance within the family system. Rather than base the *xX Factor* (*Adaptation*) on the elimination of the family perturbation, as in Hill (1958), McCubbin and Patterson (1983), actually viewed such challenging family disruptions as opportunities for families to grow. As such, the *xX Factor* in McCubbin & Patterson (1983) relates to the manner in which a family has adapted to having appraised a situation or event as stressful rather than to the amount of crisis remaining within a family as a result of their appraisal of a situation or event as stressful as in Hill (1958).

The factors that contribute to parents appraising their situations as stressful or not differ from one set of parents to another, based on their own particular sets of circumstances (King, Zwaigenbaum, King, Baxter, Rosenbaum, & Bates, 2006). Thus, considering stress appraisal is important for social workers who work with parents of children with ND as not all parents will assess similar events in the same way.

Understanding what individual parents assess as stressful will help target the most appropriate (and available) social supports.

Main Effect Model

Contrasting with the *buffering model*, the *main effect model* suggests that social support impacts health and well-being outcomes not only in the face of a crisis but on an ongoing basis because of its reciprocal nature within an individual's informal social network and this contributes to an individual's overall sense of self and mastery (Cohen & Wills, 1985). The effects of *main effect* social support are internalized by individuals as feelings of self worth and wellbeing within an organized network that provides a sense of belonging and structure (Cohen & Wills, 1985). In addition, individuals who feel better about themselves may also engage in more positive health behaviours that consequently impact their susceptibility to illness (e.g., less smoking, more exercise, better eating habits). In this sense, social support's main effect is between the various circumstances (positive and/or negative) and outcomes (positive/negative) that an individual may encounter within his social support network.

Thus, for parents of children with ND, belonging to an informal social network may provide ongoing social support that can prevent unpleasant experiences that lead to adverse psychological outcomes (stress, depression, anxiety), all the while maintaining general well being (Cohen & Wills, 1985). One's perception of the availability of social support is a key factor in the *main effect model* as it may have an over-all impact on how one views life and on one's self esteem which then has an impact on one's proneness to illness (Cohen & Wills, 1985). This notion of *perception* is consistent with current studies that demonstrate that parents of children with ND who perceive their social support as effective, regardless of the quantity they receive, have better health outcomes than parents who may receive more social support but do not perceive it as helpful (Chen & Clark, 2007).

Being integrated within a social support network is fundamental to the *main effect model*, raising the question of how the model fits for individuals who are not part of a network, or for whom their network is not consistent. While the *buffer model* operates in response to the appraisal of life events as stressful, the *main effect model* exists as a constant source of support and possible prevention to stress. The common ground between the *buffer* and the *main effect model* is that social support is beneficial to well-being, thus, social support is an important resource for social workers to explore and facilitate, for and with, parents of children with ND.

Networks of Support: Informal, Formal, Community

In this next section, a brief description will be provided about three support networks (informal, formal, community) from which mothers and fathers might seek help.

Informal Network of Support

Perhaps the most direct way to describe an informal network of support is that it is one that exists, and/or is developed within an individual's "natural environment" (Gottlieb, 1978, p. 105). Informal support networks are composed of significant people in an individual's life such as family, friends, neighbours (Antonucci, 1985; Caplan, 1974; Gottlieb, 1978; House, 1981; Procidano & Heller, 1983; Thoits, 1985), who offer help either as *spontaneous or natural systems* in which ongoing guidance and support from both *kin* (birth and/or marriage) and kith (friends, neighbours, acquaintances) is provided; or as *generalists* (well-known, well-informed, well-connected and charismatic community members); or *specialists* (e.g., community members who have overcome their own difficulties, and are sought out by others who share similar difficulties) (Caplan, 1974). Informal networks of support are personal in that they are based on who exists and is available within an individual's immediate environment, and they are fluid, in that members change as an individual's life changes. Mothers and fathers who participated in this study, thus, sought help from individuals that were located within their informal network, and who were available to provide help.

For parents to be helped by their informal network, however, presupposes that they belong to such a network. While this is the case for some parents who report the help they get as generally positive, more reliable and less disappointing than what they get from formal sources (Chang & McConkey, 2008), this may not be the case for all parents, where issues of language, culture (Ben-Cheikh & Rousseau, 2013; Huang, Kellett, & St John, 2012) created ambivalence and fear of stigma.

Formal Network of Support in Quebec

The formal network from which participants in this study engaged in at the onset of their help-seeking has changed considerably compared to the context that is experienced by parents who are newly embarking on their journey today. This is due, in part, to changes in policies and to structural reforms within the Québec Ministry of Health and Social Services that have altered organizational structures, functions and modes of operation of the establishments that provide the help that parents seek. Thus, while the participants from this study experienced their ongoing help-seeking within the current system of care, their first experiences with seeking occurred within different organizational climates, based on when their seeking began. Below, a brief overview of some of the major changes and reforms that have occurred in the health and social service delivery system within the province of Québec that have led to the help-seeking context as it is today will be presented. The history that is presented was selected to reflect the structures that would have been in place at the time when mothers and fathers from this study first began help-seeking. That time point, based on demographic information provided by them, was estimated to be 2004.

Brief History of Health and Social Services in Québec

Health and social services in the province of Québec have been regulated by the *Act Respecting Health Services and Social Services,* since its adoption in 1971 (Martin & Pompey, 2006). While amended several times in the coarse of the last decades, the:

> Act aims to maintain and improve the physical, mental, and social capacity of persons to act in their community and to carry out the roles they intend to assume in a manner which is acceptable to themselves and to the groups to which they belong (Québec, 1986)

Over a span of approximately 40 years, four (4) major structural reforms occurred within the Health and Social Service delivery sector in the province of Québec. In the early 1970s, Local Centres for Community Services (*Centre Local des Services Sociaux*-CLSC) were created in Québec, to group together various medical, preventative, and social services that would facilitate access for the population (Gaumer & Fleury, 2008). At that time, the province of Québec was divided into 12 regions, each of which was managed by a Regional Health and Social Service Council (CRSSS) that provided oversight for service organization and regional planning (Martin & Pompey, 2006). Twenty years later, through the adoption of the new *Act respecting health services and social services* (chapter 42, 1991) (*Loi sur les services de santé* *et les services sociaux et modifiant diverses dispositions législatives*) the CRSSSs were replaced with 18 Regional Health and Social Service Boards (known as Régie Régionale) in an effort to decentralize resources and grant management authority.

In 2003, another restructuring occurred under Bill 25, the *Act respecting local health and social services network development agencies* (Loi sur les agences de développement de réseaux locaux de services de santé et de services sociaux (C-21) that shifted the management from the regional level to a more local one with the creation of 15 Local Agencies (known as l'Agence), at a time of political shift from the Parti Québécois to the Liberal government. This reform was motivated by a desire to facilitate the population's access to health and social services by bringing their management closer to the public. While the power and mandate did not shift significantly from that of the Régie Régionale, an added responsibility was that of developing a proposal for a model of service organization that would create a Local Service Network (LSN). This LSN culminated into the merging of the CLSCs, of residential and long term care facilities (Centres d'hébergement de soins de longue durée: CHSLD) and hospitals (in areas where this was possible). These mergers thus formed a new entity under which was found a wide array of health and social services, each headed by its own board of directors known as the Health and Social Services Centre (Centre de santé et de services sociaux- CSSS). Ninety-five (95) CSSSs were created in Québec. It is here that parents of children with ND would seek help (Martin & Pompey, 2006). It can be noted that all the parents in this study are estimated to have begun their help-seeking during this period.

The final, and most recent reform occurred in on February 7, 2015, at the first sitting of the 41st Legislature, when the National Assembly adopted Bill 10: *An Act to modify the organization and governance of the health and social services network, in particular by abolishing the regional agencies* (Projet de loi no 10: *Loi modifiant l'organisation et la gouvernance du réseaux de la santé et des* *services sociaux notamment par l'abolition des agences régionales*). This reform represents another major step for the health and social services network and the Ministère de la Santé et des Services Sociaux (MSSS) (Santé et Services sociaux, 2017). The implementation of this reform is seen as a continuation of the changes implemented in 2004-2005. Mergers of several organizations, and restructured organizations took place resulting in 13 Integrated Heath and Social Service Centres (Centre Intégré de Santé et de Services Sociaux (CISSSs), and 9 Integrated University Heath and Social Service Centres (Centre Intégré Universitaire de Santé et de Services Sociaux (CIUSSSs), depending on whether or not they were affiliated with universities. One of the main objectives of this reform was to "improve the flow of services through the merger of various institutions to the benefit of users and the public" (Government of Québec, 2015). Under this reform, the Minister of Health and Social Services was granted much more decision-making power regarding "organizational structure and management" (Government of Québec, 2015). This is the structure that remains to-date.

Within the new restructuring, parents who were seeking help related to their child with ND in Montreal, Québec, the location of this doctoral study, were doing so within a system comprised of 90 different institutions that provide health and psychosocial care. Montreal is home to 5 of the 9 CIUSSSs in the Province and functions with 29 CLSCs, 14 rehabilitation centres (4 of which are designated to individuals with intellectual disabilities and/or pervasive development disorders); 22 hospitals (2 of which are paediatric); 60 long term care facilities (CHSLDs); and 2 Centres for the protection of children and youth (Centres de protection de l'enfance et de la jeunesse: CPJE). There are 9 programs within these organizations: 2 are geared towards the population at large (public health and general service), and 7 are specialized programs, specific to particular needs within the community including, and among these is the one for *déficience intellectuelle et trouble du spectre de l'autisme* *[intellectual disability and autism disorder spectrum]*, under which parents of a child with ND can seek help.

In addition to these programs, Québec has a vital government department entitled the '*Office des personnes handicapées de Québec' [Office for Persons with Disabilities]*, that is responsible for promoting and ensuring the rights of citizens with disabilities to engage and participate to the same and full extent as their able-bodied peers. Mandated by the Government of Québec, the Office acts as a vigilant consultant to the Minister of Health and Social Services, the Government, and other public and private partners, to support and offer council in matters pertaining to social integration. The Office also works to promote the continued evolvement of society in its responsibility regarding inclusion. Integrated within its role is the mandate to participate in evaluation and research activities within government organizations and with other partners, as well as with individuals with disabilities and their families (Office des personnes handicapées de Québec, 2018).

Community Network of Support in Quebec

A community network is comprised of groups/organizations created by members of the community who shared a similar experience or need (e.g., parents of children with disabilities) and who mobilized their knowledge in order to provide support to other members of the community who may be experiencing similar issues. While the parents in this study did not speak of having accessed support there, they are introduced here, as a third network that exists from which parents can get support. Organizations may be funded (similar to formal networks) by regular sponsors, and/or through fund raising. They may have some paid staff (similar to formal networks) and require membership (even for a 'donation-type' fee), but their services are free, open to every concerned member of the community, and are often spontaneous (as in informal networks). One example of such a network is Étoile de Patcho (L'Étoile de Pacho, 2018). This support and guidance group for parents of children with disabilities was founded by mothers of children with disabilities, who felt they had been inadequately supported by the programs and services within formal networks in Québec. They joined forces and created a support for parents, by parents, to try and fill the gap in support they experienced, so that other parents in similar situations might not feel the loneliness and confusion they had felt. Based on their own collective experiences as mothers of children with disabilities who had navigated support from formal networks, the organizing mothers brought in their shared stories, experiences and acquired knowledge to offer support and guidance to other parents who were going through journeys similar to theirs, based on the particular needs of their children and families. A community network then, is one that is comprised of these types of organizations, from which parents receive support. Such parent-to-parent forums, particularly those that are online, are increasingly available (i.e., Calgary Autism Moms for Raising Teens and Adults, Special Needs Network of Montreal) and are offering a unique type of support to parents.

Help-Seeking and Help-Seeking Models

Inquiries into help-seeking are not novel. For decades, scholars have explored and examined help-seeking to better understand its multi-dimensional nature (Keith-Lucas, 1972; MacLean & Gould, 1988). Factors such as health and well-being, personal, attitudinal, and demographic characteristics, and structural conditions facilitate and encourage, or hinder and impede the help-seeking of individuals in need (Andersen & Newman, 2005; Cauce et al., 2002; Chan, 2013; Goldsmith, Jackson, & Hough, 1988; Gross & McMullen, 1983; Pescosolido, 1992; Rosenstock, 1974; Srebnik, Cauce, & Baydar, 1996). Help-seeking occurs and is sought from informal networks (Barbee, Gulley, & Cunningham, 1990; Chan, 2013), from formal networks (Cauce et al., 2002; Fisher, Nadler, & DePaulo, 1983; Goldsmith et al., 1988; Srebnik et al., 1996), or from both (Gibson, 2016; Gross & McMullen, 1983; Pescosolido, 1992). When individuals embark in help-seeking, they do so to seek emotional support (Fischer & Turner, 1970), instrumental support (Chan, 2013), psychological support (Chan, 2013; Fisher et al., 1983), informational support (Gibson, 2016), from medical (Pescosolido, 1992; Rosenstock, 1974) or mental health professionals (Cauce et al., 2002; Goldsmith et al., 1988; Srebnik et al., 1996). Researchers have also examined how type of health condition and condition severity (Fenn, 2016), personal attitudes (Morawska & Sultan, 2016), motivations and intentions (Cohen, 1999; White, Clough, & Casey, 2018), as well as demographic characteristics such as age and gender (Eagly & Crowley, 1986; O'Mahony & Hegarty, 2009), and culture and immigration (Ben-Cheikh & Rousseau, 2013; Kang-Yi et al., 2018; Lau & Takeuchi, 2001) inform individuals' decision to seek, and the process they undertake if they do decide to proceed.

Help-seeking and decision-making are dynamic and interactive processes (Pescosolido, 1992) that also take place in a larger socially constructed reality (Lee, 1996). These are not linear but rather circular processes that involve evaluations and re-evaluations and may require revisiting previous stages along the way (Cauce et al., 2002). Asking for help can occur as a negotiated interaction, in which individuals remain fully engaged and in charge through the process of defining the problem, and finding the solution (Asser, 1978). Or, it can occur through a dyadic interaction in which an individual seeks specific and concrete assistance not only for locating solutions to their problems, but also for identifying the degree of the problem to begin with (Asser, 1978). For some individuals, asking for help is natural, a common method of problem solving. For others, it appears to be more difficult, perceived as a reflection of one's personal shortcomings resulting in negative and self-doubting feelings that often act as a deterrent to asking (Cohen, 1999; Fischer & Turner, 1970).

Help-seeking is associated with positive outcomes, and acquiring help enables individuals to accomplish tasks and manage situations they would have otherwise been unable to do (Chan, 2013). The insight and mastery that is gained through help-seeking equips individuals for potentially similar needs in the future (Chan, 2013). When individuals sense that help will be valuable to them (Chan, 2013; Goldsmith et al., 1988), and that helpers are competent, knowledgeable, and reliable (Fischer & Turner, 1970) they are more likely to seek it again in the future.

There are also personal and public costs associated with seeking help that discourage seeking. On a personal side, the sense that one is incapable and incompetent can have a detrimental impact on self-esteem and on the image one has of self within society (public image) (Barbee et al., 1990; Chan, 2013). Individuals who are preoccupied with their sense of self will be deterred from seeking help to avoid embarrassment (Barbee et al., 1990; Chan, 2013). Stigma associated with societal perceptions related to individuals who seek help (e.g., towards mental health) will also act as a deterrent to seeking (Chan, 2013; Fischer & Turner, 1970). On the public level, individuals who seek help may develop a feeling that they owe something (are indebted) to the helper in return for the help received (Chan, 2013), creating a power imbalance between the seeker and the helper (Barbee et al., 1990; Chan, 2013), a sense that the seeker is dependent on the helper, has lost their own sense of control (Barbee et al., 1990), and that one is unable to proceed without the helper’s involvement (Chan, 2013). In addition some scholars discuss the sense of individuals being cognizant of not wanting to impose or bother someone (Barbee et al., 1990).

Some scholarship provides theoretical insights about help-seeking based on reviews of extant literature that describe personal, societal, and structural characteristics that act as contributors or deflectors within individuals' decision-making process to seek, and/or within their actual seeking process (Cauce et al., 2002; Chan, 2013; Goldsmith et al., 1988; Keith-Lucas, 1972; Pescosolido, 1992; Rosenstock, 1974; Srebnik et al., 1996). One example is Chan's (2013), *goal-instrumental interpersonal help-seeking model*, a complex model that incorporates multi-level group and individual components that interact to impact individuals' intentions to seek help. Developed through a review of literature in areas of psychology (e.g., educational, clinical), the model suggests that help-seeking 'intentions' determine whether or not an individual will engage in seeking behaviours. Intentions are impacted by *salient beliefs* (control, normative, behavioural) that themselves are impacted by an individual's *task factors* (trigger event, tasks importance, problem severity) and *personal factors* such as self-esteem, goal orientation, social competence, and dependent personality. This model describes contributors to seeking based on the analysis scholarly literature.

Other scholarship contributes new perspectives about help-seeking emerging not from extant literature, but from original research studies (Asser, 1978; Barbee et al., 1990; Cohen, 1999; Fisher et al., 1983; Gibson, 2016) that elucidate a decision-making process, or a seeking process composed of steps or stages that individuals encounter and pass through. Most recently, Gibson (2016) developed a 3-stage model reflecting the experiences of 35 parents of individuals (children and adults) with Down's Syndrome, who participated in a study related to seeking for post-diagnosis information. The steps in her model lead parents from their starting point of having received a diagnosis for their child, through to a period in which they have found a sense of acceptance after having proceeded through three stages: information overload/avoidance, passive acceptance/seeking, active information seeking

(Gibson, 2016). As a process, help-seeking involves recognizing that a problem exists, making the decision to seek help, and deciding where and from whom the help will be sought (Cauce et al., 2002; Cohen, 1999; Goldsmith et al., 1988; Gross & McMullen, 1983; Keith-Lucas, 1972; Rosenstock, 1974; Srebnik et al., 1996).

What we gain from these models is insight into some of the pre-seeking conditions and characteristics that have an impact, positive or negative, on individuals' help-seeking behaviours. This information is useful for clinical helpers as they highlight both facilitators and barriers to seeking help. Understanding what conditions are best suited to encourage help-seeking, as well as those that hinder seeking equip clinical helpers to promote conditions that are helpful, and find ways to improve those that are not.

In view of the context and purpose of the research in this dissertation, and in the interest of adding to clinical practice related to help-seeking, more specifically within the context of mothers and fathers of children with ND, it is important to review existing models in terms of their usability with this particular group. Limitations of these models are considered below.

Limitations of Existing Help-Seeking Models

One of the main critiques about existing help-seeking models is that most were not developed specifically with mothers and fathers of children with ND, or in the least, with extant empirical and/or theoretical knowledge about them, or about their unique seeking contexts. Thus, characteristics of who mothers and fathers are as individuals and as parents, as well as circumstances that are particular to their reality of seeking for help related to their child with ND, are not reflected within them. This is important, as a prolific scholarship about parents of children with ND highlights considerable differences that exist between them and parents of neuro-typical children (parents in general), raising questions about how representative models that are based on a general population might be to them. As discussed earlier in this paper, parents of children with ND are greatly impacted, both physically and emotionally, by being the parent of a child with ND. Many experience a sense of grief, and of mourning about the typical child they hoped for and did not get, and they are submersed in the numerous and infinite responsibilities that arise from caring for their child, and from ensuring their various functional needs are met. Seeking, for these parents, is reported as a constant and long term fixture in their lives, and it is felt as deeply personal and intimate. While the scholarship might reflect the difficulties and challenges parents experience about the support that is available to them, it also portrays parents as determined, strong-willed and resilient in their quests. Thus, when models about help-seeking in general describe steps or stages of help-seeking, or when they describe specific factors that are said to contribute to the 'willingness' to seek, and to the 'intentions' to seek, one wonders how applicable these are to these mothers and fathers who's experiences as parents contrast to those of parents in general, based on the particularities of their parenting a child with ND.

A recent exception is the aforementioned process model by Gibson (2016) that was developed through the experiences of parents who have children with Down syndrome. Down syndrome was selected for the Gibson study because of its high prevalence within the population of the United States. Thirty-five parents participated in the study (mothers, n=34; fathers, n=1), and were asked to respond to questions specific to the type of information they needed and sought for their child (3 months to 38 years of age, m=11 years) within the last year. As well, they were asked to describe times, throughout their child's life when they had difficulty finding the right amount of information, times when they experienced having received too much information, and other times when they felt they had received the right amount of information to help their decision-making. This model describes how parents moved through and within three ranges of behaviours (avoidance, passive, and active). As the model was derived from the direct experience of parents, it captures the subtleties (e.g., emotional reactions following a diagnosis, fear of diagnosis, anger) that are specific to these parents. The focus of this dissertation is slightly different from Gibson (2016), in that it is not diagnosis-specific, and it is open to all types of help, not specifically informational help. Thus it lead to a process model that reflects seeking for help related to child function that is impacted by diagnoses that are common (for which there is a lot if help available), as well as for diagnoses that are less common (for which less help is available). (Details of the model produced from this doctoral research are described in chapter 5.)

Most models are also focused on individuals seeking help specifically for themselves, about their own concerns, directly related to their own well-being. In this doctoral study, the focus of inquiry is not only about mothers and fathers seeking help for themselves, but perhaps more particularly them seeking help for their child. This raises an important question about the applicability of existing models: are the factors that impact the process of seeking (the decision-making process and the characteristics included within that process), similar or different when one seeks for one's self versus for someone else? It might be that when mothers and fathers are seeking for themselves, their inner dialogue and decision-making processes follow along the lines of those of individuals in the general population represented in existing models. As we saw earlier, many similar interrelated factors (e.g., individual, societal, environmental) are depicted in current literature about parents of children with ND as contributors to how they experience their roles as parents, how they enact parenting and co-parenting, how they view disability, and how they interact within helping networks. Many of these mirror factors described in existing help-seeking models, where personal characteristics, culture, and structural factors are at play (Andersen &

Newman, 2005; Cauce et al., 2002; Chan, 2013; Goldsmith et al., 1988; Gross & McMullen, 1983; Pescosolido, 1992; Rosenstock, 1974; Srebnik et al., 1996). Thus, while characteristics of mothers and fathers seeking for themselves may resemble those in existing models, the nuance here is, would the factors described within existing models actually be the same had they been established with individuals whose help-seeking was focused on individuals other than themselves? This is an impossible question to answer without further research, of course, and one that may gain more clarity through the results of this study, but again, one wonders if using models based on individuals' decision-making processes regarding seeking help that is completely related to their own well-being are the most reliable/appropriate ones to use when exploring the help-seeking of mothers and fathers who's central focus for seeking is their child's well-being, and not their own.

Another point to consider about existing models is that while most contain multi-level factors that impact an individual's decision to seek help, they also tend to depict the process as one that is inherently uni-dimensional, meaning that, while individuals' decision-making processes may be impacted by many interrelated factors, ultimately, the decision to seek is about the individual, taken by the individual, for the individual themselves. This contrasts considerably with the notion of mothers and fathers as co-parenting seekers of help in relation to their child with ND. When two parents are involved in decisions about their child with ND, their co-parenting does not transpire as siloed, individual responsibilities, but more so as an interactive process where actual responsibilities may be shared, but through which communication and interaction between both parents, together, coexist (McNeill et al., 2014). For example, Maynard and colleagues (2016) highlighted how parents of children with ASD and difficult externalising behaviours work in cooperation with each other while trying to maintain the difficult behaviour. In their teamwork, both parents utilize different styles, one a more conditional approach, the other one that is more accommodating, but it is together, in each their own way, the parents succeed. McNeill and colleagues (2014), also discuss aspects of collaboration between mothers and fathers who co-parents children with chronic conditions. They define parenting roles as *complementary* when they reflect particularities such as individual strong points or personal preferences. Other roles that reflect areas that both parents can do, and that they share intermittently between themselves, sometimes based on circumstances, they refer to as *symmetric*. With both these roles, there is a sense of parents pulling forces in a joint endeavour to parent their child. The works of both Maynard (2016) and McNeill (2014), demonstrate collaborative characteristics of parents who work together in parenting their child, yet existing models do not account for a shared decision-making process or for the elements that occur within a co-parenting dyad that might also be present when co-parents seek help.

A final point that should be considered in relation to existing help-seeking models when considering their usefulness in the context of help-seeking and ND relates to what aspect of seeking, exactly, existing models describe, and the reality that most models do not report on a complete seeking process. Rather, as we have seen, some models describe characteristics that impact 'willingness' to seek, and 'intentions' to seek. Others describe characteristic that impact steps that individuals will engage in. But what is missing, is a description of a seeking process that moves beyond the pre-seeking conditions that are present in existing models (e.g., decision-making process/conditions) to include how seeking actually transpires (the active process, who seeks, for what, how and where does it unfold?), as well as what happens in the aftermath of seeking; the impacts of resuming life either with help that was sought and acquired, or without help that was sought and not obtained.

The objective of this doctoral study is to understand a complete process involved in mothers and fathers seeking help. This implies that they will not only have identified a need for help and decided to move forward with seeking, but that a process will emerge that describes how they seek, where they seek, and how seeking is experienced. Of course, understanding pre-seeking facilitators and barriers is an important part of the discussion on help-seeking, but one must consider the possibility that fully understanding help-seeking of mothers and fathers of children with ND would best be served through a model that describes a complete seeking process, based on their direct experiences of seeking. Also, to reflect the co-parenting decision-making process that may unfold between mother/father co-parenting dyads, a model should include the voices of both mothers and fathers. Finally, in order to be a useful clinical tool that informs both mothers and fathers about their own seeking, as well as informs clinicians who provide help to them, a model should detail the actual seeking process and the post-seeking process as well.

Summary

The purpose of this chapter was to introduce the reader to some of the crucial elements necessary to understand what help-seeking is, and the context in which it transpires for mothers and fathers of children with ND. To do so, some theoretical frameworks related to health and disability were introduced, and disability was situated within a human rights lens, through existing World, National, and provincial human rights legislation. Following a presentation of the prevalence of ND, empirical literature about parents of children with ND was presented that explained why parents seek help, what they seek for and how they experience the help they have sought. Finally, a discussion about existing help-seeking models then provided details about some behaviours and motivations that impact help-seeking decisions, and these were critiqued based on their perceived usefulness within investigations of the help-seeking of mothers and fathers of children with ND.

In the next chapter, the methodological approach utilized in the design of this study, and the methods for data collection and analysis, and for the evaluation of the research and theory, will be presented.

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Chapter 3: Methods

The purpose of this chapter is to present constructivist grounded theory (ConGT), the methodological approach utilised in this doctoral study about how mothers and fathers of children with neurodisabilities seek help. ConGT will be situated within a brief description of classic grounded theory, whence it emerged, and within the paradigms of symbolic interactionism and constructivism. In this chapter, the methodological procedures that were utilized in the research will also be described, and some criteria for evaluating research and the constructed theory will be presented.

Methodological Approach

Constructivist Grounded Theory

This qualitative study was designed utilizing a Constructivist grounded theory (ConGT) approach (Charmaz, 2006, 2014) to generate a theoretical understanding of how mothers and fathers of children with ND seek help. ConGT emerged in the 1990s through the work of Charmaz (2006, 2014), in her opposition to the strict assumptions about knowledge and researcher-participant engagement brought forth by Glaser and Strauss's classic grounded theory (Glaser & Strauss, 1965). Charmaz (2006, 2014) rebuffed the notion of researcher objectivity suggested by Glaser and Strauss (1965), denoting that it was impossible to negate the existence of relationships and social connectedness between a researcher and those being researched. ConGT thus incorporates aspects of relativity and subjectivity, suggesting that theory is co-constructed by both the researcher and the person involved in the phenomenon being studied (Charmaz, 2014). ConGT rejects the idea that an objective reality exists and instead, aspires to uncover multiple, constructed social realities in the data (Charmaz, 2006). The theory that results from research emerges inductively through an understanding of a phenomenon based on both party's subjective experiences of it: their shared experiences, social contexts, common points of view, and interpretations:

> *All of the processes reflect what and how the researcher thinks and does about shaping and collecting the data. The researcher composes the story; this story reflects the viewer as well as the viewed.... we can only claim to have interpreted a reality, as we understood both our own experience and our subjects' portrayal of theirs (Charmaz, 2004, p. 271).*

Grounded Theory

Grounded theory (GT) is one of the most commonly utilized qualitative research methodologies to develop theory across the social sciences (Morse et al., 2009; Oktay, 2012). It is also highly utilized in doctoral dissertations in the field of social work (Rothwell, Lach, Blumenthal, & Akesson, 2015). In their study examining Canadian doctoral dissertations produced between 2001 and 2011, Rothwell and colleagues (2015) found that of N=248 dissertations, 65.3 % (n=162) utilized qualitative methodologies, and of those 22% (n=46) were designed using GT. Grounded theory finds its roots in sociology through the work of (Glaser & Strauss, 1965). Through their seminal work *Temporal Aspects of Dying as a Non-Scheduled Status Passage* (Glaser & Strauss, 1965), the authors developed an inductive process of theory development by which data was first collected, and then served as the foundation on which theory was developed. This data-to-theory method veered from the predominantly deductive sociological research methodologies of the time that utilized data as a means of testing predetermined theories (Walker & Myrick, 2006), and contributed systematic methods of gathering and analyzing data that challenged the notion that qualitative research was loose, unorganized, and unsystematic (Higginbottom & Lauridsen, 2014). Glaser and Strauss (1967) described GT as research that seeks to develop theory that explains specific basic social processes. Embracing a post-positivist paradigm (Denzin & Lincoln, 1994), the inductive nature of GT positions the researcher as an objective observer of phenomenon. It presupposes that the researcher enters the field with no a priori knowledge of the phenomenon (Mills, Bonner, & Francis, 2006) thus, developing a mid-range theory that represents the true voices of participants and that fits with their experience of the phenomenon being researched (Glaser & Strauss, 1967).

ConGT differs with respect to a priori knowledge, asserting that it is impossible for a researcher to part from their previous knowledge (e.g., personal, professional, research). Instead, researchers remain closely in-tune by acknowledging and examining it through reflexivity, an exercise undertaken throughout the research process, to understand, "... how the researcher's interests, positions, and assumptions influenced his or her inquiry" (Charmaz, 2014, p. 344). For example, through the course of her doctoral studies, the researcher remained in constant introspection regarding how her own experience with the notion of 'help' was interlaced within the development, implementation, analysis, and write-up of the study (her previous professional work as a helper, her work as a research assistant on studies related to parents, parenting and support, as well as her own experiences as an individual who has asked for help), to ensure her own ideas did not overtake or lead the research design, discussions or analysis.

Constructivism

ConGT is driven by a constructivist paradigm that perceives the pursuit of knowledge as an endeavor stemming from needing to understand and reconstruct currently held notions of a phenomenon, both those of the researcher and those of the person being researched (Guba & Lincoln, 1994). The end objective of an interrogation then, is to come to an agreed upon construct, with the understanding that it is fluid, in that it can continue to evolve as more knowledge and experience is added. A constructivist researcher is not independent of the phenomenon being studied but contributes to the construction as a participant and facilitator. Ontologically, constructivism adheres to a relativist notion that there is not one ultimate truth but rather, several evolving realities (Guba & Lincoln, 1994). Epistemologically, constructivism presumes a subjective interactionality between the researcher and the phenomenon, such that constructs are derived through relations (Guba & Lincoln, 1994). In ConGT, constructivism plays out in the way in which the researcher and researched construct an understanding of a phenomenon based on their shared experience and interaction. Subjectivity intercepts with experience as both researcher and researched interact and interpret in co-constructed, yet fluid realities (Annells, 1996). The theory that develops is based on the interactional construction of players rather than on facts that are external to each (Labonte & Robertson, 1996).

Symbolic Interactionism

ConGT is also informed by the paradigm of symbolic interactionism (SI) (Blumer, 1969, 1986; Cooley, 1922; Goffman, 1963; Mead, 1962), through which individuals are understood according to the meanings they ascribe to interactions within their individual environmental contexts, in relation to others, and in reaction to others. The very basic premise of SI is that humans are social beings who continuously develop their sense of self through an ongoing interactional and social process that involves assigning symbols to objects to which meaning has been ascribed, and then using these symbols in performances that lead to their further development (Holstein & Gubrium, 2003). As such, it shares ontological and epistemological constructs with constructivism in that both ascribe to the notion that there are more than one reality, that reality is subjective, and that it is co-created through interactions and relationships (Holstein & Gubrium, 2003).

The three main assertions of SI are:

1. Human beings act toward things on the basis of meanings that the things have for them;
2. The meaning of such things is derived from, or arises out, of the social interaction that he has with one's fellows;
3. These meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters (Blumer, 1969, p. 2).

To these, Charmaz (1980) adds:

1. Meanings are interpreted through shared language and communication;
2. The mediation of meaning in social interaction is distinguished by a continually emerging processual nature;
3. The interpretive process becomes explicit when people's meanings and/or actions become problematic or their situations change (Charmaz, 1980, p. 25)

Both Blumer's and Charmaz's notions provide grounds through which a study about help can be understood, situating what help is, what it looks like, where it can be located, and how it is experienced, within interpretive and interactional exchanges within and between mother and father participants, and the researcher.

The theoretical underpinnings of ConGT align with the interactive, relational, professional engagement that is at the heart social work (Oktay, 2012), sharing similar tools for gathering information and making sense of it: establishing relationships with their participants and moving inquiry into understanding the meanings they have ascribed to the phenomenon, how, and why those meanings arose and were ascribed (Higginbottom & Lauridsen, 2014). This allows for a full appreciation of the person, and of the circumstances and contexts in which meaning is developed, and a comprehensive understanding of the phenomenon at hand (Higginbottom & Lauridsen, 2014). Similarly, social workers engage with clients by creating relationships through which a joint understanding of the client and client needs leads to helpful and meaningful assistance (Oktay, 2012). In this way, a ConGT approach to a study on helping in the field of social work is well aligned, and most appropriate.

The current study was designed using a ConGT methodology to generate a theoretical understanding about help-seeking parents in the context of children with ND. It sought to answer the following research question: *How do mothers and fathers of children with ND, seek help for their child and for themselves, within informal and formal networks of support?*

The next section describes the methods utilized throughout the study, beginning with ethical considerations, and followed by sampling, recruitment, data collection and analysis, and ending with rigour and a discussion on the evaluation of quality.

Methods

Ethical Considerations

Ethical approval for this study was received from the McGill Research Ethics Board (REB-II #: 164-0916) for the period of October 14, 2016 – October 13, 2017, and renewed again from October 13, 2017 – October 12, 2018. An amendment was obtained on September 26, 2017 to include recruitment from social media.

This study was carefully designed to be as little imposing on participants as possible. The study purpose, procedures and participant involvement were explained to all mothers and fathers who expressed an interest in participating by telephone and/or email, and again in person at the time of their interview. They were informed that their participation was voluntary, that they could withdraw at any time, and that any data collected from them would not be included in the analysis if they withdrew. They were also informed that they could chose not to answer questions they did not want to answer, and that they could take breaks during the interview, as needed. There was minimal risk involved in participating in this study (discomfort about disclosing personal information) and mothers and fathers were each informed that they could be referred to appropriate resources should they deem it necessary. While referrals for support were not requested, one participant requested to take a short break during the interview. Mothers and fathers (were also each assured that their confidentiality would be ensured throughout the study by the use a study code, by de-identifying audio transcripts, and by assigning them a pseudonym in any written reports.

Following the verbal description of the study mothers and fathers who agreed to participate in the study were asked to sign two copies of a consent form, one they could keep, the other for the research file (See Appendix 1). Consent forms were available in English and French. Audio files of the interviews were transferred into a password-protected file on the researcher's password-protected computer and deleted from the recording device immediately after the interviews. All word and excel documents (observation notes, research memos, journal, audio transcripts) were kept in a password-protected file on the researcher's password-protected computer. All paper documents related to the study (consent forms, completed questionnaires, contact information sheet) were kept in a locked cabinet in a locked office at the McGill Center for Research on Children and Families. Mothers and fathers who completed an interview were given a gift card in the amount of $10.00 as a gesture of appreciation for their time.

Sampling

Sampling in a ConGT study is guided by the construction of theory, the deepening of one's understanding of emerging theoretical categories that determine what data is sought next, from where, and in what quantity (Lempert, 2007, p. 245). While initial sampling establishes a starting point from which data gathering commences, it is by moving forward in data collection and analysis that theoretical sampling progresses and ensues until established theoretical categories are sufficiently deepened.

> *Initial sampling in grounded theory gets you started; theoretical sampling gets you where you want to go* (Charmaz, 2006, p. 197)

In line with the sampling guidelines of ConGT, both initial and theoretical sampling techniques were utilized in this study. The initial sample was purposively selected from a sub-sample of 12 mothers and fathers who had participated in a previous program of research, the *CIHR Team in Parenting Matters! The Biopsychosocial Context of Parenting Children with Neurodevelopmental Disorders in Canada*, and who had consented to being contacted for studies in the future. The *Parenting Matters!* full dataset consists of N=263 mothers and fathers. Charmaz (2006, 2014) suggests that sampling criteria for initial sampling be established prior to recruitment. To begin the discussion about help-seeking for this study, initial sampling criteria considered the following points:

1. Ensuring that the experiences of co-parenting mothers and fathers were included. Based on literature that suggests that mothers and fathers have both similar and divergent co-parenting experiences (Hock & Mooradian, 2013; McNeill et al., 2014; Saini et al., 2015), including them both in the study could shed light on similarities and differences within their help-seeking experiences based on the interactive nature of their co-parenting experience.
2. Participation of fathers was important to help fill the current gap in literature about parenting children with ND that stems primarily from the experiences of mothers (Bogossian, 2017; Bogossian et al., 2017; Fletcher et al., 2014) thus ensuring that findings about *parents* that emerged through data analysis would truthfully reflect/represent both mothers' and fathers' voices.
3. Ensured that parents had past the initial diagnosis phase of their child's life that is reported as stressful and critical time for parents (Meadan, Stoner, & Angell, 2015; Willingham-Storr, 2014).
4. That mothers and fathers were engaging in help-seeking within a pediatric context, based on literature that suggests that the period of transition from child to adult care focuses on different areas of need that are dissimilar to the needs of younger children (e.g., vocational, residential, intimate relationships) (Crane, Chester, Goddard, Henry, & Hill, 2016; Moh & Magiati, 2012; Rentinck, Ketelaar, Jongmans, & Gorter, 2007).

As the study progressed and theoretical categories emerged, a shift from initial to theoretical sampling was made in order to deepen and elaborate the emerging categories related to help-seeking. Theoretical sampling is a circular process of constant comparison, "... data and data, data with code, code with code, code with category, category with category, and category with concept..." (Charmaz, 2014, p. 342) that leads the researcher from data collection, to analysis, to concept generation, and back to data collection to pursue and refine ideas (Corbin & Strauss, 2015). It is utilized, not as a means of increasing sample size, but as a way to move forward to theoretical conceptualization (Charmaz, 2014; Corbin & Strauss, 2015). Theoretic sampling may lead researchers to seek out more participants, conduct participant observations, or to refine questions within an interview guide to include questions that focus more specifically to the emerging categories (Charmaz, 2014).

Theoretical saturation refers to deepening theoretical understandings of a category until no new layers or dimensions are added through new interviews (Corbin & Strauss, 2015). It has been achieved when, "...gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical categories" (Charmaz, 2014, p. 213). While theoretical saturation has become the gold standard with which qualitative researchers establish the point at which they end data collection (Charmaz, 2014; Corbin & Strauss, 2015), some scholars debate it, suggesting that it is based on judgement that is impacted by aspects of the research context (e.g., time or money (Wiener, 2007), or that it is misused, resulting in simplified theory development of otherwise complex medical data (Thorne & Darbyshire, 2005). Dey (1999) has challenged the claim of 'saturation', as it implies that category generating has been exhustive, while it is impossible to , "... predict accurately whether the very next round of data collection... might throw up something that suggests an important modification or even a new perspective" (Dey, 1999, p. 117). Instead of claiming saturation, Dey (1999) suggests the concept of "theoretical sufficiency" (Dey, 1999, p. 117), ... the stage at which categories seem to cope adequately with new data without requiring continual extensions and modifications" (Dey, 1999, p. 117). With this in mind, in this study, it is Dey's (1999) notion of *sufficiency* that determined that enough data had been collected, prompting the end of recruitment.

Recruitment

A purposive sample (N=12) of mothers (n=6) and fathers (n=6) was recruited from four different sources: i) existing database ii) snowball sampling iii) Facebook advertising iv) word of mouth, based on the following inclusion criteria:

1. They were a mother or father of a child with ND;
2. They actively co-parented with their child's other parent, (whether or not they lived together);
3. Their child with ND was aged 5-17 years;
4. They could communicate in English or French;
5. They had been recruited from an establishment within the province of Québec (referring to participants recruited from database).

Parenting Matters Database

Parenting Matters! The Biopsychosocial Context of Parenting Children with Neurodevelopmental Disorders in Canada (PM!) is a *Canadian Institute of Health Research (CIHR)* funded study aimed at understanding *parenting* within the context of children with ND through 4 related projects (an analysis of Canadian policy, a systematic review of the literature, a population-based study, and a clinical study). It was conducted between July 2011 and April 2014 and involved caregivers who were recruited from pediatric care facilities in three Canadian provinces, Alberta, Ontario, and Québec. Participants from PM! indicated their interest in participating in future research by ticking a box on their study consent form. The names and contact information of twelve parents who met the inclusion criteria for study, and who had agreed to participate in future research were provided to the researcher by a research assistant associated to the PM! study. A telephone call was made to each parent, and details about the study were discussed with them, or left on an answering service with return contact information, if parents were not available. Of the six parents who were reached (six were unreachable or did not return messages), three expressed an interest in participating in the study. Of these, one was excluded due to there not being any contact with the child's other parent, resulting in two parents recruited. These parents were asked to solicit the participation of their child's other parent, after which the other parent was also provided with the details of the study and asked if they were interested in participating. This was done to ensure that the other parent had the opportunity to either confirm their interest or change their mind, regardless of their initial expression of interest, and to do so directly to the researcher, without any possible pressure from the other parent who was initially contacted. This helped to ensure, as much as possible, that all mothers and fathers chose to participate (or not) by their own volition. Only once a conversation had transpired with each parent individually, and that each had agreed to participate, were interviews scheduled.

Snowball Sampling

Following each interview conducted, each parent was given a study recruitment pamphlet and was encouraged to share it with other parents they thought might be interested in participating in the study. Parents who expressed an interest in the study via snowball sampling either made contact with the researcher directly, by telephone or email, or asked their friend to make the initial contact. Thus, details about the study were sometimes provided by email, telephone or a combination of the two. The study explanation and recruitment procedures followed as per that of the initial sample, and interviews were scheduled accordingly.

Facebook Advertising

As the study progressed, recruitment sources were widened to include specific parenting groups geared at supporting and advocating for and with parents of children with disabilities through Facebook. Social media has increasingly been described as a regular and informative source of support by parents of children with disabilities (Fostervold Wells, 2016; Hall, Culler, & Frank-Webb, 2016; Haslam, Tee, & Baker, 2017; Mohd Roffeei, Abdullah, & Basar, 2015; Wong et al., 2015). In line with theoretical sampling, and following McGill Ethics Board Approval, an invitation to participate in research was extended to parents on the researcher's personal Facebook page as well as within three parent groups. Until this point, participants of the study had all been linked to the original PM! database (directly or through snowball sampling). Widening the recruitment scope provided for the possibility of including parents with other experiences. (Please see appendix 2 for Facebook advertisement). Facebook: Following the posting of my study advertisement on my personal page and 3 parent group pages, two parents contacted me and expressed an interest in getting more information about the study. An initial discussion about the study took place through messenger, followed by telephone contact(s) to finalize details. Both parents expressed an interest in participating in the study and recruitment procedures followed as per that of the initial sample, and interviews were scheduled accordingly.

Word of Mouth

The researcher spoke about the doctoral study to many individuals, in academic and professional settings, and in her personal environment, and provided recruitment pamphlets to anyone who thought they knew someone who might be interested in obtaining more information, or in participating. Through this method, two individuals expressed their interest in the study via email. Their initial sources of contact were not previous participants of the study, but had heard about the study through friends. One parent expressed interest in participating and was able to solicit the participation of their child's other parent. Recruitment procedures followed as per that of the initial sample, and interviews were scheduled accordingly.

Data collection

Data for this study were primarily collected through in-depth, intensive, semi-structured, individual interviews conducted with mother and father dyads of a child with ND. Interviews are considered one of the most utilized methods of data collection in ConGT. Mothers and fathers were interviewed separately in a location of their choice. Interviews were conducted in English and/or French according to participants' preference, each lasting between 64.52 minutes -104.43 minutes (M=86.71 minutes). A preliminary interview guide *(see appendix 3)* was created for the purpose of this study and was utilized to help guide the discussions. Following ConGT guidelines, open-ended questions were designed to elicit discussions about family context; types of help needed/sought; characteristics and relationships of help-seeking; decision-making; and help-seeking over time.

In addition to interviews, descriptive data about mothers, fathers and their child was collected through a 26-question demographic questionnaire (available in English and

French). *(Please see appendix 4 for the complete demographic questionnaire)* Each parent was asked to respond to questions related to themselves and to their child (e.g., age, family composition, income, employment status, child diagnosis, school, types/location of help sought). Additionally, in line with the non-categorical approach utilized in this study (described on page 26), descriptive data about the children of parent participants focused on function, rather than diagnosis. Data concerning child functioning and the impact of functioning on child's participation in 8 domains was collected using *About my Child* (Ritzema, Lach, Rosenbaum, & Nicholas, 2016), a measure of child function, (available in English and French): (1) physical function (2) activities of daily living (eating, toileting, dressing, sleeping); (3) communication (4) behaviour; (5) mood; (6) cognitive abilities; (7) social skills (with peers and adults); (8) participation in activities outside of school . *(Please see appendix 5 for the complete About my Child measure)*

Data analysis

There exists, in ConGT, a crucial, interlinked relationship between collecting and analyzing data, where collecting provides the source from where engaging with data occurs and whence analysis stems, and where analysis leads the way, and sets guidelines for all subsequent collecting. Immersed within is the researcher whose inseparable connection to both culminates in the development of substantive theory. Data analysis in ConGT is a heuristic process in which the researcher interacts with data closely and early on, in order to develop initial ideas that will guide future interviews. Analysis occurs through a constant comparison of data (Charmaz, 2014; Corbin & Strauss, 2015) within and between interviews, applying different levels of coding, from general to more focused, from which analytic categories begin to develop. Constantly comparing data, codes and categories allows the researcher to remain connected not only to the data, but also to the participant, the interview, and the manner in which the interview unfolded, allowing for the deepening and refining of perceptions and interpretations (Charmaz, 2014). Theoretical construction develops through an iterative process of looping back and forth from data collection, to analysis and coding, to theorizing, and back again, until a theoretical understanding has occurred.

> *It is through coding that the conceptual abstraction of data and its reintegration as theory takes place* (Holton, 2007, p. 265)

At the early stages of the analytic journey, this researcher had the great honour of private luncheon with Dr. Charmaz, and heard first hand about the importance of establishing closeness to data, and of remaining connected throughout the entire analysis and theory construction process. At that time, Dr. Charmaz's words were understood at a cerebral level, but it is only by progressing forward that her message about the word 'connect' was actually 'felt'. Following the discussions with mothers and fathers who shared very personal stories and experiences, not only about their help-seeking, but also about their child, themselves and their families, analysis occurred as a methodical, engaged, activity of connectivity. It involved reading and re-reading, and remembering and reliving interviews, where they took place, the sensation of interviewing, and of hearing what parents had to say. It was about constantly wondering what is this about? What else is happening here? Why is this important, and what is its connection to help-seeking?

Analysis of the interviews in this study began immediately following the first interview, as per ConGT guidelines. Interviews were transcribed verbatim and de-identified, as soon after the interview took place as possible. They were then imported into Dedoose, an on-line application for organizing and coding data. Dedoose was utilized for initial and some focused coding, and for sorting and categorizing data. For deeper comparative work, and for conceptual theorizing however, the researcher moved away from the small screen of the computer and utilized printed copies of interview excerpts, codes, categories, and memos to sit with, write on, underline, and highlight. Through Dedoose it was possible to print out excerpts from specific categories, and this allowed for them to be examined individually, against others, and in combination with others as well, evoking the constant comparison method (Charmaz, 2014; Corbin & Strauss, 2015). And so, the analysis method not only moved back and forth within and across data, it also moved back and forth between technology, and pencil and paper. Descriptive and child functional data were each entered into prepared documents using Microsoft Excel for Mac, version 14.5.7. These were verified for missing data and parents were contacted for details when necessary.

Interviews were analyzed according to ConGT guidelines (initial line-by-line, focused, memos) that involved asking analytic questions of the data to develop the understanding of *help-seeking* that guided the theoretical direction of further interviews.

Initial Coding

Initial coding is the first analytical step in ConGT and is crucial in generating the ideas that will be explored in greater depth in forthcoming interviews (Oktay, 2012). It involves thoughtfully reading through data, one line at a time, selecting words, phrases and sentences, and ascribing one or more descriptive words or short phrases to them that summarize their meaning. As the analysis progresses, within and between interviews, excerpts are linked to existing codes when the fit is right, or new codes are created that more specifically describe their essence. In coding, the researcher moves beyond the written word and begins questioning the essence of the data (Charmaz, 2014). "Mining the data" (Corbin

& Strauss, 2015, p. 88) depicts the researcher interacting in the process of looking beyond the actual words and into discovering the meaning behind them. For example, in this study, the code *changing personality* was given to excerpts from parents who spoke about how they felt their personality had been altered as they engaged in seeking help. Line-by-line coding allows the researcher to prepare and organize data into categories.

Using gerunds, the verb-form of nouns, captures the process and movement behind data that might otherwise seem static (Charmaz, 2006, 2014). For example, network (of support) becomes networking support; acceptance (of help) becomes accepting help; location (of support) becomes locating support. Coding with gerunds prepares the researcher for "seeing sequences and making connections" (Charmaz, 2006, p. 136) and for capturing "implicit meanings and actions" (Charmaz, 2014, p. 121) that reveal hidden processes.

At times, within the interview participants use such vivid descriptions that their exact words can be used as codes. These *in vivo* codes seem to perfectly capture the essence of an experience and are used verbatim, as codes, categories, or as part of the substantive theory (Charmaz, 2014; Corbin & Strauss, 2015; Oktay, 2012). In this study, for example, mothers and fathers spoke about a complicated process of seeking help that involved trying to locate support, trying to figure out how access it, waiting for help, and often being denied help and needing to start again elsewhere. One mother said, "it's like a game of snakes and ladders"(Simone)[iv] to describe her experience. Her description offered such a vibrant visual representation of the experience she and other mothers and fathers were experiencing that it became a theoretical category, and eventually the metaphor for the substantive theory presented in Chapter 5.

[iv] Quote was translated into English from it's original French: *C'est comme un jeu d'échelle et glissoire*

Focused coding

It is through focused coding that researchers elevate their initial codes analytically, into higher level codes, based on their "adequacy and conceptual strength" (Charmaz, 2014, p. 140). Focused codes are more abstract and conceptual than initial codes, and represent the analysis and examination of larger portions of data than initial codes. Focused coding leads the researcher to re-examine initial codes and to look for the way(s) in which they represent data. By interacting with codes in context with other codes, the researcher moves into analyzing how they might fit together theoretically, thus arranging, organizing, and categorizing. While it seems like focused coding is part of a sequential process, it does not prevent the researcher from returning to earlier data and re-examining it through a new lens (Charmaz, 2014).

Balancing each other out is a focused that was developed in this study after returning to examining initial codes (e.g., *being there for me*, *having my back*, *keeping me sane*, *making me smile*, *lifting me up*), that is related to helpful things parents did for each other that they expressed as having given them a sense of equilibrium. When considered individually, within their own interview, each code described an individual excerpt about a specific helpful incident. But when examined across interviews, coded incidents were thought, collectively, to describe how parents reciprocally supported each other when the other was down. Thus, all initial codes were relabelled under the new focus code. As data were collected from new participants, and as analysis ensued, this code was later sub-categorized under *Supporting each other*, a category that encompassed supportive behaviours, actions, and thoughts parents shared with each other and that had positive impacts on them as individuals and helped in their seeking.

Memo-Writing

> *If data are the building blocks of the developing theory, memos are the mortar* (Stern, 2007, p. 119)

An important piece of the analysis process in ConGT that researchers engage in from the start is memo-writing. Memo-writing is a spontaneous and informal exercise allowing the researcher to write down thoughts elicited by specific excerpts and/or specific codes, on the spot. In memoing, the researcher engages with the data analytically, very early on in the research. In this research, some memos were visceral reactions about the excerpts, others were questions that left the researcher wanting more details, or that elicited thoughts/criticisms about different aspects of help-seeking and the experiences parents had of seeking. For example, here follows a memo written in response to an excerpt from a mother who described her personal reaction to having left her young child with a new in-home respite worker, for the first time:

> *This is a powerful statement from this mom. She really felt like she was leaving her child with a stranger! What parent ever has to do this? When parents typically find a babysitter, there is usually an introduction process involved. The parent meets the babysitter and they get to know each other, and interview each other before the parent agrees to leave the child with the sitter. This is not the case when parents are assigned a respite provider. They do not have the same 'control' over the process of finding and interviewing and accepting the worker. The worker is found for them and assigned to them. They do not really have a say in the matter, unless there is a real problem. The respite person comes to the home and the parent leaves their child with this person without knowing having any background information about the person. Basically feeling like they are leaving their*

> *child with a stranger, even though the respite worker is a professional. Are help providers aware of this? I had not thought about it before now. The role of help providers is to find the respite but once the respite person is found, what responsibility does the help provider have in acknowledging parents' possible apprehension about using strangers? How can help providers reassure parents about the professionalism of the respite workers? What information can parents be given about the respite worker's credentials, etc. to put their mind at ease?*

This particular memo opened the thought process about the other side of seeking, about what happens after parents receive the help they sought. Until then, the researcher had been focused on the venture *into* seeking, but this particular moment broadened the parameters to allow for an exploration of different sides of seeking, specifically, what happened *post* seeking. Throughout the course of this study, the researcher engaged with memoing regularly, and with increasing agility and depth, realizing the tremendous benefit it had to the scope of thought process and analysis.

Charmaz (2014) suggests "coding everything early in your research and see where it takes you" (p. 112). In this study, coding the first three interviews generated over 750 codes that required enumerable hours of sifting and reworking to develop conceptual categories, some that related specifically to developing theoretical understanding of help-seeking (e.g., active seeking help, making decision as parents, putting child first, supporting each other), others related to aspects of being a parent, of parenting, and of experiencing having a child with ND. While each of these categories connected and provided insight and depth into help-seeking, the researcher decided which had more connected more closely to the developing theory compared to others. New participants were interviewed with the goal of verifying and deepening selected categories in mind, while other, codes that were less "theoretically central" (Charmaz, 2014, p. 140) were placed aside.

Rigour

Ensuring quality in qualitative research encompasses a consideration of both the degree to which the study adhered to the methodological design of the study and the manner in which it was conducted, and of the knowledge generated from the study (Corbin & Strauss, 2015; Oktay, 2012; Padgett, 2017). In this section, the criteria utilized to appraise ConGT and the substantive theory produced, and the manner in which they apply within the study are described.

Evaluating Methodological Rigour

Oktay (2012) brings to the forefront the seminal work of Glaser and Strauss (1967), *The discovery of grounded theory: Strategies for qualitative research* regarding elements they recommend as essential in evaluating the credibility of grounded theory research. Glaser and Strauss (1967) identified five key factors: immersion in the field; generation and testing of hypotheses in the field (and not before the start of data collection); the use of memoing; detailed description to support the theoretical understanding of the phenomena, and the pursuit of alternative explanations and negative cases. In this study, *immersion in the field* is reflected in the researcher's engagement with research participants over a period of 15 months during which interviews were conducted and analyzed on an ongoing basis, allowing for a constant and engaged period with data over time. In addition, the researcher had previous and ongoing experience in research related to parents of children with neurodisabilities. *Generation and testing of hypotheses* occurred by means of developing theoretical categories through data analysis, and following up and deepening these ideas with new participants. Using a modified version of the interview guide to reflect the emerging ideas, the researcher could 'test' how these ideas resonated with new participants to deepen the understand of them. For example, as the study progressed, the researcher often introduced ideas by way of: "I have heard from other parents that ... can you help me understand this?". *Memoing* was utilized throughout the course of the study and provided a means by which the researcher could write about impressions, reactions, and make links within and between participants' data, that were then integrated analytically throughout theory generating. *Detailed description* was provided in the writing of the findings generated by the study where descriptions of theoretical categories, the substantive theory, and the help-seeking process model were highlighted by the usage of participants' verbatim quotes. Throughout the analysis and interview process, the researcher constantly endeavoured to gain *alternative explanations* and to explore *negative cases* to ensure that categories were sufficiently defined (Dey, 1999) and explicated. For example, early interviews lead the researcher to understand seeking as an action that was difficult and dreaded, yet some parents described it as easy. This prompted further exploration about personal characteristics and circumstances that would explain how these two divergent experiences could co-exist within the same phenomenon.

Evaluating the Substantive Theory

The second element to consider in determining the quality of a ConGT relates to the theory itself. Here, (Charmaz, 2006, 2014) suggests that it is the audience who will ultimately determine how useful a theory is. With this in mind, she recommends researchers consider 4 criteria: (1) Research should denote a sense of *credibility*, in that the researcher has ensured the methods of producing theory (coding, creating and deepening categories, constant comparison) have been sufficiently utilized so that the reader will concur. (2) The theory should demonstrate *originality*, in that it adds something new to existing knowledge about the phenomenon. (3) The theory should have *resonance* within the participants or an audience of individuals "...who share their circumstances" (Charmaz, 2006, p. 183) (4) The theory should have *usefulness* in that it translates into every world and contributes to knowledge..." and to "...making a better world" (Charmaz, 2006, p. 183).

Conclusion

This chapter presented ConGT, the methodology that was utilized in the doctoral research presented in this dissertation. The underpinning theoretical framework and paradigm of ConGT were described and the methods used in conducting the study were explicated to provide a detailed account about the underlying ethical considerations that were maintained throughout participant recruitment, data collection, and data analysis. Further, a discussion was presented about the evaluation of research and theory quality. The findings of the doctoral study, the substantive theory (*The journey of ladders and snakes: Help-seeking mothers and fathers of children with ND*) and a process model of help-seeking (*Cyclical process model of help-seeking: Mothers and fathers of children with neurodisabilities*) are presented in the next chapters, 4 and 5.

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Linking Statement

Chapter 4: The Journey of Ladders and Snakes: Help-seeking among mothers and fathers of children with neurodisabilities (ND) (Manuscript 1)

Chapter 5 – Cyclical process model of help-seeking: Mothers and fathers of children with neurodisabilities (ND) (Manuscript 2)

The following two chapters represent the two articles that make up this manuscript-based dissertation. Both are representative of elements that are typically produced within a constructivist theory, and they are presented separately here, based on their different levels of abstraction. The first manuscript, *The journey of ladders and snakes: help-seeking among mothers and fathers*, presents the methodological aspects of the study, and then describes the experiential components of the substantive theory that was produced through the analysis of the data collected from mothers and fathers about their experience of seeking help. These components illuminate the essence of mothers and fathers as seekers of help: who they are as individuals and as co-seeking parents of a child with ND, how their individual and co-parenting decision-making process unfolds, what roles they undertake both individually and together, and how they experience and enact their relationship with help-seeking.

The second manuscript, the *Cyclical Process Model of Help-Seeking*, conceptualizes the theoretical experiences of parents through a deeper level analysis, into a process model that explains stages of seeking that mothers and fathers pass through, fluidly. It renders the experiential essence of seeking that is explained in article one, the 'being' of help-seeking, into a process of 'doing' help-seeking.

The articles, as presented within, exceed the page count that would normally be accepted within an academic journal. This is intentional and meant to provide the reader with full, uninterrupted, and fluid renderings of the empirical study, the analytic process and theoretical components that provide the richness to the substantive theory and process model. Presenting these articles in a shorter format would have meant removing many of these elements, and placing them into appendices, and this would have interrupted the natural flow of each piece.

Chapter 4: The Journey of Ladders and Snakes: Help-seeking Among Mothers and Fathers of Children with Neurodisabilities (ND)

(Manuscript 1)

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Abstract:

The purpose of this article is to present The *Journey of Ladders and Snakes* (JLS), the substantive theory that represents the help-seeking experience of mothers and fathers of children with neurodisabilities (ND). The JLS emerged from the analysis of data obtained through a constructivist grounded theory (ConGT) study. In the study, 6 mother/father co-parenting dyads (N=12) each participated, separately, in a semi-structured interview regarding their process of seeking help for their child as well as for themselves within informal (e.g., family, friends), and formal (e.g., health and social service organizations) networks of support. This article describes the *journey* as a highly emotive one that begins from a place of grief and sadness about an expected child who ever came. It is a lifelong journey that begins at the first indication that something is 'different' with their child, and it is ignited for each identified need, thus several simultaneous processes unfold at once. The JLS represents mothers and fathers seeking primarily for their child through roles they each adopted that are reflective of their personalities, personal preferences, and skillsets. Along their journey, mothers and fathers encounter *ladders* that facilitate their journey (parental transformation, privilege, complementarity, relationships), and *snakes* (negative encounters with professional helpers, difficulty navigating formal support networks, and gendered support availability), that render their journey more challenging. The *Journey of Ladders and*

Snakes is recommended as a tool for healthcare professionals to engage mothers and fathers in a discussion about their own help-seeking: their experience, individual needs, co-parenting needs.

Background

Seeking help to assist with the daily care of their child is important to parents of children with neurodisabilities (ND). Yet, little is known about what their process of seeking is like, or what engaging in seeking entails. Numerous studies have documented the physical and emotional distress faced by parents of children with ND; they have higher levels stress, anxiety, and depression (Finzi-Dottan, Triwitz, & Golubchik, 2011; Thomson, Glasson, Roberts, & Bittles, 2017; Wang et al., 2013), and anger and grief (Sahu, Banerjee, Mukhopadhyay, & Sahu, 2017) when compared to parents of typically developing children. Their well-being is even more compromised when their child has behaviour problems (Lach et al., 2009). Support, when available and perceived as helpful, is expressed by parents as reducing these negative effects on them as parents (Al-Gamal & Long, 2013; Hassall, Rose, & McDonald, 2005; Kilic, Gencdogan, Bag, & Arican, 2013; Wang et al., 2013), as well as on their child (Ritzema et al., 2015). Yet parents who have sought help express not always being aware of where to look for help (Bussing, Zima, Gary, & Garvan, 2003), and they often experience support as not available or accessible, and as lacking the proper *fit and feel* (Boulter & Rickwood, 2013). In addition, parents report fearing stigma (Sahu et al., 2017), of being judged (Bussing et al., 2003), and express having engaged with help providers who lacked knowledge about resources and who did not relate with parents in a manner that they experienced as caring or empathetic (Nowak, Broberg, & Starke, 2013).

The experience of ‘being’ a parent of a child with ND is sometimes similar between mothers and fathers (Johnson, O'Reilly, & Vostanis, 2006; Kenny & McGilloway, 2007). However, the *manner* in which they co-parent may vary, as each takes on specific, individual, *complimentary* roles based on their own personal preferences and individual skills (McNeill et al., 2014). While mothers and fathers may be partners in parenting (Mueller & Buckley, 2014), if the family context they create is more traditional, mothers take on the role of the carer, and fathers the provider (Carpenter & Towers, 2008; Meadan, Stoner, & Angell, 2015). However, the impact of these different roles and structures on the *help-seeking* of mothers and fathers is not known. Existing scholarship provides insight into parents’ personal experiences of ‘being’ parents, and of ‘parenting’, and elucidates impressions about how they experience support access, availability, and adequacy. What remains unclear is how parents move towards seeking help in the first place. This study will shed light on precisely that process.

Help-Seeking Literature

The notion of help is solidly embedded within the profession of social work, from early inceptions of social workers as “helping people” (Jordan, 1979, p. 1), to the current definition that social workers are, “...concerned with *helping* (emphasis added) individuals, families, groups and communities” (Canadian Association of Social Workers, 2018). However, helping infers that there is a relationship between the help provider and the help seeker. Therefore, insight into how parents go about seeking help is needed into order to better understand how providing help is aligned with seeking help.

To date, much of the literature about parents of children with ND has been largely based on research with samples comprised primarily of mothers (Bogossian et al., 2017;

Willingham-Storr, 2014). More recently, researchers have identified this serious gap in knowledge and studies have begun contributing important information about father involvement in many aspects of the life of their child with ND (Hannon & Hannon, 2017; Meadan et al., 2015; Paynter, Davies, & Beamish, 2017). Including the voices of fathers within current scholarship that is overwhelmingly about mothers will increase what little we know about father involvement and outcomes related to having a child with ND, thus promoting a more inclusive and meaningful understanding of support.

Understanding what mothers and fathers need to assist them with the care of their child (what they seek for) and having knowledge about what support is available to help them is a familiar and important responsibility for social workers who engage with parents of children with ND. The other side of 'helping', however, and perhaps more important, is understanding the introspective nature of decision-making that impacts *how* mothers and fathers seek, as co-parents as well as individually: how they decide who seeks, for what, and under what circumstances. It is *that* process that will ultimately lead or hinder mothers' and fathers' journey to initiate seeking in the first place.

Context of the Study

This doctoral research was conducted in partial fulfillment of the first author's Doctor of Philosophy degree in Social Work. Members of the doctoral committee offered guidance and support as co-authors. The aim of the study was to understand how mothers and fathers of children with ND experienced seeking help for their child and for themselves, how they established help-seeking roles within their mother/father dyads, and how they navigated through and within support networks. This ConGT research project sought to answer the following research question: *How do mothers and fathers who co-parent their child with ND seek help for their child and for themselves from within their informal and formal networks?*

Methodological Approach

This qualitative study was designed utilizing a ConGT approach (Charmaz, 2006a, 2014) to generate an understanding of how mothers and fathers of children with ND seek help. ConGT is one of the most commonly utilized qualitative methodologies in social science research (Morse, 2009; Oktay, 2012), and it aligns with the interactive, relational professional engagement that is at the heart social work. Ontologically and epistemologically, ConGT presumes an evolving reality that is co-constructed between researcher, research participants and the phenomenon being studied (Guba & Lincoln, 1994). Similarly, social workers' engagements with clients aim to create a relationship through which a joint understanding of the client and client needs leads to helpful and meaningful assistance. As such, a ConGT approach to a study on helping in the field of social work is well aligned, and most appropriate.

Method

Recruitment

A purposive sample of mothers and fathers was recruited from four different sources: i) existing database ii) snowball sampling iii) Facebook advertising iv) word of mouth. Initial recruitment began through the *Parenting Matters! The Biopsychosocial Context of Parenting Children with Neurodevelopmental Disorders in Canada* (PM!) database consisting of 263 caregivers (n=198 mothers, n=52 fathers, n=13 other) of children with ND (n=91 female, n=147 male) between the ages of 3-13 years (M=8.18 years, SD=2.51) (Ritzema, Lach, Rosenbaum, & Nicholas, 2016). Parents from that study who had consented to being contacted for future research were contacted for this study if: (1) they were a mother or father of a child with ND, (2) they actively co-parented with their child's other parent, (whether or not they lived together), (3) their child with a ND was aged 5-17 years; (4) they could communicate in English or French; (5) they had been recruited from an establishment within the province of Québec. Subsequent recruitment was conducted through snowball sampling, advertisement Facebook groups for parents of children with disabilities, and word of mouth guided by the same inclusion criteria. A total of twenty-one mothers and fathers were identified as potential first contacts through this process, and each was contacted by the first author using available contact information (emails, telephone number) who described the study to them and inquired about their interest in participating. Of those, 7 expressed an interest in participating and were asked to solicit the participation of their child's other parent (mother or father). Only 2-parent dyads were included in the study, and only data collected from both parents of a dyad were included in the analysis. Interviews were conducted face to face in a location chosen by each parent (home, private library room, private work office, coffee shop) between November 2016 and February 2018. After having completed their interview, each parent received a $10.00 gift card for their participation. A total of 6 mother/father co-parenting dyads (n= 6 mothers, n=6 fathers) participated in the study.

Sampling

In line with the sampling guidelines of ConGT, both initial and theoretical sampling techniques were utilized in this study. Initial sampling served as a starting point through which the first author began engaging with participants in the study (Charmaz, 2006b, 2014), based on the inclusion criteria established for the study. In particular, given the dearth of fathers' personal experiences in current literature about parents and parenting children with

ND (Meadan et al., 2015; Willingham-Storr, 2014), it was imperative to ensure the participation of both mothers and fathers. As preliminary categories were developed through the analysis of the first 3 interviews, theoretical sampling commenced allowing for categories to be further developed and verified, and for relationships within and between them to be established (Charmaz, 2006b, 2014). Additionally, interview questions were modified, added, and/or removed as interviews progressed in order to deepen the discussion about aspects of help-seeking (e.g., parent roles, relationships between parents and sources of help) that would add depth to developing categories as the eventual theory was formulated. In lieu of using theoretical saturation, the point at which "gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical categories" " (Charmaz, 2014, p. 213), as a sign of data gathering completion, the end point of recruitment for this study was based on Dey's (1999) concept of *data sufficiency*, the understanding that reaching a point of category exhaustion is likely impossible, thus, leading to the necessity to the achieve a point of "good enough", "... the stage at which categories seem to cope adequately with new data without requiring continual extensions and modifications" (Dey, 1999, p. 117).

Data collection

Data for this study was collected through in-depth, semi-structured, individual interviews with mothers and fathers who co-parented their child with ND, in a location of their choice. Interviews were conducted in English and/or French, each lasting between 64.52 minutes -104.43 minutes (M=86.71 minutes). Signed consent was received prior to the interview, and participants were reminded that they could pause the interview to take a break, and/or end the interview completely should they decide to terminate their participation. A preliminary interview guide consisted of open-ended questions designed to elicit discussions about family context; types of help needed/sought; characteristics and relationships of help-seeking; decision-making; and help-seeking over time. Descriptive data were collected through a 26-question demographic questionnaire, and data about child functioning were collected using *About my Child* (Ritzema et al., 2016), both of which were available in English and French.

Data analysis

Audio-recorded interviews were transcribed verbatim and de-identified by the first author (one interview was transcribed by an individual outside of the study), verified for accuracy against the audio, and then uploaded into Dedoose, an online application for conducting data analysis. Descriptive and child functional data were each entered into prepared documents using Microsoft Excel for Mac, version 14.5.7. These were verified for missing data and parents were contacted for details when necessary.

Interviews were analyzed according to ConGT guidelines that involved asking analytic questions of the data to develop the understanding of *help-seeking* that guided the theoretical direction of further interviews (Charmaz, 2006b). Analysis began with line-by-line coding, a heuristic process through which each line, or small portions of text were attributed one or more codes using short phrases and/or gerunds when possible, that represented their essence. Initial coding resulted in the production of over 700 codes that were then viewed and reviewed in order to find commonalities. Iterative in nature, the ConGT coding process involved a constant comparison back and forth within and among past and new interviews. This established links and relationships that lead to a preliminary conceptual map of the theory being developed.

In the next level of coding, *focused coding*, codes were named and renamed and transcript excerpts coded and recoded accordingly, providing deeper insight into their significance to the emerging theory. This lead to the development of initial categories in which significant codes were then organized, and that elevated the analysis to the beginning of a theoretical level (Charmaz, 2014).

The final level of coding for theory development was exercised in combination with Dedoose and printed compilations of categories and associated excerpts extracted from it. Re-examining the categories using axial coding (Strauss & Corbin, 1998) meant that they were organized and examined based on their relationships to each other, "answering questions such as when, where, why, who, how, and with what consequences" (Strauss & Corbin, 1998) and leading to an elevated conceptual understanding of them.

An important component utilized from the beginning and throughout the analysis process was the use of memos. Memos provided the first author a means of writing about codes, of pondering initial and subsequent ideas about data, of creating a "...methodological link, the distillation process, through which the researcher analytically transforms data into theory" (Lempert, 2007, p. 245)

Results

A total of 14 mothers and fathers (n=7 mothers, n=7 fathers) comprising 7 parenting dyads were recruited into this study. One parent withdrew and so that parent dyad was eliminated from the study. The final sample consisted of six mothers and six fathers (6 parenting dyads) each of whom participated in one semi-structured interview. Parent's ages ranged between 39 yrs.–54 yrs. (M=46.11 yrs.) with mothers being slightly older (M=47.88 yrs.) compared to fathers (M= 46.16 yrs.). All parent dyads comprised mothers and fathers who were married to each other except one in which parents were divorced. The mother of this dyad had remarried and the father remained single and they shared custody of their child 50/50. All were biological parents to their child except for one dyad who had adopted from abroad. Most parents worked full-time (n=9), two parents worked part-time, and one parent was home recovering from illness. Three parents reported also being in school part-time. Individually, parent's reported annual incomes ranging from \$30,000-\$39,999 to \$80,000+ (n= 1 \$30,00-\$39,999; n=3 \$50,000-\$59,999; n=3 \$70,000-\$79,999; n=5 \$80,000 +). (See table 1)

Table 1: Individual Parent Characteristics

Parent Code	Parent Name**	Child's Name**	Age	Annual Income	Education
02-Fa	Marc	Annabelle	39 years	\$80,000 +	High school
02-Mo *	Nathalie	Annabelle	40 years	\$80,000 +	Technical school
03-Fa	Victor	Connor	44 years	\$30,000-\$39,000	Technical school
03-Mo *	Helene	Connor	42 years	\$70,000-\$79,999	University degree
05-Fa *	Charles	Paul	51 years	\$50,000-\$59,999	University degree
05-Mo	Simone	Paul	53 years	\$80,000 +	Some university
07-Fa *	Alex	Charlotte	42 years	\$70,000-\$79,999	Technical school
07-Mo	Bridgette	Charlotte	40 years	\$70,000-\$79,999	Some university
10-Fa	Trevor	Mike	48 years	\$50,000-\$59,999	University degree
10-Mo *	Nicole	Mike	48 years	\$50,000-\$59,999	University degree
11-Fa	George	Mathew	53 years	\$80,000 +	University degree
11-Mo *	Anne	Mathew	54 years	\$80,000 +	University degree

* Indicates the parent who was the first contact in each parent dyad ** Parent and child names represent pseudonyms.

Mothers and fathers were parents of boys (n=4) and girls (n=2) between the ages of 8 years and 15 years (M= 10.66 years) who attended specialized classes within regular schools (n=4) or specialized schools (n=2). They reported being concerned about 3-20 (M=13.8) items of their child's functioning (out of a possible 26 items), within 9 domains, for complexity impact scores ranging from 0.65-2.57 (M=1.6) out of a range from 0-3. (See table 2)

Table 2: Child Characteristics

Name	Age	Domains of concerns * (0-9)	# of Concerns (0-26) *	Impact score (0-3) *
Annabelle	9	Physical function; daily activities; communication; mood; cognition; social skills; participation	17	1.7
Connor	10	Daily activities; communication; behaviour; mood; cognition; social skills; participation	14	2.03
Paul	10	Physical function; daily activities; communication; behaviour; mood; cognition); social skills; participation	19	2.3
Charlotte	8	Communication; behaviour; mood; social skills	6	.65
Mike	12	Daily activities; communication; behaviour; mood; cognition; social skills	10	1.3
Mathew	15	Physical function; daily activities; communication; behaviour; mood; cognition; social skills; participation	20	2.57

* *About My Child* (Ritzema et al., 2016) is a 26-item measure about child functioning and its on child's participation within eight domains: (1) physical function (2) activities of daily living (eating, toileting, dressing, sleeping); (3) communication (4) behaviour; (5) mood; (6) cognitive abilities; (7) social skills (with peers and adults); (8) participation in activities outside of school. A *complexity score* determines the number of functional indicators that a parent is concerned about. For this score, parents are first asked to indicate whether they are concerned about the 26 functional items by indicating yes/no. The number of 'yeses' is totalled. For each *yes* item, parents are then asked to indicate to what degree they perceive the item impacts their child's ability to participate in everyday activities (not at all, a little, somewhat, or a lot). A numerical value ranging from 0-3 is attributed to each impact answer. The mean of the total score is then calculated for the *impact score.* Higher scores indicate greater complexity. *About my Child* has a high level of internal consistency (Cronbach's alpha = .84). It is estimated that the completion of both measures will require approximately 10-15 minutes, combined.

Substantive Theory: The Journey of Ladders and Snakes

The *Journey of Ladders and Snakes* (JLS) describes the process that mothers and fathers of children with ND undertake when they seek help for their child and/or for themselves within formal and informal support networks. JLS is about decisions mothers and fathers face, roles they adopt, and the actions and sometimes inactions of mothers and fathers that led them to locate "*...resources for him, for his path*" (Helene), as well as "*the information that you need that can come to your aid for whatever it is that you're looking for*" (Marc). JLS recounts their process of looking for guidance, and of wanting to be helped by *"...someone who is helping me* *find what I need"* (Bridgette). It stems from coming to the realization "*...that there's something that's not right, and I want to find out what that is, because I felt, if I knew what that was, then I could help her*" (Victor). JLS is about focusing on today, anticipating the future, and knowing that the seeking will be "*ongoing since, you know, when you have a child with his profile, it's a constant, you know*" (Nicole), because, "*when it comes to the brain, you're never out of the woods*" (Nathalie). Help-seeking is an emotional plea that "*for me was not crying but screaming out, saying, 'I need help'*" (Simone).

The Metaphor: Ladders and Snakes

The help-seeking *Journey of Ladders and Snakes*, a perpetual version of the well-known board game, has a clear-cut objective: to claim success after reaching the end of the first board, then keep playing the game as the next board appears. The journey on each board is neither straightforward nor linear. It is unclear how quickly one will reach the end of the board. The journey cannot be predicted, and it is determined by the toss of a die and by the path the toss will cast. Some tosses offer safe passage forward, a methodical and uneventful movement from one square to another, sometimes more than one square at a time. Lucky tosses lead to a ladder that raises higher, faster, closer to the end of the game. Unlucky throws spiral participants downward and backward, along the back of a slithering snake, where they wait, uneasily anticipating their next toss, and where that toss may lead. A mother's or father's predominant motivation for taking the journey is their child. Every roll of the die, climb up a ladder, and spiral down a snake, largely dedicated to their unfaltering journey of seeking the help their child needs. Most of the journey is taken by following the formal rules and regulations leading to the unfolding path ahead. Other times the pace of the journey is neither accelerated by a ladder nor decelerated by a snake, but rather continues forward in a step-by-step manner. Arriving at the final square at the end of a help-seeking journey indicates they have taken all necessary steps and have arrived at the end of that particular journey. While not all arrivals are necessarily victorious, those that are offer mothers and fathers the added benefit of relief that indirectly, is helpful to their own well-being.

The Journey

The *Journey of Ladders and Snakes* is informed by whom mothers and fathers are as individuals and as co-parents, by how they determine when help is needed, and by what steps they need to take in seeking it. The perception of help-seeking as a *journey* emerged from mothers and fathers describing seeking as ongoing and continuous; as a series of interconnected decisions, discussions, and actions that occurred between themselves as co-parents, and with external helpers as they searched for help. "*It's a continuous battle. So you, you think about it, that it's going to go off, but it's continuous. With these conditions, it will never disappear*" (Charles). The *journey* had a known starting point that arose, mostly, from a declaration and acknowledgement of their shared concerns about their child. The endpoint, however, was not always clear, suggesting a forward movement towards help that was sometimes halted or sent backwards by expected and unexpected twists and turns, only to commence again, in a forward motion. Thus, help-seeking as a *journey* was depicted by a route, a course, a path that mothers and fathers took both alone and together, as they sought help.

The help-seeking metaphor of *ladders and snakes* emerged as mothers and fathers described aspects that either facilitated their journey forward, or hindered it. Specifically, the adoption of *ladders and snakes* as the metaphor of this substantive theory came directly from the words of Simone, mother of Paul, as she described embarking on a journey to obtain respite care for her child. It was the first time she had attempted to gather information from resources in her community, and she had made several calls, left numerous messages, and spent ample time waiting and wondering what would come out of it all. Using her hands animatedly to indicate directions, she stated:

> *So there you tell yourself, ok. You, you do this, and then I'm going to go there, and I'm going to ask to go here, and then I'm going to go there. And when that's done, I have to call here, and then take him there. It's like a game of snakes and ladders*[v]. (Simone)

The visual image of Simone tossing a dice, and of her moving tentatively forward, not knowing if she would land on a ladder that would propel her forward, or on a snake that would sent her spiraling back down, very clearly characterized the journey she had been on, and linked closely to how other parents described their own journey.

Whether living together or apart, mothers and fathers in this study described their journey as one that typically evolved with their child's other parent. It played out through specific roles that each adopted, that formed the seeking patterns specific to their own seeking process. Most parents shared the sentiment that the roles each adopted within their seeking dyads occurred naturally between them, (without discussions about who would take charge of what). Some parents explained that roles were based on their personalities and preferences. Parents who were quiet, more timid, more contemplative and gentle in nature, often contributed to seeking help by researching and gathering information through the internet, (e.g., on websites, in parent groups), rather than initiating and interacting directly with help-providers. Parents who were more outgoing sought human contact through telephone calls, attending information sessions, participating in parent groups. Helene

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[v] This last section of quote was translated into English from it's original French: *C'est comme un jeu d'échelle et glissoire*

described how contrasting characteristics between she and her child's father played in the roles each took on:

> *I do a lot of the help-seeking, I suppose because, uhm I always say, I do the macro and Charles does the micro. So, I'm the one who, and he would agree, I'm pretty sure, I'm the one who found the school. I got the dog. I found the money. I get this. I fight for that. I do that. And he keeps Paul on track as much as he can. So really, it works a lot like that. Like, it's always, uh, partly because I'm so impulsive, not exactly impulsive, but I need to have results fast, so I'll pick up the phone and start, you know, complain and complain and find this and that. And my husband is a little more methodical, and takes his time to make decisions (laughs). So I think that's part of the reason. Like, I'm always off uh, off the starting gate right away to find solutions about this or that, for better or worse (laughs), and he takes his time.* (Helene)

Roles also were adopted based on particular parental skillsets. These were particular concrete skills such as being one's ability to focus, being a problem-solver, being organized, being computer savvy. Skills were also interpersonal, where some parents had more ease with communicating, or were a 'people person', more personable, more comfortable talking things through. For Alex and Bridgette, seeking was shared between his comfort with locating resources, and her ease in initiating the asking process:

> *Uh, being more resource savvy than Bridgette, I'm usually the one whose good about finding certain resources, getting those phone numbers, yup, yup. And then she's good about making that first contact and following up, and getting things started.* (Alex).

George and Anne adopted their roles based on Anne's ease and comfort with gathering help (e.g., related to health, education, socialization), and George's ease with implementing and integrating help into the routines of everyday life (e.g., learning about, understanding, and applying help). While Anne engaged with help networks to locate documentation and understand the support options available for their son Mathew, George absorbed the practical aspects of help and implemented programs and other recommendations within the home. In a sense, Anne and George's help-seeking roles relegated Anne as the 'gatherer' of help, and George as the 'doer' of help, each complemented the other:

> *Like, getting the specific help for Mathew, he would listen really carefully to the educators about what needed to be done. ... Like, I think he was really on it much more than I was, for the strategies. You know, the de-escalation, stop talking and all that. He, he absorbed that* (emphasis) *help, much more than I could. The more specific stuff about finding the help, I was really more the one who did those, in the institutions, the fighting, the calls.* (Anne)

Sometimes it was not parent characteristics that lead to certain roles over others, but life situations and circumstantial conveniences; parents did what needed to be done based on who was available to do it. "*When things need to be addressed, you need to address them*" (Charles). Trevor explained that for he and Nicole, employment circumstances determined their seeking roles:

> *Well, I think we just kinda fell into our roles but, um, I can't remember us discussing it. Yeah, I was starting a new business ... and, you know, I think we just fell into the roles where, after she*

> *stopped working, she would look into all this and that and I would support her as much as I could when I got home. So we sort of fell into those roles and it really* (emphasis) *hasn't changed that much since then.* (Trevor)

Mothers were typically identified as the parent who recognized the initial concern(s) that set (the first) help-seeking process in motion, "*At the beginning, she, she recognized, something's wrong, there's something not right with Charlotte, the way she behaves, you know, reacting to situations and all that.*" (Alex) Once a concern surfaced, mothers and fathers together, determined if they would proceed, with each then embarking on their respective roles:

> *Yes, yes, we both generally come to a consensus that, yes, there's something going on, we need to find what we need. Uh, being more resource savvy than Bridgette, I'm usually the one who's good about finding certain resources, getting those phone numbers, yup, yup. And then she's good about making that first contact and following up, and getting things started.* (Alex)

Mothers were also considered to be the main parent in charge, the one who oversaw the evolution of a help-seeking process, who planned and scheduled appointments, and who ensured necessary follow-ups took place. Trevor used the analogy of being on a locomotive to describe how he and his child's mother journeyed:

> *Well, if you look at, like being on board, like, it is (emphasis) like a train. And she'll be the engineer. I'm on the train. I will go to the meetings and I will listen and I will give my feedback and everything else, but she (emphasis) is really setting up these meetings. She is really, she could give you a complete hospital history of Mike... I couldn't do that. But she knows it, you know, flat! And*

> *she's the one who fills out all the forms... So, I'm behind her and I'll support her. I'll go to the meetings and I'll talk and I'll, you know, be funny and everybody laughs and all that, so that's great. I'm doing my part. And it's rare that there's a father in those meetings, so it's always good that I'm there, to sort of get the father perspective. But yeah, she's running the show. She really is.* (Trevor)

Mothers and fathers described journeying as something they did 'together' in terms of their decision making process of initiating seeking help; discussions they had about their concerns, and whether or not they felt the concern warranted them seeking external help. The notion of togetherness was also reflected in their process of sharing and discussing details about the various supports each had located on their own, in their attending appointments together, and in their making decisions about how to proceed once seeking had begun. Simultaneously, mothers and fathers described journeying as something they did alone, with each engaging in their specific roles, independently of the other, while seeking and/or implementing help. The *journey* was at once a partnered experience, and a solo undertaking.

Help-Seeking Starts from a Place of Grief and Loss

Help-seeking was expressed as a deeply personal journey that for most mothers and fathers began from a place of mourning, heartache, and loss over the child they had expected, but did not receive. It is a journey that some described as encompassing unexpected sadness about their child's non-typical development, whose birth had altered/shattered the hopes and aspirations they had anticipated and looked forward to, about what it would be like to be a parent, how their parenting would unfold, and what family and family-life would entail. Simone, the mother of twins, explained her experience(s) of grief after having received a diagnosis for her son Paul:

> *... they said, 'well, he's only three, three and a half, but this is what, this is our diagnosis. He's (name of diagnosis) child, um, high functioning ... child... and with, a uh, most probably with (possible second diagnosis), and also uh, (possible third diagnosis), uh, we don't know...' But, he was too, they're too small, they don't really say it but they said, 'we suspect'. So, that came. So I said ah, it's another grieving I have to do, because I have other grievings (pause). When they were born because, not knowing if they'd survive. Not knowing if they would be okay. Not knowing if they, you know (pause). And as soon as time went by, I sort of went "ok".* (Simone)

For some, being the parent of a child with ND required delicately balancing the grief for the lost of normalcy of one child, while simultaneously experiencing the joy of normalcy of the child's neurotypical siblings. For others it required a rapid adjustment to the newness and suddenness of entering an altered state of parenthood.

For some parents, loss was intertwined with other simultaneous situations, adding complexity to an already emotive experience. Trevor's sense of loss emanated from two interconnected losses: the loss of fathering a biological child (he and his wife were unsuccessful at conceiving), and the loss of being a father to a typical child (his adopted child has a ND). As an added layer to his grief, his only previous experience with adoption had been in his own childhood, as the neighbour to an adopted child with "special needs", whom he had feared as a child, and with whom he had hesitated to interact. He described:

> *... because he* (his son) *has special needs, I'm never going to have the same relationship as maybe I would with my own child, or with a child without special needs... So, you know, I grieve over my worse case scenario adoption. I grieve that my relationship with Mike is never going to be like my neighbour's relationship with his boys.* (Trevor)

Victor's account of the place that grief held along his path of the help-seeking journey summarises the sentiments of many mothers and fathers:

> *Definitely not the child I was expecting to grow up with... I think about my own childhood, and I look at friends' children and all that, and you get sensitized through TV as well, thinking of what growing up is supposed to be like. So I had this mental image of, of, a happy- go-lucky family and all that, where you know, yes, you have your little arguments and things to work on. I'm sure there are going to be some hurdles... But then, when you have a child that is difficult, and who almost seems to refuse to want to learn, your, your, your, your vision of what childhood ... what's a childhood supposed to be, in your head, it's not the same anymore. And, not that I didn't have that vision in my head, but, it's sort of disappointing to not be the father that I was hoping to be.* (Victor)

Parents' expression of their help-seeking also tapped into the visceral and private aspect of the process. For Alex, seeking help was a:

> *... spiritual thing where, you know, you're either just asking the universe, 'I need help with this. What am I going to do?', you know? So you sort of tell to yourself, from there (uh), you start looking to 'ok, what are the resources available to me to help me find the help I need or want'. You know (laughs). So, for me, it starts internal.* (Alex)

Parents also reported feeling dependent, out of control, and unsure when asking for help. Seeking help required that they take a step back from their independence and accept being in a place of vulnerability, where they were not the one in control, and that it was okay. Asking for help did not demean who they were as individuals, but to parents, this is how it felt.

> *Under normal circumstances, I am someone who is independent, ah, goal oriented, I know how to get from point A to point B, I can figure out what the steps are. But when it came to the circumstances surrounding my son, I'm not in the same water. I'm not in the same comfort zone as how I typically go about doing things.* (Simone)

Parents also described the sense of not having ever fully understood the full meaning of what having a child with ND would entail. Despite being given a diagnosis and subsequent information aimed at explaining and describing the condition and its possible impact on child and family, retrospectively, parents recounted that nothing did, nor could have, ever prepared them fully about what to expect. Marc recalled exiting the medical ward of the hospital where his infant son had just been diagnosed. In the elevator with him was one of the interns who had taken part in the diagnosis who, without saying anything to him, gave him a look that he interpreted as one of pity, gloom, and sympathy. The father remembers clearly feeling so hurt and angered:

> *Looking back today, I know why he gave me that look (nervous laughter), but at the time I didn't appreciate it. But um, you're never ready for, um, what's to come. You're never ready. No matter what your parenting, as much as you think you're going to be able to deal with it, yeah, you can (emphasis) deal with it, but it's (pause) it's hard. So, now I understand his look.* (Marc)

So, help-seeking is a journey that not only involves tossing the dice, but doing so from a place of intense affect. It is about a concrete process of mothers and fathers taking actions and making decisions related to locating support that will enrich and/or maintain their child's and their own quality of life. It is also an intensely intimate, private, and personal, process that for most, was linked to a sense of loss.

Help-Seeking is About the Child: "I'm OK if she's OK"

The help-seeking journey that mothers and fathers described through this study focused predominantly on the manner in which they sought help for their child. This help-seeking was directed at acquiring a diagnosis, trying to understand what the diagnosis meant in terms of their child's functioning, currently and for their future. It was also directed at locating specific therapies that would help increase and/or maintain abilities, to ensuring communication and socialization, education, and also about thinking of and planning for the future, in terms of living arrangements and vocational possibilities. Overwhelmingly, parents seemed to attribute a greater sense of urgency to seeking for their child than for themselves, a sense that their child depended on them to be their seeker, and that it was their responsibility to ensure their child's health and well-being. Parents adopted advocacy roles to push for their child's rights (e.g., for education, planning for future), rights that children would not be able to push for themselves. This, they did out of the sense that no one else would take on that role with the same commitment as they would. Alex and Nicole described it in this way:

> *There's, (pause), um, I don't know how to describe, there's more of a need, when, when I'm, I'm asking for help for Charlotte. It's like there's a greater importance to, to get something started. I think it's because I'm, I'm sort of responsible for her well-being, therefore I'm responsible to make sure that she gets the help that she needs vs. well, looking for help for myself. I'm responsible for that, yes, but I'm in more control of that for myself, or can judge for myself and all that, but I can't necessarily judge for Charlotte of what's going on in her head. So, for me as a parent, and her father, it's important right away, right, you know?* (Alex)

> *My thing with him has been that I've always been worried that if we didn't advocate for him, especially when he wasn't speaking. I mean he can't even speak for himself right now. I always worry that when he's a certain age, that he would look back at me and say, "why didn't you help me with this? or why didn't you fight for this for me", so I wanted to make sure that whatever he would want to do with his life, that we would have given him, kinda, the best chance to do it so.* (Nicole)

The focus parents placed on seeking for their child (first and foremost) did not denote a lack of recognition of their own personal needs for help. On the contrary, mothers and fathers were aware that along this journey they, too, encountered struggles and challenges that were difficult for them to manage. Rather than focus on themselves, parents suggested that, tucked away along their journey of seeking for their child first, their own sense of well-being was often reinforced by the knowledge that everything possible had been done to ensure the best help for their child. Therefore, while not all parents in this study sought help directly for themselves, most felt that when their child was well, they too, were well. In that sense, within helping their child, they were also helping themselves. Victor, Trevor, and Bridgette expressed it this way:

> *anything for Connor. I don't know what it is. I allow, as long as they're* (referring to his wife and child) *taken care of, I guess I say that, you know what, if they're taken care of, maybe their happiness will make me feel better. But, I don't, I wouldn't necessarily, if I had a choice, I would definitely, kids, Helene (wife), take care of them. Anything for Connor. Ask anything. For me, no.* (Victor)

> *If I know Mike is taken care of, he's going to a good school, he's got the right therapists, he's got the right social worker, whatever the case may be, yeah, it is (emphasis) a relief for me. And I can take, you know, that (emphasis) off my plate, knowing that he's taken care of.* (Trevor)

> *I never really thought I (emphasis) needed help, me personally, I always figured that if Charlotte is doing well, then I'm doing well. Um, that was not the case (laughs). But in my mind, you know, once she's okay, then I'll be okay* (Bridgette)

The sense of urgency seemed to shift in the case of a parental emergency, whence help for themselves momentarily exceeded their child's. Once the emergency had passed and things had fallen back into place, parental help-seeking shifted back to child being first. The justification for the momentary shift of urgency was explained as, if parents are not well, they cannot be there for their child. George explained it this way:

> *Mmm, well... you know, so it's all relative. I guess, if my immediate health and welfare is at risk, well, Mathew's therapy, it could wait. (laughs), You know. I know I'm taking it to the extreme... when it's a priority then, I know I have to be number one.* (George)

When mothers and fathers did seek for help for themselves, their overall experience of seeking differed from seeking for their child. While understanding the importance of their own health in relation to being able to parent their child, and in acknowledging that they did have needs of their own, they described having lower expectations of the support, and less demands of the helpers, when help was sought for them versus when it was for their child. For their child, they would push, and keep pushing until they had exhausted all possibilities. For themselves, they were willing to accept less:

> *I think I would be more demanding of the person I was asking for help if it was for (son). Um, for myself, I would accept, not a half-assed job, but you know, if I only got 80% completed, of the task completed, or 80% of whatever I needed, I'd be okay with that, if it was for myself. If it was for Mike, no. I think I would push.* (Trevor)

Older parents, while still ambivalent about seeking for themselves, suggested that aging had changed their perspective on seeking. Where they had once been thinking primarily about their child's needs, they had recognized the importance of addressing their own in order to be healthy 'for' the child:

> *It might be, I don't know if it's that but, maybe differences because of age, but, I think as we age we, we, also think, um, a little bit more about ourselves also. For me anyhow, I try (laughter) to because I tell myself, I have to think of myself if I want to be there for him.* (George)

When fathers sought help for themselves, they expressed being less decisive about the process than did mothers. Fathers were weary, tentative, and doubtful, not only about seeking help, but about indulging in help themselves. They described that for them, needing help was a sign of weakness, thus they only sought help after having exhausted every possible alternative they could imagine. Help-seeking was a last resort. Victor, avoided seeking help until he broke down at work, unable to function:

> *I broke down. I broke down at work... I felt, everybody has shit to do so, 'Victor, you know, like, what makes your situation any different?', you know, 'people have parents at home and they're still trying to do their thing'. One time he was at the hospital, and I just broke down... I'm doing the work, but you know, you're, you're working but you're not there. You're physically there but, you know what I mean, in mind, you're not there. So, yeah, I had to basically be (pause), crying at work, and that's, that's not me. So the day off, the uh, I went off that day. (Victor)*

When fathers found comfort in speaking with others, this was underlined by a sense of needing to justify how helping themselves would ultimately be in their child's favour:

> *there are some resources you can go to talk and, like this discussion group. (phew, let's out a deep breath) It was like a therapy for me.* (Charles),

> *you're doing it because it's going to benefit your child. You have more respite time for yourself, which I feel guilty doing but, you got to. You got to, but it always has to be in the child's interest.* (Marc)

Most fathers described that sharing activities, such as movies and video games with their friends was supportive to them, not because they spoke about their difficulties, but because they got to escape them for a while. For fathers, seeking help was thus, not always about addressing their needs directly, but about finding time during which they did not need to think about them. Overall, fathers had a sense of not wanting to show emotions, and of wanting the focus of seeking to be on their child and on their child's mother:

> *But yeah, I should have used someone from the (name of organization) to come in, because it was hard, right. I'm all emotional and sometimes, as a male we don't want to show it because, if she's emotional, and I'm emotional, how are any of us, I can't really help her because I'm already in the same emotional state... But I would say, give it to Helene. Let her have it. Maybe it's that whole macho thing, you know, "suck it up, Victor. You know, you'll just dust yourself off and move on". But I would say, help, yeah, I would relish it. I would love to have someone come in and talk to me, you know... one on one. I would love (emphasis) it. But if there was the opportunity, I would say, let Helene get it.* (Victor)

Mothers did not share the same narrative and personal view about seeking help for themselves that fathers did. Nor did they have the same hesitancy and reluctance to engage the help of others. Rather, they described seeking help for themselves as something that was normal and natural. Despite still favouring seeking for their child, mothers sought help, mostly for emotional support, from social workers, psychologists, and counsellors: "*Uh, I go to psychologists without any hesitation if I feel I need it*" (Ann). Mothers also described having established helping bonds within their informal networks, connections with family and friends that were reciprocal in nature. Thus, 'help' was not only something mothers sought, it was also something they provided. And at times, when support was not available, they created their own support groups, informally, within their social circles.

Seeking Different Kinds of Help Through Different Types of Networks of Support

Mothers and fathers expressed that their help-seeking journeys transpired with helpers from both *informal networks* (e.g., mothers' and fathers' own parents, siblings, friends), and *formal networks* (e.g., health and social services organizations, community organizations, alternative treatments). Networks were differentiated not only by the manner in which help was sought, but also by the types of help that were sought from each:

> *I'm not asking for the same help though. Um, when I'm asking for help from organizations and things like that, Um, I need hello, in the sense of, I need techniques, I need uh, insight on what works for a child who has (condition), you know? That's the kind of help I need. That's what I need from them. But my family and friends, i need emotional help. I need a shoulder to cry on. I need someone to listen t me. Uh, I get that from them and I want it more from them because from them, I want the " I'm here for you, I love you, I'm listening to you". You know, I could hear (emphasis) my mother hugging me, you know, on the phone (emphasis)! It was comforting, even though she didn't understand, like, she doesn't understand my experiences.., but, you know, she's had different difficulties and she's had heartaches, and she's been sad, so she can empathize in that way. Sometimes she doesn't say anything. I have a friend at work, they just listen, and sometimes, there's just, there's no answer or anything. I'm just letting it out because it has to come out, and it's like 'I hear you, and that sucks'. And it's like 'thanks'. That's all I needed to hear. You know, not advice, 'try this', no, no. Just 'man, you had a sucky weekend'. Like, 'I'm hoping this one is going to go better'. And that's all I need. I'm not going to get that from an organization.*
> (Bridgette)

Help Seeking from Informal Networks

Reflecting upon their experience of asking for help from family and friends, parents described it as almost seamless, and effortless, as a source of support that seemed to always be there, waiting to be called upon. Parents' access to informal networks varied. Some mothers and fathers had access to help from family members who lived close by; their own parents, sisters and brothers, aunts and uncles. Others sought help from friends, neighbours, and colleagues. While some had access to all sources, some, whose family members resided out of town, province or country, or who had not established relationships with neighbours, had access to less. Informal networks were asked to provide help related specifically to the child: spontaneous, action-specific help such as babysitting or providing transportation, or for emotional help, as well as for parents, themselves. Asking for help from any source within their informal network was weighed carefully by parents in terms of 'what' they were asking, how much they asked for, and how often they asked, to ensure the requested help lay within the helper's capacity and was not too intrusive. Victor's contemplation about how asking for help might be perceived by friends was shared by parents from this study who were cautious about not imposing requests on individuals who would feel uncomfortable to refuse:

> *But you, you are always in your head, trying to think of, like, you're trying to get into their head like, Ah, they're doing this because you're a good friend to them but they don't really want to but, uh, just take the help and run with it. But I can't. I'm always thinking, "what are they really thinking". I mean, you're forcing someone to do something. You ask them, "oh, my son is sick at the hospital, would you like to help"? They're not going to say "no". They're going to say "yes", because if they say "no", what does that look like?* (Victor)

In addition to family and friends, parents also described their child's other parent as a great source of support from their informal network. While the spontaneity of the help was more limited and required more planning when parents were not living together, parents, whether living together or apart shared a source of comfort, consistency and reliability with each other that was unique within their informal network. Further, parents reported that help from other parents of children with disabilities, whether in person or within social media parent groups such as Facebook, was another dependable and useful source of support, appreciated by parents. A great source of mutual understanding that naturally transpired between parents of children with disabilities, it was described as unique in that only other parents of children with disabilities could truly understand their shared experience. Parents' mutual understanding of what parenting a child with ND was like meant those parents, compared to parents of neurotypical children, were better able to offer support that was relevant and caring. Nicole explained that:

> *I have a lot of friends. And my friends all have typical kids. And it, it's not the same (laughs). They provide support in a certain way but it's, it's not the same because they, I don't think they understand the same way. So it's different getting support from somebody that understands it more. For me, anyway. So I appreciate my friends with the typical kids but, if their greatest worry is that their kid didn't cut their meat properly, and on that particular morning my son had a complete meltdown because his sock didn't go on perfectly, we're not on, it's not the same.* (Nicole)

An added benefit about engaging in parent support groups on social media, beyond the convenience of their being available during all hours of a day, was that they offered parents anonymity. As well, parents could engage within the group at a level they were comfortable with. For some parents this meant they actively engaged with other parents, both seeking help and offering help. For others it meant participating silently, without engaging, yet still benefitting from the silent support that appeared on the screen.

Help-Seeking from Formal Networks

The journey of seeking help from formal networks was described as more laborious than seeking from informal networks by parents from the study. Parents perceived that they expended a greater amount of emotional resources into seeking help from formal networks compared to what they expended when seeking in their informal networks, for what the seeking provided in return, and this from professionals whose roles it was to provide help. Thus, if help was not forthcoming from their informal networks, it was not seen as harshly as when help was sought and not received formal networks, as parents understood the mandate that helpers from formal networks operated by:

> *I just think, you know, this is your job (emphasis). I don't want to come down, like. I'm always about, this is your job, this is your role. I'm a job type of person. The help that we got at the hospital and the school, like, that's what you do. That's what you're expected to do.* (Victor)

Overwhelmingly, seeking help from formal networks was described as exhausting, combative, requiring mothers and fathers to compromise in terms of the quality and quantity of help they sought, versus the help that was made available to them. Parents shared the feeling that they competed with other parents, for similar supports, within a formal system they sensed was depleted of both tangible and professional resources. Further, they reported having unfulfilling and frustrating encounters with the professional helpers whom they knew were hired in a helping capacity, but whom they feared were not always equipped to provide the help they hoped for:

> *We got in some good arguments, and most of the time, we make compromises. Never 100% of what you want. I used to say, "let's, can we make a win to win relationship". I always try to make a win-win. And, let me tell you that sometimes you have to take a deep breath. Because when your kid, when first you get the diagnostic and all that, and then you go for your help. Sometimes it's not the frequency you want, and you have to say to yourself ok, what is it that I want? What is better, this or nothing? So then you have to, I mean, you take your choices struggling inside, I mean, struggle, maybe if I get this 2 days, then we'll talk about it in a month, in 2 months, And then you may ask, if there is a cancellation, may I take this cancellation. So I was trying to uh, to uhm you call me 24 hours before and I take the kid for that cancellation, to take that place. So we can do that. So it's always a bit of negotiating with them.* (Charles)

> *Some times when we looked for help, we weren't satisfied with the help that was offered because, you know, well, some times you land on a good worker in good organizations but they are restricted by, well, by finances and bureaucracy, and so there are good people and then there is not enough money to hire trained workers either.* (George)

Parents reported that the journey of seeking help from formal networks required persistence and determination, and that they needed to keep on top of things to ensure they got what they perceived was the little help available. Bridgette's emphatic description highlights the sense of frustration and exasperation that parents reported, and the degree to which they would go to ensure their child received the support they felt they needed:

> *You know, I always tell them, there's so many people, and I understand why there are waiting lists, and I understand why, you know, they want to help everyone. I'm sure they do. And, not to seem rude but, I really don't give a shit about all those other people. I care about Charlotte. That is who's important to me (emphasis). So I'm going to work my ass off for her (emphasis). And, if I want to be heard, and I want to stick out for them to hear me, then that's what I'll do. And by doing that, people hear you because, they kinda don't have a choice. And I don't know if, if it seems like I'm willing to work harder for my child than others. It's not the message that I want to give, but if that's going to let me [get] the help I need, hey, that's the message I'll send out. Make yourselves stick out so that they look at you, they remember your name, and then they will take you when it's the next one. And it might sound awful, someone might have been on the list for the last 2 years, but hey, if they didn't call again, that's, that. I know that there are other families, but mine is the one's that's important. Am I worried that I took someone else's place? No, because I don't have time to worry about that. I'm already worried about my kid. And if you're worried about yours and you're pissed off because I took your place, well then, scream and shout that I took your place.* (Bridgette)

For some parents, help-seeking from formal networks meant they needed to learn the fine balance of strategizing. At times, their chosen approach was to maneuver according to what they perceived helpers expected of them, following the rules and procedures in place. At other times it meant knowing when to lay back and let things happen. Charles explained how he and his child's mother shifted back and forth from being active to taking a step back:

> *So we, I imagine every parent seeking help, they need to play an active role. They can't be passive... because, yes, we've had those discussions where, sometimes Simone would be very emotional and say*

> *'we have (emphasis) to do something about this', or 'that doctor's wrong, we have to go and do x, y, z'. I'm like, 'no, no, no. These are the instructions for a reason. You know, they have rules and processes in place for a reason (laughs)'. So, there was a mixture of the two. And other times I (emphasis) was too passive and she said 'oh, we have to call them back', so you know, so there was a good balance of sort of um, keeping each other in check.* (Charles)

Another aspect of strategizing involved actively seeking and acquiring as much knowledge as possible so as to be seen by helpers as someone who has done their research and who wants to be informed rather than to be more passively waiting for help to be provided. Victor described how being prepared for appointments with doctors was seen positively by them. His sense was that when parents sought medical help from a stance of knowledge, they were provided more respect and courtesy than if they sought without knowledge:

> *Like, you can go to the hospital, speak to a nurse, and they might treat you one way or someone goes in ... and she'll be completely different. So .... I think it's the hospital. So, when we're sitting in front of the doctor, we're trying to sound as knowledgeable as them. So maybe that helps. Maybe that helps because they're like "maybe this person is doing their research. They're not just waiting sitting there waiting for the news". We're not like that. We're making sure that we're going out, like, he has this but we've heard that when he has this, and we have our research so we're doing our own little diagnosis, just to kinda coincide with them. And so, we have a lot of questions. Every time we see them (doctors), we have a lot of questions. They're like "guys, this is what we want from every parent", like a checklist, like, and we're like "we're not leaving till you answer our questions".* (Victor)

At all times, strategizing involved managing the tension between following vs. altering/challenging the rules of the game. Nathalie felt that it played in her favour to be "nice" to those she sought from: "*You know, that way, it's also a little bit sneaky but, that way, if they're rude, or whatever, for whatever reason, I'll be like "ok. I've been very nice to you"... so it gives me a little bit of ammunition if ever someone is uncooperative*". Alex was concerned with the notion of compliance and the impact that being judged non-compliant would have on him accessing help, the sense being that if he did not act accordingly, the help provider, in this case a medical professional, could be a gatekeeper. Thus for him, playing by the rules of the game was important. He and his wife had discussed the balancing of compliance in the past:

> *"So... I guess... if we weren't compliant parents, you know, following her instructions and giving her that, uh, feedback that she, she requested and needed, would she have been so willing to, you know, make those phone calls to the (names hospital) for us. Maybe not, because, 'well, the parents, they're really not helping themselves to help their child, so I can't do much more for them'.* (Alex)

The desired outcome of any strategy used with a help provider was to obtain the help mothers and fathers thought their child needed. Mothers and fathers described immense differences between the supply and availability of resources between public and private sectors. Parents with the financial resources to seek within the private sector who could purchase help resulted in their accessing support quicker and more efficiently. Consequently, their child benefited from support more expediently than children whose parents relied solely on the public sector. Thus, seeking help also required that parents strategically use help from every source available to them, when possible:

> *It was easier when I engaged. The (name of organization), they have information but they're always second-guessing. Like, "we can maybe get this service but I'm going to have to check back with so-and-so. We might not have the person available or it might not be offered in your area, or it might not be offered because you don't meet the criteria," or this or this or that. It's a lot of hassle.*
>
> *Whereas, when I engage, I know exactly what I need and my needs were immediately with getting professional to come, for me paying out of my pocket for it... So, the (name of organization) would come by for their consultations. People would come in. I'd get the equipment, I would get the service. But they [in the public sector] just don't have the capacity to be there when I need them as frequently. I have to make an appointment and it's phone tag back and forth for the person to make the assessment whereas I can get an (names occupation) to come in and do the same assessment, have it done faster. So it's less wait. It's fortunate that I have that, otherwise I'd be completely dependent on the (name of organisation).* (Marc)

The Changing Nature of Help and Help-Seeking

The journey of help-seeking was described by mothers and fathers as one that is ongoing, in that there are constantly instances, especially in their child's life, that elicit the need for help. Not only was seeking constant, parents described that the seeking roles they established in their early experiences of seeking, regardless of how they were established, remained constant over time. While mothers and fathers adopted each others roles temporarily if one or the other was momentarily incapable, for the most part, the roles they began using within both formal and informal networks did not change as time passed: *I'd say that, yes, it's um, it's funny eh, it's been, let's say, it's been about twelve years and, um, yes, it was like that,* *I'd say, it's always been like that.* (George). Where change did occur, was in terms of the types of help that were needed, and where the help was sought within formal networks. As their child aged, grew, and developed, and as they and their family evolved, needs changed in relation to different life transitions (e.g., entering/exiting school, exiting pediatric supports, planning for future vocational and residential needs). As these changes occurred, mothers' and fathers' help-seeking also evolved from pediatric settings, to young adult and adult supports. This meant that as they continued seeking, they did so for different things, from different organizations, thus requiring them to expand the breadth of their seeking resources in terms of types of supports, help settings and help providers. In addition, parents who sought help from their own parents described that as their child aged, so too, did their parents. As such, while their manner of asking for help did not change, mothers and fathers were more aware of the type of help, quantity and frequency with which they sought. Finally, the changing nature of help-seeking also reflected changes in parents themselves, as they became more knowledgeable of what seeking entailed, and so they could anticipate their process with more clarity.

Ladders and Snakes

Along their *journey* of seeking help, mothers and fathers were both enabled (ladders) and/or hindered (snakes) by experiences they encountered along the way. Sometimes these were personal in nature, reflecting aspects of who they were as individuals, and as co-parents. Others were based in policies and practices that, while meaning to be helpful, mired the seeking process, rendering it limiting and restrictive. Others still, were related to societal beliefs about disability, family, and the notion of family responsibility in care of its own members.

Ladders

A Sense of Transformation

When mothers and fathers thought retrospectively about themselves as individuals prior to the birth of their child, and then projected forward to themselves as they were on the day they participated in their research interview, they reported that their journey of seeking help had had an altering effect on them. The effect was that of being empowered, of having gained a sense of determination, and of them not feeling intimidated by the journey or the trail. It was of them being more confident and assured in the way in which they sought help. Mothers and fathers who recalled themselves as being laid back, reported having found a place within themselves that shifted their personalities into 'fighters'. These changes occurred as parents gained knowledge about their child's condition, as they learned more about what support was, what types of help were, or were not available, where the available help was located, and what the procedures for accessing it were. The changes also occurred through mothers' and fathers' necessity to push and persevere so they could obtain the help they sought. Bridgette described how her experience of needing to constantly call helpers back to keep her requests moving forward had transformed her into "*a pit bull*":

> *That's always been my experience so far, of asking help, not from a friend, but from anything like uh, a company, an organization: follow-up, follow-up, follow-up. You want something? You need to keep at them (slaps edge of hand on table)! Keep at them, 'I'm still here. I still need help. I still need this', you know? ... I think I've become more like a pit bull, than a squeaky wheel. It's more of a, you're just ah, 'you can't, I won't let you forget me, because this is what I need'. And especially in this case, this is what I needed for my child (emphasis)! No, I wasn't going to stop.* (Bridgette)

For Anne and other parents, the transformation was one that occurred specifically in relation to seeking for their child, so that when they were actively seeking, they engaged in manners that were more forceful than they would otherwise, in other circumstances:

> *...my personality tends to be more timid if it's about anything other (emphasis) than my son. So, if I had received a report on myself that I felt was wrong, I think I would probably have been more shy to question it. Where as for him, I don't even think. I just, like, out it comes!* (Anne)

While mothers and fathers in this study continually described the process of seeking as difficult and strenuous, they also described it as having provided them a feeling of strength of character that enabled them to keep pushing forward, even in the midst of adversary.

A Sense of Privilege

During the interviews, mothers and fathers spoke of the benefits that socioeconomic privileges permitted them in terms of the help they were able to seek and acquire for their child and themselves. Mothers and fathers recognized that being well educated and having the capacity to search and to learn increased their possibilities of locating help. Having access to computers at home and/or at work ensured quick and easy access to a world of information, and parents who were comfortable and at ease with the manoeuvres of "*googling*" (Marc), stated that they found a wealth of information through internet searches, and that computer searchers were one of their main sources of information, especially early on, during the period of diagnosis for their child. Mothers and fathers suggested that parents who were less educated, computer savvy, and less comfortable conducting computer searches would be disadvantaged:

> *We, we, read more and, it's not to say we are better but, it's sure, we have the chance, my wife and I, to be, to be, (name of their profession) and to be able to read a lot on the subject. But it's for sure that a single parent, or a parent who has less education, uh, it must be uh, I tell myself that it must be hard for those parents, seeking help, it must really be something. I don't know, I think about a single mother who is a recent immigrant, who has an autistic child, perhaps she will not have the same experience as we do. So, uh, that's it. Seeking help is quite the challenge!* (George)

For some mothers and fathers, their privilege of being financially at ease permitted them to access and pay for support that they otherwise would not have been able to afford. These were traditional aids and treatments that were typically available within the public health and social service sphere of support from whence most parents sought help (e.g., rehabilitation therapies, personal care, communication aids). These parents either had the monetary capacity to pay for support from private sources themselves, or they had private health insurance that refunded their expenditures. Financial means permitted parents to expand their seeking from the public health and social service sphere sectors of support, into the private market where they could access functional aids to address their child's mobility and safety, and where they could also locate and hire private therapists. Simone's experience went like this:

> *Ah, so, with the (name of organization), they introduced me with the (other organization) and the lady there sort of talked me into going into a sort of psychological evaluation where she introduced me to the (another organization), which is where they do, ah, psychological tests for (name of diagnosis), all kinds of things. And she said 'but its private so you'll have to pay'. So I said 'I don't mind paying. I mean uh, let's do it'!* (Simone)

Through access to private therapists, parents acquired functional assessments that were essential to their child much faster than they would have within the public sector, where most parents and their children waited. In addition, private therapists had more flexible schedules that meant parents could plan their own time more efficiently: "*Just because, again, it's the timeline of things. It just made more sense for our schedule*" (Marc). Private therapists also sometimes provided the therapeutic interventions that their child required, in an expedited fashion, meaning they did not have to wait for prolonged periods of time.

Some mothers and fathers in the study spoke also about having the added advantage of being able to acquire expensive alternative treatments for their child, that were not part of the traditional help available within the public sphere:

> *So Annabelle came out of the hospital and we went and did a lot of alternative therapies for her, (names two different therapies) ... and saw a lot of improvements ... so, we continued that for quite a number of sessions. I think she had over 400 sessions.* (Marc)

Having been able to purchase alternative treatments for his daughter, Marc was able to observe improvements in her, and so the high financial investment he made was worth it for him. Thus, financial ease granted mothers and fathers the ability to supplement or substitute the help they would otherwise have had to wait for in the public sector, and to gain access to alternative treatments that were not available to the general public.

A Sense of Complementarity

There was a sense from mothers and fathers in this study that they had naturally fallen into a process in which the limitations of one's capacities were bridged by those of the other, keeping momentum and a consistency going in the manner in which they sought help, and integrated help. This complementary manner of seeking rested on each of them adopting roles that had the best fit for who they were, what they were good at, and what they preferred doing. Parents talked about this complementarity of sharing responsibilities in terms of them creating a balance between one another:

> *I just, honestly, I feel that we kind of balance each other out. Because she's always ready to act (emphasis), and I'm always just ready to wait, give it a second. So it's kind of a balance. It's definitely a balancing act. Yeah, it's a balancing act. It has to be.* (Victor)

> *Yeah, yeah. We definitely each have pros and cons that, you know, uh, that balance each other out. Work off each other. No, it's good team-work* (Alex)

Balancing each other out was a way of rendering seeking more efficient, as each parent undertook elements of seeking that they were most comfortable with, to then come back together to discuss and make decisions. Parents described this complementarity as a means of each supporting the other:

> *And, for, for each other, so there's a balance between the work that we do. We are each other's support. You know, you're so involved in this, you know, that, I think so. I think, we need outside help too, but I think that uh, what I find really, we don't have conflict. You know (laughs). Almost*

> *none. And I think it's a great deal of solidarity, you know. Like there's a lot of love and affection.* (Anne)

Thus, complementarity between mothers and fathers was expressed as a positive aspect of their seeking journey as it provided a sense of sharing of responsibilities.

A Sense of Relationships

Within some health and social service organizations that parents described as impersonal and distant, parents occasionally encountered a "*bonne personne*" (George: Translation: a good person). These professionals were described as those who had gone beyond the call of duty to connect with mothers and fathers and their child in a personal and caring manner that felt reassuring and welcoming. These helpers' personal approach within their professional mandates rendered help-seeking more fulfilling by allowing for the necessary time that would permit them to truly listen to parents, to fully answer their questions, and to address concerns they might have about their child. Simone spoke about a contact she had had with a help provider in her formal network who had helped her understand some of the implications of her sons condition. This had been helpful to her because, as a mother to a child with a condition she knew nothing about, she felt seeking help could only take place if she had knowledge about what the problems were:

> *And this is why you, you could be very knowledgeable, very intelligent but, if you don't know, you don't know that you don't know. And you can't say, "let's find the solution", you don't even know what's going on. To find a solution you have to know the problem, eh!* (Simone)

Feeling they were engaged with professionals who cared about them was expressed as highly important by mothers and fathers who contrastingly, often felt they were rushed through appointments too quickly to establish any rapport, or to be provided with accurate and complete details of the situation(s) they had sought help for. Such fast-paced, rigid, and impersonal encounters not only left parents feeling bewildered and uncomfortable, they generated a sense of mistrust and wariness. For mothers and fathers, help-seeking with professional help providers was greatly influenced by the 'feel' of the relationship, and this set the pace/tone for future engagements. Helping relationships that felt nurturing and caring encouraged the maintenance of future help-seeking engagements with the same or different professionals. Those that felt colder and less personal created weary anticipation. Also, locating help was described as such a laborious process, and parents who reported having been provided the 'nuts and bolts' of what they could expect were appreciative. While knowing what to expect did not completely dismiss the frustrations that the journey would still entail, it removed the element of surprise, the element of unknown that added layers to an already complicated process:

> *Well, again, they're, they're advertising themselves to help the public and all that, and you have expectations right, I have expectations that you're going to respond to us in a timely manner and, and, you'll be upfront with us, you know, if there's going to be a long delay, ah, what the process is and all that. Just to be upfront and transparent from the beginning. For us, for me, it makes it easier, when all the cards are on the table. I know what to expect, what the path is going to be.* (Alex)

Parents suggested that at times, having relationships with the right people, individuals who either worked within the formal support system or knew individuals who did, or individuals who had a better understanding of how the formal system worked than they did themselves, seemed to facilitate the journey. The 'right people' were sometimes sources from their informal networks or from their formal networks who guided parents so their seeking was as efficient as possible. In these cases, mothers and fathers reported having been able to locate support more efficiently. Nicole described that for her, knowing the right people and pushing for support were essential:

> *You have to know the right people. It's unfortunate but if you don't, that's the reality. If you don't push and you don't ask, and the faster you figure that out (laughs), the faster you realize that (emphasis), the more you're going to get. Because, as a parent, if you're not pushing, someone's not going to push for you.* (Nicole)

When Simone was trying to locate support for her son, she recounts having contacted every person possible in her effort to seek help:

> *I've called people that I have not spoken to in many years. I don't care! "Get in here and help me" (laughs). So yes. I called because they know people, who know people, who know people. So yes, if you have a social network or you know, friends or family or, family that know people, uh, yeah, that helps.* (Simone)

Snakes

As with any long journey, along their paths, mothers and fathers encountered situations that made it more difficult for them to reach their destination. The main areas of difficulties stemmed from mothers' and fathers' interactions within formal support networks.

Difficult Relationships

Some parents in this study described difficulties in their relationships with help providers from formal networks in relation to their understanding of their child, suggesting that professionals in helping roles did not fully 'know' their child to the same degree and depth that parents knew them, and this, they suggested, was reflected in the evaluations they performed of their child's needs. The problem for parents, was that the evaluation reports produced by help providers were essential tools used in determining their child's eligibility to supports, and so, when they did not describe their child's level of functioning adequately, they, at times, hindered parents ability to obtain the help they had sought. An example of this was shared by Helene, who was contesting a decision about a tax credit she had applied for but had been denied. The application form had been completed by a health care professional, and when Helene called to contest, she spoke with someone on the phone who was unfamiliar with the rare diagnosis of her child, and who could only engage with Helene based on what was written on the form about her child, that, according to her, did not provide a clear description of her child's condition. The added component of complexity for her also was that her interaction was conducted over the phone with a worker whom Helene considered rude:

> *I met with uh, over the phone, the most repulsive people and most disrespectful people towards a parent. "Stop telling me what your kid can't do, tell me what your kid can (emphasis) do". I said, "but that's not what the form is. You denied me my request. You don't know anything about my child. I'm calling to follow up to say you need to check this over because you don't know my child".... I just can't take "no" for that. Because, if I (emphasis) don't know about (child's diagnosis), then I don't think the person on the other end of the phone is going to know about it. And what is written on paper is not what you're going to present with in person. That's hard. So I said, "let me speak to the doctor".* (Helene)

Parents furthered this notion by describing that it was not just about professionals' knowledge of their child, but also how respected they felt their own knowledge about their own child was. They felt very strongly that they knew their child the best, and unfortunately, this was not always appreciated by professionals, whose recommendations did not always seem to 'fit' with what the parents knew about their child. Thus, parents may have sought help, but their impression of how knowledgeable professionals were about their child, and how suited their recommendations seemed to fit their child, impacted their motivation to implement the help they might receive:

> *So, right now we know, and I think, like I said to Alex, not like I'm not listening to anyone any more, I listen, but, I'm really going much more on my own instinct, on how I feel and what I feel is good for Charlotte. I listen. I'll take points where I agree, but uh, I'm to the point where I am the expert on Charlotte! I know her more than anyone. And I know what works and doesn't work. So, I'm willing to try things and yes, I listen but I'm, it's been so long now that now I know, I know what works for her.... Because, I know they're professionals. But they're not the professionals of Charlotte. I am!* (Bridgette)

Parents also reported that, within formal networks, dealing with the ups and downs of help-seeking was an "*ongoing*" (Simone) and "*continuous battle*" (Charles) that threw parents into a sense of constantly needing to prove the legitimacy of their child's needs and of having their views cast aside in favour of the views of professionals. Bridgette provided an example of how this happened in one of her interactions with educators in her child's school. The sense of not being trusted did not stop parents from seeking. On the contrary, parents stated they were dependent on help from formal networks. The impact of feeling they were not trusted meant that they sought with a sense of greater vulnerability and caution:

> *Yeah, they wouldn't believe us. We, I often got that. Whenever I was meeting a new uh, (professional) or a new uh (other professional), um, it's like, uh, if the people ... like if they, when they would say something, oh! But when it just came from us, it always seemed like we were exaggerating. It always seemed like, well... But, when they got the same information from (professionals) (emphasis), oh well, then it's got to be true*" (Bridgette).

Difficult Navigation

Another common concern for parents in this study was how difficult their seeking was rendered by a formal network that they described as complicated and difficult to manoeuvre. Parents spoke about not being aware of what help was available and about not always knowing where to find it when it was. When they did find it, there were most often long waits for evaluations, and then for the help to commence, or there were strict eligibility criteria that made it impossible for their child to qualify for it at all. Parents reported being sent from one organization to another, through a process in which they repeated the same information, to different professionals. Trevor's experience summarizes this shared experience:

> *Lots of phone calls, being on the phone. Someone would call and I'd be, "ah, finally someone's going to give us something", and then they'd be like, "hm, sorry, you don't really qualify". But, I mean, it's, I totally, it's not their fault. Like the people we were speaking to were saying, "we feel really bad. But these are the parameters that I have and based on the report that you sent me, he doesn't fit in this box. But you could try over here (gestures with hands). (laughs) So then they would refer and then that person would call. And I think it wasn't until he got a little bit older and there was some behavioural issues coming out that now, all of a sudden, the (organization) is kinda like, "ok, now we can help you". But when he was younger, and not (name of diagnosis), and not, like, having maybe a little (emphasis) bit of behaviour, but nothing severe, it was like, 'you don't qualify for (name of program), and it's not enough to come over here (names other program). You're right in the middle and, "sorry, we can't help".* (Trevor)

This sense of being ping-ponged from one place to another was heightened for parents whose child had a rare diagnosis, one that was not familiar or common to support networks and for which few specific supports existed. Nicole experienced that added layer of complexity as her child "... *has always been the type of kid who's in the crack*", meaning the characteristics of his diagnosis never quite met up with the inclusion criteria used by organizations to allocate services. And so her journey of help-seeking was not only rendered stressful by the unpredictability of locating support but also by diagnostic-specific criteria, resulting in her child often being excluded from the few supports available:

> *... so he wasn't (name of diagnosis). He may have some tendencies but technically, he's not (name of diagnosis), so he doesn't fit into that group. ...Then he has (name of diagnosis characteristic), but until he started showing signs of like, more (name of diagnosis characteristic), because then they have that (name of program), but they would basically bat us back and forth, ... we sort of got dumped. And then I sort of tried to get us back in for help ... and then they didn't want to assign us a SW because they said he didn't really belong here, and then we went over here (gestures back and forth with hands), and we literally, we did this ping-ponging back and forth where this one would say, 'I'm pretty sure you belong over here', and then that one would call me and say, 'I don't understand why they sent you to us because, if you belong anywhere, you definitely belong over there'. So we kinda walked away from the (organization) because it seemed like, not happening.* (Nicole)

Another element that rendered seeking difficult was the impression parents had of needing to be in a crisis to gain support. That, unless their request was urgent, they would have to wait for support:

> *But uh, what I find in that. It's like, you have to have an extreme condition. If you don't fill a certain pattern, like a heart condition, extreme condition, you fall down. They don't take you. Sometimes you fall off of the list. Down or off of the list completely.* (Charles)

Difficulty in Consistency of Care Providers

For some parents, another difficulty in seeking help from formal networks of support related to their perception that networks were under funded, understaffed, and that the impact of this was of poor quality and consistency of care. George gave the example he felt regarding emergency placement units his son had utilized. He had experienced a turn over of personnel that made it impossible to establish and maintain a routine for his son and the other residents of the home. In addition, he described the workers who staffed the homes as inexperienced and ill trained for the job that was required of them:

> *Individuals who should take care of him (child) on the ground have ended up in uh, offices and are in charge of planning and they're instructing home care personnel how to intervene, but they have no experience.* (George)

In terms of help-seeking, George and other parents did not stop seeking when these situations arose. However, the impact these experiences had on their impressions of quality of care were great. For another parent, the turn over of staff had a two-fold impact, that, although not shared by other parents, it is presented herein as it highlights the very delicate nature of and privacy of intimate personal care. For Marc, the turnover of care workers from one day to another meant a lot of time was spent training staff and then retraining new staff. This was not only time consuming but very difficult for his child too. Much of the care offered to his child was very personal in nature and so having different people every day meant Annabelle exposed her body to new people on a regular basis:

> *So someone came in, we trained them and told them what they had to do. They would wash Annabelle and get her ready for bed. And that worked, until the next appointment, when it was somebody new* (Marc).

Not only was this difficult for personal reasons, the turn over also meant that for Annabelle: "*one says good-by and she's gone*". Marc stated that Annabelle would create bonds with the individuals who came to bathe her, but at the end of the day, when they left, she never knew if she would see them again. Annabelle was not only forced to allow different people to touch and clean her body, she also never knew if people she liked would return.

Difficulty Regarding Assumptions about Gendered Nature of Care

Both mothers and fathers in this study spoke about the gendered undertones related to seeking and being provided help by formal networks. Fathers described themselves as not willingly or easily asking for help for themselves, in particular when it was about issues that had an emotional connection to them. However, they also recognized that they sometimes experienced situations for which they could have benefited from help, even though they did not seek. In discussions, fathers described that they were not offered many opportunities, from professionals, to speak about their own difficulties, and that the typical mechanisms and support strategies that were available to mothers were not attractive to them, as fathers. For example, fathers spoke about individual counselling sessions and about discussion groups that were available to the mother of their child. These supports were also offered to fathers, but fathers were not drawn to these types of support, and so they did not participate. In addition, while mothers were often asked about their mental health by professionals, fathers reported that they very seldom were. Although when they were, even though they were not always forthcoming, they identified being appreciative about being acknowledged. While the forum for them to discuss their difficulties did not have the proper 'fit', fathers appreciated being acknowledged and appreciated when their personal experience was taken into account. Nicole recounted:

> *I don't know. Like anything, maybe because it's still set up where the man is working, I don't know. I would have thought that in this day and age it would be more even. But, I don't know. I find the guys, it's like in their mentality that, they should be able to handle things on their own. And it's, I guess, a sign of weakness to ask other people. Or maybe it's a privacy thing. Like, not wanting to, I don't know. I just find that for me, and I can think of specific examples where something has happened and I come home and I either phone somebody or ever, like one time I had an incident where I came home and I emailed some of my special needs friends. I was like, "this just happened and I'm a basket case". I said, here's what happened. I really don't want to talk about it. I don't want anybody phoning me. I just needed to put it out, and they all emailed me back, "I totally get you. This happened to me. If you want to talk you call me". But it was enough. It was enough to just lay it out and have somebody validate that it was okay that I was feeling this way. For me that's enough. But from what I can see, there's all these feelings that maybe feel like they're not (emphasis) okay, and there's nobody sort of validating for him. I try, but I don't think it's the same coming from me. Like, I think it would be good to have someone else kind of validate, as a dad, you know. Like, "I go through these troubles with my child too. This is not abnormal, what's happening to you guys".* (Nicole)

As a separated father who shared custody of his daughter and so, spent every other week parenting as a lone father, Marc described experiencing an added layer of complexity in seeking help because of societal views that held fathers to different standards about caring for their children. For Marc, not only was he a single dad, he was the father of a daughter. Support that was available for single mothers was not readily available for him:

> *Parenting is different if you're a mom versus a dad, and how you're viewed. And when you're biological parents who are separated you hear, "the poor mom and the dead-beat dad", that's the common theme. But when people talk and you know, what you see in the mainstream media is, you know, and I'm not trying to downplay women, it's not my (laughs) goal here. No, but you hear all this talk about the women, and the single women and the dead-beat dad, you know. And when the roles are reversed, there's no talk of it. There's no support for single dads, there's no groups, you know, but I'm giving the same level of care. There's no difference, except, I'm raising a daughter. What do I know about being a woman?* (Marc)

Discussion

The Journey of Ladders and Snakes is a substantive theory developed through the analysis of interviews conducted with six mothers and six fathers (six parent dyads) of children with ND in the course of this study on help-seeking. It reflects the process that mothers and fathers experienced as they sought help for their child and for themselves within informal and formal networks of support. It portrays seeking as an embodied and experiential combination of not only what mothers and fathers 'do' while seeking, but also who they are and become as individual seekers within a co-parenting context. It also connects to mothers' and fathers' desires and aspirations about becoming parents, and to their sense of loss and mourning at becoming a parent to a non-neurotypical child. At its core, help-seeking is about mothers and fathers being at a place they identify as one they are personally incapable of attending to themselves and for which they need assistance from sources external to themselves.

Help-seeking, as a *journey,* describes the movement of parents advancing forward from a starting point of need, towards a point of having left no stone unturned, in their quest to locate and secure help. The *journey* captures a coalescence of parental decision-making related to identifying need(s) and a desire to seek, and the roles and responsibilities each had assumed and implemented along the way. The *ladders and snakes* illustrate some of the catalysts and hindrances that parents encounter along their way, and it emphasizes their agency in creating the momentum they require to maintain forward motion. The *Journey of Ladders and Snakes* is at once a combined experiential process described by twelve mothers and fathers that is simultaneously unique to each parent and parenting dyad.

Mothers' and fathers' help-seeking occurs through relationships, those that occur between them, and with their child, and those that occur with the larger systemic context that includes sources of support from informal and formal networks, that operate within a socio-political context, on a continuum of time. These interconnected elements are reflected within the "ecological environment" of Bronfenbrenner's (1979, p. 3) ecosystems framework, a framework that is central in social work as it situates individuals within their greater contexts of influence. In his model, Bronfenbrenner (1979) identifies and situates the relationships that individuals have to other proximal and more distal subsystems that have a role to play throughout a child's and family's development. The individual being, composed of biological aspects and personal characteristics that comprise his uniqueness, is the innermost level. Extending outward from the individual, the *microsystem* represents those elements of influence that are closest to the individual and that impact them directly (e.g., home, school, peers). The next level, the *mesosystem*, reflects the ways in which various microsystems interact. The *macrosystem* represents a broader and more distant set of influences that include socio-political dimensions and culture. Lastly, the *chronosystem* adds the notion of the passage of time and it's impact on the evolution of an individual's development as they change through life transitions. Bronfenbrenner's model (1979) clearly situates the *Journey of Ladders and Snakes* as a process through which mothers and fathers interact with and are impacted by factors interacting at various contextual levels along their quest for help.

Grief and loss

The *Journey of Ladders and Snakes* brings grief and loss to the foreground as a common starting point for all mothers and fathers in this study as their help-seeking was initiated in response to their being a parent of a child with ND. Having a child with ND was not what they had expected when becoming parents, nor was it a possibility they had imagined or planned for. On the contrary, parents had anticipated the arrival of a healthy and neuro-typical child. They had dreamed about, and looked forward to activities they would engage in with their child, and had anticipated how being a family would play out for them. They had envisioned their child learning to walk and talk, and in their mind's eye had witnessed them entering school, graduating from university, getting married, and of them having children of their own.

These expectations and dreams were interrupted by the unexpected and surprising arrival of a different and unfamiliar child that crushed the vision they had anticipated. Parents of children who received a diagnosis early on after their child's birth or whose child had begun exhibiting atypical behaviours later all experienced significant grief and loss. These experiences were not dissimilar to what is already documented in the literature; parents of non-neurotypical children express difficult, sad emotions and grief in relation to their child and experience a loss of dreams (Fernández-Alcántara et al., 2015; Mulligan, MacCulloch, Good, & Nicholas, 2012). In their study on the adaptation of mothers to their child being diagnosed with autism, Lutz, Patterson, and Klein (2012) described mothers as being filled with sadness, anger and grief about having been "thrown a curveball" (p. 208), and about having to grieve the loss of dreams long term, from childhood to adulthood, as each goal they had anticipated for their child was not achieved. Fernandez-Alcántara and colleagues (2016) found similar accounts in their study on parents of children with autism who feared hearing the word 'autism' and who were saddened by the loss of the relationship they thought they would have had with "a healthy child" (p. 316).

Mothers and fathers in this study reported feeling angry that their child had a disability, and sadness about how the disability would likely change the course of their and their child's lives, they questioned and challenged medical diagnoses, and searched for alternate answers regarding the delayed development of their child. They questioned 'why me', how could they have been responsible for the condition? These reactions are somewhat in line with conventional ideas about the experience of loss (Konigsberg, 2011), and they are also different in that the mothers and fathers in this study were not mourning the death of their child, but experiencing sadness related to having a child who was present in their life, but who was different from the child they had anticipated. Their experience is perhaps more closely linked to the concept of ambiguous loss described by Boss (2000, 2016), who described the sense of loss that individuals can experience when a loved one has either disappeared, but remains closely present in the minds of their loved ones (physical ambiguous loss), or psychological ambiguous loss, the experience of having a loved one physically present, but in a psychological state of absence (e.g., individuals with Alzheimer's disease, memory loss). It is within psychological ambiguous loss that mothers and fathers more closely align, as they "...construct their own meaning" (Boss, 2016, p. 270) of their child, of themselves as parents and co-parents, and of their concept of family "... within a paradox of absence and presence" (Boss, 2016, p. 270). When contemplating help-seeking, it is important to remain connected to the experiential and emotional place that seeking stems from, to not forget that behind a seeking client, is a grieving mother or father. The experiences of grief and loss expressed by the parents in the *Journey of ladders and snakes* are important to keep in sight as they highlight an added layer of complexity to help-seeking in that, while mothers and fathers engaged in a process of looking for help, they were doing so from an emotional place of grief.

Networks of support

Informal networks

This study situated the help-seeking journey of mothers and fathers as one that transpired within both informal and formal networks of support. Each network was experienced differently, and mothers and fathers not only sought for different types of help from each, their expectations from each, in terms of what they thought they 'could' get verses what they thought they 'should' get also varied.

From informal networks (composed of their child's other parent, their own parents and immediate family, friends, and sometimes neighbours), mothers and fathers experienced seeking help as simple, straightforward, as 'helpful', (at times more so than support from formal networks), and offered through an emotional connection of care and concern that was appreciated by mothers and fathers. While seeking in informal networks transpired cautiously, with consideration of not asking for too much, too often, or for too long, mothers and fathers also had a sense that they knew what to expect from their journey within informal networks. This particular group of parents had a sense that the help that awaited them from their informal network would be experienced as reassuring. These findings resonate with current literature in which help from informal networks has been described as having a positive impact on parental well-being (Ekas, Lickenbrock, & Whitman, 2010; Hsiao, 2014; Jeong, Jeong, & Bang, 2013; Manor-Binyamini, 2014; Markoulakis, Fletcher, & Bryden, 2012). One example comes from the mothers in Caley (2012) who described their social support as dependable, calming, and caring, as one that provided a sense of being accepted. In contrast, some literature suggests that help-seeking from informal networks is impacted by circumstances that may render it more difficult to access. Cultural beliefs about disability sometimes impose a sense of isolation for parents who kept to themselves (Kang-Yi et al., 2018; Shang & Fisher, 2014; Wang et al., 2013) rendering seeking for these parents more tentative. Additionally, the help-seeking of newly immigrated families who may not have established informal networks are also impeded (Ben-Cheikh & Rousseau, 2013). Thus, help from informal networks, when available, sought, and received can be helpful. However, from a practice perspective, it is important to consider ways in which this help is negotiated and experienced as the particular circumstances of parents and their informal network relationships vary.

A common source of hep from within informal networks were mothers' and fathers' own parents, their child's grandparents, most of whom provided a consistent and dependable source of support such as child minding, cooking meals, transportation. This was also found in a study by Findler (2000) with mothers of children with cerebral palsy. Mothers from that study related that their own mothers was a constant source of support to her family and grandmothers were ranked as one of the most utilized source of support. While they were a reliable source of support, some mothers and fathers in this study spoke about how, as their child aged, they were conscious about that fact that so did their own parents. Thus, they found themselves continuously asking less from these very important sources of help. This is an important factor to consider within social work and for other health care professions (HCP), when discussing support with mothers and fathers. It is not enough to simply know whether or not grandparents (or others) are active sources of help, but in the case where they are, there is a need to also remain cognizant of how their availability and capacity to act as helpers may change over time.

Mothers and fathers in this study also spoke about how the internet had made searching for various types of information (regarding the diagnosis of their child as well as supports that could be effective for improving their child's condition), more easily accessible. In particular, the discussions revealed their use of social media as a tremendous source of support. In this study, many mothers and fathers participated in on-line parent support groups (e.g., Facebook parent groups). These groups were considered helpful as they were constantly available, and they allowed for parents to participate within the safety of relative anonymity if they so desired. They could either be active and contribute their comments to postings, and write posts of their own, or they could 'log on' and silently absorb the ongoing conversations passively. These findings are congruent with recent studies about the gaining popularity of social media as a source of support for parents of children with disabilities. In these studies, on-line support groups are described as a place where parents could offer and seek help within flexible time frames (Mohd Roffeei, Abdullah, & Basar, 2015; Reinke & Solheim, 2014).

Formal networks

Help sought from within formal networks was experienced with less satisfaction than from within informal networks. It was consistent with a vast empirical scholarship that has investigated support needs of parents of children with ND, in which it is described as bureaucratic and difficult to navigate (Nowak et al., 2013; Olsson & Roll-Pettersson, 2012; Whitehurst, 2012), and in which parents experience long wait times for access (Ben-Cheikh & Rousseau, 2013; Connolly & Gersch, 2013). In this study, mothers and fathers described having a lack of awareness about what support were available to them, and even when they did know what was available, the access mechanisms were detrimental to seeking, rendering the entire experience difficult and confusing.

Mothers' and fathers' experience of being unaware of what they needed highlighted the importance for help-providers making information about support more readily available (Alsem et al., 2017; Nowak et al., 2013). Overall, mothers and fathers experienced the formal support network as constraining and difficult to manage, and they described experiencing long and uncertain wait periods for supports their child needed but that were often not available or accessible. For example, mothers and fathers described seeking help that was based on diagnosis-specific eligibility criteria that was unavailable to parents' children who did not have the required diagnosis. In this study, data from the *About my Child* (Ritzema et al., 2016), demonstrates that the children of parent participants shared several similar functional concerns, despite having five different diagnoses. This suggests that a non-categorical approach to accessing services based on functional concerns rather than diagnoses may improve and increase access if functional concerns are used as eligibility criteria rather than the diagnosis itself. Support availability from within formal networks is characterized as lacking (Kirk, Fallon, Fraser, Robinson, & Vassallo, 2015; Lin, Huang, & Hung, 2009; Samadi, McConkey, & Kelly, 2012; Shin & McDonaugh, 2008). As with help from informal networks, aspects of culture and immigration also contribute to parents' experience of hep-seeking from formal networks. Compounding these difficulties are socio-demographic variables related to poverty and language that make learning about the availability of help and the systems in which they are located more challenging (Ben-Cheikh & Rousseau, 2013; Jennings, Khanlou, & Su, 2014).

Co-parenting

While the aforementioned findings speak directly to the manner in which mothers and fathers 'experience' the help they sought, they do not speak about the actual 'journey' they undertook whilst seeking the support. Mothers and fathers in this study described their *Journey of Ladders and Snakes* through formal networks as a process that was highly demanding of their time and input, and that evoked a notion of them needing to 'battle' for support. Their journey required constant action and maintenance on their part in order for them to remain abreast of support that was available, and on top of support that had already been initiated. It required strength, persistence, and determination. Yet, while these demands on parents were portrayed as exhausting and depleting, they also highlighted an aspect that may be particular to this sample: the personal investment that mothers and fathers made in help-seeking was characterized as teamwork.

Mothers and fathers in this study described their help-seeking as being highly collaborative, and complementary. While they expressed having adopted individual roles (sometimes unique to them, other times shared), they portrayed these roles as highly connected to each other, and as being equally important in the help-seeking process. Where one may have searched for information on-line, the other made direct contact with individuals. Where one may have gathered and organized the available resources, the other worked with therapists to integrate recommendations into daily family life. This sample of mothers and fathers experienced a co-seeking process that has not yet been documented.

Current studies are most often composed of samples that include one or the other parent, in most cases, a child's mother, or where the co-parenting focus of the study is on parent relationships, not help-seeking (Saini et al., 2015; Sim, Cordier, Vaz, & Falkmer, 2016).

The co-seeking experience of mothers and fathers in this study is linked to the work of Maynard and colleagues (2016) who highlighted how parents of children with ASD utilize different styles of intervening with their child with ASD, and most particularly, with the work of McNeill and colleagues (2014), who define both complimentary and symmetric roles that parents of children with ND adopt with their children. The commonality with these studies, being the co-parenting. In this study, investigating the relationship between mothers' and fathers' was possible, as solely mother/father parenting dyads were included, thus the *journey of ladders and snakes* adds to the co-parenting literature by extending an existing discussion about parental role establishment into how these established roles work together through a help-seeking process. It also adds to the small body of literature about help-seeking within the context of parents of children with ND, and to the even smaller body of literature where the help-seeking adds the perspective of co-parents. Admittedly, the findings speak to ways in which parents co-operate with one another. The parents in this study chose to be interviewed about how they navigate help-seeking, together and apart. Thus, it does not reflect help-seeking among parents whose communication is problematic, where negotiation of roles is a source of conflict, of where parents are seeking help solely on their own.

Ladders and snakes

Through the discussions with mothers and fathers in this study, and through the analysis of their narratives, there emerged elements that they encountered along their journey that helped make it unfold more efficiently, or, on the contrary, rendered it more difficult and heavy. Of these, two are particularly salient and will be highlighted: gendered experience of seeking and support, and helpful relationships.

Gendered and personal experience of seeking and support

Mothers and fathers in this study were asked to speak about seeking help for their child as well as for themselves, and the manner in which the help-seeking transpired differed, depending on who sought, from which network, and for whom. First, when it came to asking for help from within formal networks, despite the systemic complications mentioned above (e.g., system navigation and lack of available support), both mothers and fathers had no personal hesitance when the seeking was related to their child. They believed that professionals were paid to provide help, and so they did not hesitate to push for what they felt they should be provided. However, mothers reported being invited into discussions related to help for their child, while fathers reported that they were often not automatically invited. And while they consistently made efforts to attend meetings, it seemed to fathers that professionals aligned their discussions more towards their child's mother.

When it came to seeking for themselves, however, while mothers maintained that they asked for what they needed; fathers, more often than not, did not seek help within formal networks. This is not to say that they did not recognize that they could have used help, it reflected their sense that, not only did they perceive seeking for themselves as a show of weakness, the support available, and often that which their child's mother utilized (e.g., support groups), did not seem like it would be useful to them. Existing literature about help-seeking in the context of ND, that also includes the perspectives of fathers is limited, and when studies do include fathers, the focus of research is mostly in terms of help for a child. That said, findings from this research align with some current literature about fathers' experiences of 'being' the father of a child with ND, and to their relationship with the help that is provided to their child. As in this study, Carpenter and Towers (2008) found that fathers were open and willing to speak about their relationships with their child, and that they felt helped when they knew their child was helped. In addition, as with this study, their findings also indicated that most of the fathers did not have extended support networks, and that they relied mostly on their spouses for support. When they engaged with HCP who were working with their child, most reported that they were never asked about how they were doing, or if there was anything the HCP could help 'them' with. Pelchat, Lefebvre, and Perreault (2016) found that, compared to mothers, fathers were more reluctant to seek help because they were concerned about not wanting to impose on others. Frye (2016) reported that fathers' needs were also related to their child, and that, similarly to fathers in this study, they wanted to be involved in the care plans, and they wanted honest information. And in a 5-year, longitudinal study in which 7 fathers were interviewed about their child with an intellectual disability (T1= 6-months post diagnosis, T2= 1 year after first interview, T3= 5 years after first interview), Boström and Broberg (2014) found that over time, fathers moved from a strategy of avoidance, to a vulnerable openness (fathers speaking about their child with sadness about being incapable of helping their child), and finally to a contained openness (more stable balance between 'being' with child and emotional response to child) when it came to their emotional responses. Over time, fathers became more comfortable with interacting with their child. While the focus of their study was on fathers' parenting experience, the authors did suggest that, given the increase in engagement of fathers with their child over time, perhaps supports aimed at engaging fathers with their child would be more effective for fathers than traditional supports aimed at eliciting discussions.

Second, when it came to seeking help from family and friends in informal networks, mothers and fathers differed again. Mothers reported having similar engagements within informal networks as they did with formal, regardless of whether the seeking was for their child or for themselves. Fathers, however, became more concerned about the privacy of family matters, and about how they might be perceived as being weak, and thus reported feeling more reluctant about seeking help from informal networks. The nuance here is that some fathers reported 'being' supported by friends, but through informal activities that allowed them to escape from their concerns for the duration of the activity. These fathers did not overtly 'seek' help, but they 'felt' help through the activities they engaged in.

Over all, discussions with mothers and fathers about their help-seeking, especially for themselves, had different undertones. Mothers were vocal, and seemed to seamlessly interlace emotive aspects of their seeking within descriptions of more concrete and task oriented tasks. Fathers, on the other hand, spoke about the emotional aspects of their help-seeking openly, but in a more controlled manner. Mothers spoke 'with' emotions, fathers spoke 'about' emotions.

This study has highlighted a number of contrasting experiences between mothers' and fathers' personal experiences of help-seeking, especially from formal networks: mothers are invited into discussions about their child by helpers in formal networks; fathers are not. Mothers feel included in decisions about their child from within formal networks; fathers, when they are able to attend, feel excluded by professionals who direct discussions towards their child's mother. Mothers feel comfortable seeking help for themselves within formal networks, and feel supported by the resources available to them there; fathers are hesitant to seek for themselves (from both networks), and do not think available supports would meet their needs if they did. While these findings touch upon many important and vast bodies of literature (e.g., social construction of gender roles, conceptions of masculinity, feminist theories about mothering, to name a few) that by far, exceed the purpose and scope of this dissertation, they are tremendously useful to consider through the lens of social work intervention. In particular, they emphasize how help from formal networks systematically excludes fathers from decisions about their child. Recent literature indicates that including fathers in the decision-making process regarding issues about their child is important (Addis & Mahalik, 2003; Bogossian, 2017; Hartley & Schultz, 2015; McHale & Negrini, 2018), and more and more, fathers are making it known that they want to be included (Addis & Mahalik, 2003; Hartley & Schultz, 2015), highlighting the importance of welcoming fathers into these important conversations. Fathers experience 'needing' help differently than do mothers, and experience 'being' helped in ways that differ from mothers too (Addis & Mahalik, 2003; Burrell, Ives, & Unwin, 2017; Hartley & Schultz, 2015; Paynter et al., 2017; Pelchat et al., 2016) therefore the supports that exist do not effectively meet the needs of fathers, and fathers miss out on support they identify needing.

Helping relationship dichotomies

The final point of discussion brought forth by mothers and fathers in this study is that of helping relationships. More specifically, how the manner in which relationships with helpers within formal networks contributed to their experience of the seeking process as either positive or negative, welcoming or distant, inclusive or alienating, and ultimately, helpful or unhelpful. In this study, when parents felt they were invited into the decision-making process, that their knowledge about their child was valued, and that their concerns and input were listened to and considered with respect, they gained an overall sense of the process as being helpful, and they carried this with them into their next seeking processes. Contrastingly, most parents experienced helping relationships in quite the opposite way, resulting in them anticipating future seeking processes with apprehension and dread. As we have seen earlier, current literature does not characterise parents' experience of help in a positive way.

Personal and caring characteristics are fundamental to a helping relationship, and those who embark in a profession that is dedicated to providing help, do so from a place of caring and with a personal desire to 'be' helpful. This is in line with findings from Staniforth, O'Brien, and Fouche (2011) who, in their study conducted with social workers in New Zealand, asked participants to define what social work meant to them. Responders defined social work not in terms of theoretical frameworks or evidence-based approaches but on how they actually performed or 'did' social work, highlighting elements such as engagement in supportive roles, partnering with clients, establishing relationships with clients that will promote empowerment (Staniforth et al., 2011). These definitions highlight the relational aspect of helping relationships the parents in this study spoke about wishing for.

Investigations of client-professional relationships within current literature describe several elements that parents suggest would positively impact their relationships with professional helpers. And these findings align with similar elements described by parents in this study. For example, parents (N=120) of children with ND from Prezant and Marshak (2006) suggested several actions they considered would be helpful; being listened to and feeling respected, being empowered and supported, that HCP should engage with them from a place of knowledge, competence, collaboration, and with a holistic approach that focused on the child and family. These findings align with Mulligan and colleagues (2012), whose participants (N=10: n=8 mothers, n=2 fathers of children with ASD) also suggest that communication and transparency, inclusive partnerships, and assistance with systems navigation were elements that could improve helping relationships. These findings were echoed by the work of Morris, Muskat, and Greenblatt (2018) who added the perspective of social workers (N=14), who engaged with parents of children with ASD in pediatric hospitals in Canada.

These findings have important practice implications for social work and for other HCPs who engage with parents, as contacts with HCP typically serve as the catalyst towards many of the supports parents seek for their child, thus for parents, engaging with HCP is somewhat inevitable. Within a journey that parents of this study consistently described as challenging and fraught with obstacles and uncertainties, while a positive helping relationship might not eliminate these obstacles, it could make the journey more tolerable. These findings highlight the importance for HCPs to be introspective about the manner in which they enact their professional helping roles so that parents experience them in the manner they describe as most helpful.

Practice Implications

The results of *The Journey of Ladders and Snakes* informs the development of guidelines for practice with mothers and fathers of children with ND. In order to provide help to mothers and fathers of children with ND, it is important to understand both the child and their capacities and functional levels, and the impact these have had on mothers and fathers. These are related to the types of help parents are seeking, for their child as well as for themselves.

For social workers and other HCPs:

- It is important for HCPs to recognize that for mothers and fathers, help-seeking stems from a place of grief and loss about the child mothers and fathers expected, who never came. These feelings reside in a place deep within mothers and fathers, and speaking about them is not easy. Making room for this discussion, by opening a space in which loss is an acceptable topic, would offer parents a place to voice this grief. In addition, as parents in this study expressed feelings of anger about their child's condition, followed by guilt for having those feelings, informing them that these strong feelings are shared by other parents, may help them feel less guilt.
- Mothers and fathers in this study sought help from informal networks and they recognized that as their child aged and changed through the passage of time, so too, did their sources of support. This is important to consider as support from this network was also characterised as helpful. Thus, it is important to be aware of whether or not mothers and fathers have informal networks, who is in them, what roles they play, and how their accessibility may change over time.
- All parents sought help from formal networks and they described not always knowing what they needed or what to ask for, and when they did know what to ask for, they struggled to navigate a system that was confusing. Accompanying mothers and fathers through the navigation could not only help parents better understand what the systems offer, but also help them find help in a more timely fashion. Being forthcoming with information regarding available support rather than waiting for mothers and fathers to request specific supports themselves, is important. When parents don't ask for help, it does not necessarily mean that

they do not need help. Rather it could be an indication that they simply do not know what the problem is, or what to ask for. Help-seeking is therefore a negotiated process, a conversation between HCP and mothers and fathers.

- Both mothers and father contribute to help-seeking, therefore it is crucial that both be welcomed into all matters relating to their child. Informing mothers and fathers that seeking roles exist, and that they remain stable over time, even when needs may change, is important. Opening a discussion with mothers and fathers about their roles and about how help-seeking transpires between them could ensure that the roles they establish early on are adequate, and that they understand how each contribute to the process. Discussions related specifically to mothers and fathers, as individuals as well as co-parents, jointly as well as individually could help each parent express their own experiences and subsequent concerns, and could also help illuminate to them the roles and responsibilities each has taken related to help-seeking.
- Mothers and fathers also experience 'needing' help and 'being' helped differently, thus promoting and developing support that will be felt as meaningful by both mothers and fathers is imperative.

Policy implications

In order to make help accessible to both mothers and fathers, it is incumbent upon organizational policy-makers to prioritize the inclusion of co-parents and to allow for the structural elements within the organization to be flexible so that help can be sought at times that are convenient to both mothers and fathers (evenings, weekends, holidays), and that proper supports are created that will meet the needs of not only mothers, but fathers as well.

In addition, in order make help accessible to as many children as possible policy-makers involved in the creation of support programs and services can shift away from the current diagnostic-specific eligibility criteria to prioritize the functional concerns and needs of children instead; as such, conforming to a non-categorical approach of service provision and delivery.

Research Implications

This study sets the stage for investigating further into the help-seeking process by addressing the following:

- Engage a more heterogeneous sample of parents, from different geographical locates within the province of Québec, and parents who are less cooperative with one another
- While the interviews in this research were about seeking help for their child as well as for themselves, parents focussed the discussion primarily on help sought for their child. As parents identified that they also needed help, more research on the experience of seeking help for one's self could deepen the current knowledge.
- Mothers and fathers described their experience with help-seeking from the formal network. Research with social workers and other HCP would deepen the current knowledge about what they know about how parents seek help and how this informs their practice. Understanding how being a help provider is experienced could illuminate areas of convergence and divergence between parents and HCPs.

Limitations

There are a number of limitations to this study. (1) Parents in this study all began their seeking journey years prior to this study taking place and so their initial seeking experience occurred within a different social service delivery context than that of today. As such, this study does not account for the insights and experiences of parents who are beginning their journeys under new policy and regulations in the province. (2) Some of the participants involved in this study were recruited using snowball sampling. This means that their identity may have been known to the person who referred them to the study. In addition, it also meant that, given their familiarity with each other, parents may have shared similar journeys. (3) In most cases (except 2) parents from same dyads were interviewed on different days and while the first parent was asked to not reveal the content of the interview to their child's other parent it is impossible to know to what extend this was maintained. As such, it is possible that the second parent interviewed had already engaged in a discussion after having received some insights about the interview content and structure from the first parent. (4) As one parent from each dyad was responsible for soliciting the participation of their child's other parent, it is impossible to know if any pressure was placed on the second parent by a first parent who was keen to participate. It did not seem like any parents participated begrudgingly. (5) Although all interviews provided rich and deep discussions, it is impossible to ensure that participants felt completely at easy sharing their personal experiences. (6) This was a very homogeneous and highly functional sample of mothers and fathers: heterosexual mother/father co-parenting dyads, educated, with similar family income levels, long-standing Canadian citizens, situated within a large urban metropolitan city. Findings may have been different with a more varied and heterogeneous sample.

Conclusion

Why is *the Journey of Snakes and Ladders* important? Understanding help-seeking broadens our understanding of parents as seekers: 'who' seekers are, what personal characteristics and other factors facilitate or act as barriers to their seeking, where they are seeking, and what aspects of support services are seen as beneficial to them. With this knowledge we are better equipped to create and provide support that is deemed pertinent and helpful and that parents report as meaningful. In a parenting dyad of mothers and fathers, we need to find ways of being more inclusive in our approach to service provision. Assessing help-seeking among mothers and fathers increases the likelihood that connections are made and/or maintained with formal and informal networks that meet the unique needs of both.

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Linking Statement

The previous chapter, *The journey of ladders and snakes: help-seeking among mothers and fathers of children with ND* presented the methodological aspects of the empirical study, and the experiential elements of the substantive theory. The following chapter, the *Cyclical Process Model of Help-Seeking: Mothers and fathers of children with ND*, presents the process model that emerged from the empirical study. It is the second article of the dissertation, and is being prepared for publication.

Chapter 5 – Cyclical process model of help-seeking: Mothers and fathers of children with neurodisabilities (ND)

(Manuscript 2)

Glidden, G., Tétreault, S., Flanagan, T., & Lach, L. M.

Abstract:

The purpose of this article is to describe a model of help-seeking that represents the experience of mothers and fathers of children with neurodisabilities (ND). The model is based on a substantive theory, *The Journey of Ladders and Snakes,* that emerged from a constructivist grounded theory (ConGT), conducted with 6 mother/father co-parenting dyads (N=12). Mothers and fathers participated, separately, in individual, semi-structured interviews regarding their seeking help for their child as well as for themselves within informal (e.g., family, friends), and formal (e.g., health and social service organizations) networks of support. This article describes the *Cyclical Process Help-Seeking Model.* The model depicts three distinct emotional and cognitive and affective processes that mothers and fathers engage in when seeking help: (1) ***What's going on here?***: identifying a situation as one that they need help with and that requires mobilization, one that is imminent and that they must respond to, or one that will require them to respond to in the future, (2) ***Exploring all avenues***: embarking on a search for all possible supports, (3) ***Dealing with today***: settling back into family routines given uncertainty related to extent and nature of current and forthcoming help (i.e. integrating offered help, waiting for forthcoming help, no help forthcoming). These processes repeated for each identified need, resulting in more than one process unfolding simultaneously, over a continuum of time. The *Cyclical process*

Model of Help-Seeking is recommended as a practice tool for opening and elaborating dialogue with mothers and fathers about their help-seeking.

Key Words: (3-8) Help-seeking, neurodisabilities, childhood disability, mothers, fathers, parents, process model

Introduction

Mothers and fathers of children with ND often seek help from both informal (e.g., family, friends) and formal (e.g., health and social service organizations) networks to assist them with the daily care of their child, yet, little is known about what their *process* of seeking help entails: the introspective nature of decision-making that determines who will seek, for what type of help, under what circumstances, and through what process. This article seeks to address that by describing a model that emerged from a study on the help-seeking of mothers and fathers of children with ND that identifies a three-stage process they experienced in their seeking for help.

A substantial body of literature describes different aspects of the parenting experience. Some of this literature illustrates elements about parents' physical and mental health that are considered as the main contributors to physical and psychological strain such as depression (Blankenship, 2010; Grant et al., 2013; Kilic, Gencdogan, Bag, & Arican, 2013; Singh, Ghosh, & Nandi, 2017), anxiety (Grant et al., 2013; Kilic et al., 2013), and stress (Grant et al., 2013; Theule, Wiener, Rogers, & Marton, 2011; Wang et al., 2013). Other literature depicts the experience parents have about the various supports they felt were essential to their child and to their own well-being. For example, having access to information and supportive services, when percieved adequate, is helpful to them (Al-Gamal & Long, 2013; Hassall, Rose, & McDonald, 2005; Kilic et al., 2013; Wang et al., 2013). At the same time, help is difficult to locate (Bussing, Zima, Gary, & Garvan, 2003), and it is often lacking in availability, and 'fit' (Boulter & Rickwood, 2013). Although relationships with professionals who offer help are reported as essential to support being experienced as positive (Wodehouse & McGill, 2009), mothers and fathers report that interactions with helpers can be judgemental, uncaring, and lacking in knowledge (Nowak, Broberg, & Starke, 2013). Both groups of studies describe elements that illuminate some of the reasons why parents might be led to seeking help.

Scholars have been examining help-seeking and evaluating the behaviours, motivations, and attitudes of help-seekers for decades. Through this literature, help-seeking has been described as a process that combines personal, societal, and health-system determinants, whose interactions act as contributors to service utilization (Andersen & Newman, 2005), and to active help-seeking behaviours (Andersen & Newman, 2005; Cauce et al., 2002; Chan, 2013; Goldsmith, Jackson, & Hough, 1988; Gross & McMullen, 1983; Pescosolido, 1992; Rosenstock, 1974; Srebnik, Cauce, & Baydar, 1996). Help-seeking involves recognizing that a problem exists, making the decision to seek help, and deciding where and from whom the help will be sought (Cauce et al., 2002), a process that is influenced by individuals' perception of problem urgency, attitudes towards the problem and about seeking help, and their personal coping capacities and support systems (Goldsmith et al., 1988; Srebnik et al., 1996). When individuals engage in help-seeking they do so to address medical concerns (Pescosolido, 1992; Rosenstock, 1974), and/or for support related to emotional and psychological support (Cauce et al., 2002; Chan, 2013; Fischer & Turner, 1970; Fisher, Nadler, & DePaulo, 1983; Goldsmith et al., 1988; Srebnik et al., 1996). Help-seeking transpires through engagement within both formal (Cauce et al., 2002; Fisher et al., 1983; Goldsmith et al., 1988; Srebnik et al., 1996) and informal (Barbee, Gulley, &

Cunningham, 1990; Chan, 2013) networks of support, and at times, from both (Gibson, 2016; Gross & McMullen, 1983; Pescosolido, 1992). Help-seeking is a process that is interactive and collaborative (Pescosolido, 1992), and that unfolds within a larger socially constructed reality, through a circular process of evaluations, re-evaluations and the revisiting of stages in one's process (Cauce et al., 2002).

For some individuals, help-seeking is considered natural, while for others, it is more difficult, and accompanied by feelings of self-doubt that can deter seeking (Cohen, 1999a; Fischer & Turner, 1970). In some cases help-seeking engagements are deterred by one's sense of personal cost (e.g., the perception that one is giving up some control and losing self esteem, fear of changing the balance of power within an existing relationship, and being cognizant of not wanting to impose or bother someone). In other cases, it is the sense of public costs that can deter help-seeking (e.g., feeling that one owes something (is indebted) to the helper in return for the help received (Chan, 2013), a power imbalance between the seeker and the helper (Barbee et al., 1990; Chan, 2013), a sense that the seeker is dependent on the helper, has lost their own sense of control (Barbee et al., 1990), and that one is unable to proceed without the helper's involvement (Chan, 2013). These are offset by the skills individuals gain through seeking help (e.g., accomplishing tasks that one was previously incapable of doing, (Chan, 2013), gaining insight (Chan, 2013). They are also offset by the impressions individuals have about how important the help will be to their well-being (Chan, 2013; Goldsmith et al., 1988), and by how competent and knowledgeable they perceive their helpers to be (Fischer & Turner, 1970).

Some help-seeking models have been produced through the analysis of existing theoretical scholarship (Cauce et al., 2002; Chan 2013; Goldsmith et al., 1988; Keith-Lucas, 1972; Pescosolido, 1992; Rosenstock, 1974; Srebnik et al., 1996). An early example of this, that is referred to in more contemporary literature (Cohen, 1999b) is Keith-Lukas's (1972) 4-step model of asking for help. In this model, the author describes the steps that an individual must go through in order to decide to engage with help-seeking. These steps require that an individual: 1) ... acknowledge that he is unable to deal with his current situation on his own; 2) ... be willing to discuss his problem with someone else; 3) ... be willing for this person to either direct him, or actually do for him; 4) ... be open to making some changes within himself. The belief here is that although concrete solutions may be found that will alter specific situations, unless a person is willing to be introspective and make adjustments to their inner self, the situation that lead to help-seeking in the first place will reoccur (p. 20). Other models emerge from original research, where steps or stages are presented as essential components to one's seeking (Asser, 1978; Barbee et al., 1990; Cohen, 1999a; Fisher et al., 1983; Gibson, 2016).

What these scholars highlight is the notion that help-seeking must begin with an individual having appraised a situation as one they are unable to handle. This, in turn sets forth a series of behaviours that either trigger or hold back the help-seeking process. For parents in this study, the preliminary step of situation identification may occurred when a disability was identifiable at birth (or in-vitro), for others it occurred later, when their own suspicions about their child's development was ignited, either by themselves, others within their personal informal social networks, or through professionals (e.g., daycare settings, schools or health care facilities). At its basis, help-seeking requires the recognition of circumstances that one deems to be insurmountable alone, and the suggestion is that once a situation is recognized as such, an individual can then move into locating help.

While these models provide insight into some of the important pre-seeking characteristics that are experienced by individuals, they are mostly drawn from the field of physical health, psychology, and mental heath and so, they do not necessarily reflect the context of parents who seek help in relation to their child with ND. They also often depict the experience of individuals who are seeking help for themselves, rather than for someone else, as the mothers and fathers from this study did. In addition, they also represent the decisions individuals have made in their help-seeking, as having been made by themselves, about themselves, and for themselves. In this study, while mothers and fathers may have adopted individual help-seeking roles within their family, the decisions they made, in particular about help for their child, were decided together. Existing models of help-seeking do not account for a co-decision-making process. Thus, what is known about help-seeking pertains mostly to the decision-making process that leads to individuals seeking help for themselves (or deciding to not seek), often in the context of health and mental health, and scholarship pertaining specifically to the experience of mothers and fathers seeking help related to their child with ND is lacking.

The purpose of this article is to describe a help-seeking process model that will help address this gap in the scholarship. An overview of the substantive theory, *Help-seeking*: *the Journey of Ladders and Snakes* (see previous chapter) from whence the model emerged is first reviewed. Then, the *Cyclical Model of Help-Seeking* is described and its contribution in relation to existing help-seeking models is discussed. Recommendations for practice and research are also made.

Methodological Approach

This study utilized a constructivist grounded theory (ConGT) approach based on the work of Charmaz (2006, 2014) to understand how mothers and fathers of children with neurodisabilities (ND) sought help. Stemming from classic grounded theory methodology

(Glaser & Strauss, 1967), and underpinned by constructivism (Guba & Lincoln, 1994), ConGT (Charmaz, 2006, 2014) posits that reality is subjective, socially constructed, and constantly evolving, and that the theory produced through research is co-constructed between the researcher's and the research participants' common experience and interactive interpretations of these. Through this approach, the goal of research is to produce a theoretical understanding of a phenomenon that emerges through an interactional and iterative exchange between the participant and researcher.

Study Methods

Recruitment

A purposive sample of twelve mothers and fathers (n=6 mothers, n=6 fathers) comprising six co-parenting dyads participated in this study. They were recruited from (1) an existing database of 263 caregivers (n=198 mothers, n=52 fathers, n=13 other) of children with ND (n=91 female, n=147 male) between the ages of 3-13 years (M=8.18 years, SD=2.51) who had participated in a parenting study entitled Parenting Matters! The Biopsychosocial Context of Parenting Children with Neurodevelopmental Disorders in Canada (PM!), and who had agreed to be contacted for future research (Ritzema, Lach, Rosenbaum, & Nicholas, 2016), (2) snowball sampling, (3) Facebook advertising, (4) word of mouth.

Ethics and Inclusion Criteria

Following approval from the McGill University Research Ethics Board, mothers and fathers were recruited into the study based on the following inclusion criteria: (1) they were a mother or father of a child with ND, (2) they actively co-parented with their child's other parent, (whether or not they lived together), (3) their child with a ND was aged 5-17 years; (4) they could communicate in English or French.

Sampling

Guided by ConGT principals, initial and theoretical sampling were utilized in this study to provide the starting point of inquiry, as well as to further deepen emerging theoretical categories (Charmaz, 2006, 2014). Recruitment ensued until each theoretical category had been sufficiently explored, based on Dey's (1999) concept of data sufficiency.

Data collection

The main source of data collection utilized in this study was in-depth, intensive, semi-structured, individual interviews. Mothers and fathers were interviewed separately, in locations chosen by them, in English or French based on their language preference. The mean duration of interviews was 86.71 minutes (range: 64.52 minutes -104.43 minutes). The interviews consisted of open-ended questions related to mothers' and fathers' individual and co-parenting help-seeking experiences, relationships and decision-making processes, and to how help-seeking evolved through the passage of time. In addition to interviews, a demographic questionnaire (available in English and French) created for this study provided descriptive data about mothers and fathers and their child (e.g., age, family composition, income, employment status, child diagnosis, school, types/location of help sought), and *About my Child* (Ritzema et al., 2016), a measure covering eight domains of child functioning and their impact on child's participation was completed by mothers and fathers. Each participant provided signed consent prior to data collection.

Data analysis

All interviews were audio-recorded interviews, transcribed verbatim, and de-identified by the first author (one interview was transcribed by an individual outside of the study). Transcript accuracy was confirmed against interview audio before being uploaded into an online data analysis program, Dedoose. Demographic questionnaires and child function measures were verified for missing data and mothers and fathers contacted to provide details when necessary. Data were entered into excel sheets using Microsoft Excel for Mac, version 14.5.7.

ConGT principals guided the iterative analysis of data from initial, line-by-line coding through which preliminary codes were established, to focused coding through which deeper significance was acquired, leading to the emergence of initial theoretical categories (Charmaz, 2006, 2014). Axial coding (Strauss & Corbin, 1998) was utilized as a final level of analysis to examine the relationships between categories and their associated excerpts that lead to the development of the substantive theory.

Findings

Analysis of the data from this study resulted in the production of a substantive theory that is disseminated in two complementary and interlinked manners: (1) The *Journey of Ladders and Snakes* describes the experiential components of the substantive theory that emerged from the analysis and interpretation of participants' recounting of their experiences of seeking help. The elements of this theory reflect the concrete decisions, actions, and behaviours that mothers and fathers undertook whilst seeking, nuanced by mothers' and fathers' essence of themselves as individuals and as co-parents. They are summarized herein, and provide the theoretical foundation for the process model of help-seeking that is the focus of this article. (2) The *Cyclical Process Model of Help-Seeking*, represents the procedural manner in which the experiential elements of the theory fit together, translating into a practical description of seeking elements that occur, and reoccur over a continuance of time.

The Journey of Ladders and Snakes

Th*e Journey*: Mothers and fathers described help-seeking as an ongoing and lifelong journey, a cycle of seeking that began, sometimes at the birth of their child or later in the child's life, with their first suspicion(s) that something was not right (with their child): "*But then around age 3, we noticed, you know, he was nonverbal. Even the words he'd picked up before age 3 were slowly getting lost, as well. So, and then we started all the, you know, testing and analyzing, and trying to figure out what's going wrong*" (Trevor). Seeking occurred at a junction of discussions that mothers and fathers had about difficult situations and whether or not seeking would ensue, and the seeking roles they adopted and maintained (based on personalities, personal preferences, skillsets, convenience) as part of their co-parenting dyad. While mothers were typically recognized as the parent in charge, both mothers' and fathers' individual roles within the seeking process were invaluable. The process was at once one taken with their child's other parent, and one taken alone, through individual roles:

> *So, it's like, usually my wife who will bring the topic up, and then, of course, of course we discuss it. That has never been a problem... and then, then our roles are actually quite well defined... it's Anne who gets the ball rolling. It's her who, right away goes to the computer, who does the research, um, who makes phone calls. That's really her, really her specialty...Once help has, once she has found the help, once the helpers come here, well then, ... that's, that's where I am involved. I am much more involved with the helpers, once they have been found.* (George)

Overwhelmingly, mothers and fathers focused their seeking on the help required to assist in their child's development and overall well-being, placing their own needs for help aside:

> *And to, always when you're a parent, you forget yourself, particularly with these kids, I mean, you need to forget yourself even more* (Charles)

> *It always has to be in the child's interest. The child comes first... And as the advocate you, you can't put yourself first. It's your child that comes first.* (Marc)

Seeking for help within informal networks of support (e.g., spouse, family, friends, other parents), was described as natural and uncomplicated, and focused on such things as child care, providing opportunities for socialization, offering transportation to appointments, that was provided in a caring, sensitive and loving manner. Contrastingly, help sought from formal networks (e.g., pediatric hospitals and rehabilitation centers, health and social service organizations) was portrayed as arduous, combative, and draining. Similar in type to some of the help from informal networks, it also had a more specific focus related to child development, education, integration, and future vocational and living arrangements. Help from formal networks required constant follow-ups on the part of mothers and fathers, and was often perceived as cold, strict, and confining. While mothers and fathers stressed the importance of seeking help from both informal and formal networks, overall, they stated recognizing the differences in the help they sought and received from each network:

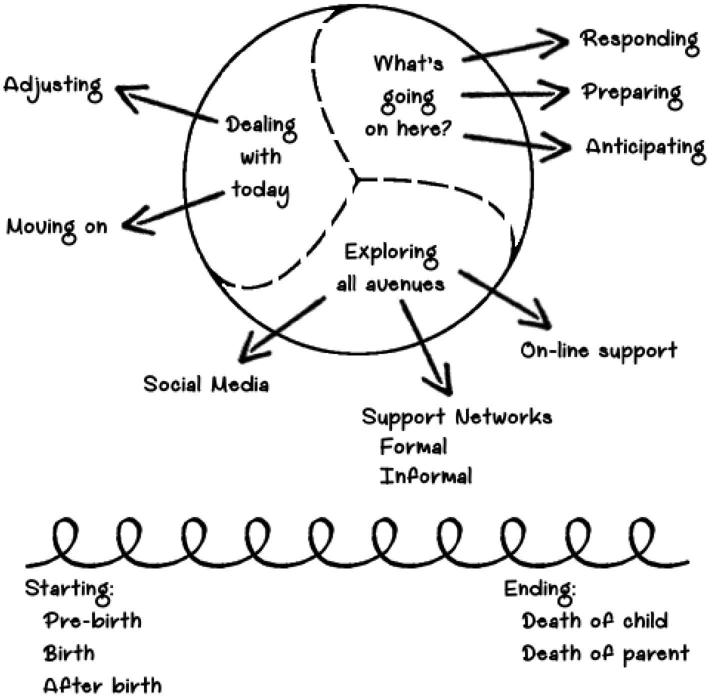
> *… well yeah. Because, family and friends, they're going by experience. And the organizations, they're going by knowledge. They're going by, um, other cases.*
>
> *Um, it's very, it's more um, I guess, more clinical if you want. Like, they're, they're not just going by what they've seen, they're going by knowledge of what other people have done, like... Compared to family, it's like, 'I remember one kid', or you know, 'my first-born did this but my second born did that', but that is all, you know, by experience and you know. They gave advice on what worked for them (emphasis). But compared to, well, 'this technique works well because 150 people', verses, well, 'my nephew did this but my son does that'. That's the, the, the big difference.* (Bridgette)

The *Ladders and Snakes*: The seeking journey was one during which mothers and fathers expressed encountering factors that both enabled their seeking, or rendered it more difficult, some personal, others, systemic. Helpful factors were related to the complementarity that existed or that developed between mothers and fathers through their ongoing seeking, relationships with helpers who went out of their way to be supportive, and personal privileges such as financial ease and education that enabled mothers and fathers to search and afford help within the private sector. Factors that impeded seeking were described as encounters with helpers who seemed ill-informed and poorly trained, complex support navigation within formal networks that were confusing, and experiencing support that reflected the needs of mothers over those of fathers.

Cyclical Process Model of Help-Seeking

The *Cyclical Process Model of Help-Seeking* presents a practical application of the theoretical elements presented above. The help-seeking undertaken by mothers and fathers was not experienced as a one-time, episodic event, but as an ongoing and lifelong cycle during which many seeking processes unfolded, each initiated by specific situations for which mothers and fathers determined the needed help. The model, presented in figure 3, thus, represents two interlinked aspects of seeking: As a *process*, it contains three elements that parents experience as they determine they need help (*What's going on here?*), while they proceed with seeking (*Exploring all avenues*), and as they resume life following a seeking process, whether that process was fruitful or not (*Dealing with today*). These elements will be explicated below. As a *cycle* it portrays the process as one that is recurrent and ongoing, that has a start and finish, that is initiated for each need that arises, thus, a repetitive and ongoing occurrence representative of one's journey. The *process* provides the elements contained in seeking, the *cycle* provides the movement and longevity of these, through time.

Figure 3: Cyclical Process of Help-Seeking



What's Going on Here?

What's going on here? is the first element of the help-seeking process, and represents the moment(s) in time when a mother and/or father identify a situation or event they deem themselves incapable of managing, one for which they determine they are needing help. *What's going on here*? is a quote, taken from an answer Alex provided during his interview about 'where' help-seeking took place. Alex's reflection and response depicted help-seeking as something that occurred from the inside, at a spiritual level in which he opened himself up to the universe in his quest to find out: "*What's going on here? How should we deal with this? What are you thinking?*" His words echoed the sentiment of inquiry expressed by other mothers and fathers who recounted the moments in their lives when they had faced situations they did not understand, events they could not manage, and circumstances that were out of their realm of knowledge. These recognitions of the need for help were often identified by mothers and fathers themselves, stemming from their own observations and interactions with their child, or they were suggested by others, outside of their parenting dyad, loved ones and/or professional helpers from informal and/or formal networks.

What's going on here? steers mothers and fathers into contemplation about their child's quality of life in terms of mental and physical health, development, and functional capacities, and it presses them into decision conversations about seeking help that will decipher/explain, improve, and/or maintain these. At times, mothers and fathers were *responding* to specific situations or events that were occurring in the present. These were at times functional concerns relating to aspects of their child's development, communication capacities, socialization, or mobility. They could also be in terms of the child exhibiting difficult behaviours, experiencing emergencies, and moments of crisis that were difficult to handle. Trevor recounted how help-seeking was initiated between he and his wife:

> *...he progressed very quickly. Standing, walking, running. But then around age 3, we noticed, you know, he was nonverbal. Even the words he'd picked up before age 3 were slowly getting lost, as well. So, and then we started all the, you know, testing and analyzing, and figuring out what's going wrong. We had people saying, you know, Einstein didn't talk until he was 5, stuff like this so, anyways, that's when it really started for me, that there was something wrong with Mike.* (Trevor)

For Simone, it was a crisis that initiated some of her help-seeking, and it was a crisis that ensured and maintained support:

> *One time when I was seeking help, it was because there was a crisis... And then it took another crisis to make things happen again. The organization is still present in my life, but when I'm not in a crisis, they don't give services.* (Simone)

At other times, *What's going on here*? represented seeking help related to *preparing* for something imminent that was episodic (e.g., needing transportation, baby-sitting, respite) or more long-term (e.g., life transitions such as entering daycare, primary school, exiting school). It was also related to their child's ongoing development or health (e.g., therapies related to communication, mobility, pediatric nutritionist). Here, parents were foreseeing events, occasions, and situations that would take place in their child's life on an ongoing basis, and/or in the near future, and that required planning in advance.

For Helene, some of her preparing was for her son's future registration for high school, and it was also about aspects of her child's social and community life:

> *I work a lot with (specialized school) in terms of setting up plans. I don't leave anything until the last minute for him. Like, he's in grade 4 now but next year I'm considering looking at high schools (planning ahead) where he might be able to go.* (Helene)

> *...in addition to that, help-seeking for me was support for, still him, but a different kind, not medical in terms, but more in social work and different areas that would support him in his social life, in the community. So that kinda broadened my scope for help-seeking for him.* (Helene)

For Marc, *preparing* meant securing early therapies and interventions for his daughter that would be part of her ongoing routines: "*I think I got her all the alternative therapy and services at the early development stages of her life to bring her where she is today*". (Marc)

Finally, *What's going on here*? represents situations in which parents were seeking help in *anticipation* of a situation or event they foresaw happening in the future, at a time they knew would come, but that was not in their immediate existence: *But (wife nickname) and I are already like, 10 years from now, where is he going to be, you know what I mean*? (Victor). *Anticipating* most often related to mothers and fathers thinking about their child in the future, as a young adult, in relation to vocation, independent living, accessing support from within an adult system of care (medical and psychosocial). *Anticipating* also occurred with mothers and fathers wondering what would happen to their child when they, themselves, were no longer able to care for them, either because of incapacity or their own death: pondering about where would they go, who would take care of them, how they would spend their days. For mothers and fathers, anticipating their child's future always occurred early on, while their child was still in primary or high school, and it most often left them feeling unsettled as a result of the unknown related to what supports would be available.

An example of this was described by Anne, who talked about how she and her child's father constantly wondered about what the future held for their child. Their child was in his teens, and their anticipating this transition time for him began when he was only ten years old. Thinking long-term, they were concerned about where he would live and about who would be there to care for him when they were no longer around:

> *First of all he couldn't be alone. He couldn't live alone. So he has to live with other people... So then it's got to be in a situation where he's not going to be abused or neglected or, you know, just be sitting in front of a television... So then it's, it's asking for help, worrying about what's going to happen. And I started working. I joined a parent's organization then. I went to seminars on, on housing for adult (name of diagnosis) people. Like, we want him to live with us, as long as he can, you know. We have a little granny flat back there (points to the back of the house) and our dream is, you know, we could have some younger person who could live there for free and who could help us out from time to time. Um, but if we drop dead tomorrow... who's going to take care of my son, there's nobody. Right? And that's a huge, huge thing for us. It's complicated and who do you, you know, who? My sister, probably one of my sisters would come but... You know, I have a sister who's, who's my older sister who would do anything to help someone in the family but, you know, it's not, she's older than me so you know, that's really not it. And you don't want to mortgage the future of your child so I can't exact promises from my 17-year old (other child). You know. We hope (emphasis) she'll be involved but there's no way we're going to put that in a contract. I'm reading a lot about the different types of, uh, types of, like care circles and all that. I would certainly do something like that but when it comes to the nuts and bolts, my son will be in the hands of the government if we die tomorrow.* (Anne)

Within the help-seeking process, *what's going on here* related to the concerns that mothers and fathers had about their child's current and future quality of life, and their own, that initiated their seeking for help that would address their concerns.

Exploring all Avenues

The second element within the process of help-seeking, *exploring all avenues*, is about mothers and fathers engaging with every possible sources of support, in both informal and formal networks, until no other conceivable possibilities existed at that moment in time. It is a discussion with Helen that elicited the words, "*exploring all avenues"*, an experience shared by other mothers and fathers who participated in the study. Helen described some of the work and coordination she needed to accomplish in order to locate help. Based on her experience, the types of help available were never simply offered to parents, but required them to undertake an active role in the process of acquiring them. Her seeking was about not leaving any stone unturned:

> *Like, there's nothing served, and like 'here's what you need, here's things for parents, here's resources'. So, the paper work and all of that, it takes a lot of time. You go and see the paediatrician, getting people to sing off on it, so I learned about that. And then there's the uh, child tax credit for children with disabilities. I learned about that through a friend. So, you explore every avenue that people tell you. I picked up on it and wrote it down to share with other people.*
> (Helene)

Exploring all avenues placed mothers and fathers in contact with different types of help providers and types of support (e.g., occupational and physiotherapists, speech and language pathologist, educators, respite) from different networks of support. Some mothers and fathers sought from family and friends, neighbours, or other parents within their informal networks where help was sometimes offered directly, or from sources that would lead to help elsewhere. All sought within a formal network (public and private sectors) from which they tried to gain access to supports. They also engaged in on-line research for information and resources, and they participated in parent groups through social media such as Facebook. Mothers and fathers reported that for some situations, their seeking occurred only within one network in particular. For example, some specific therapies or supports (e.g., physiotherapy, financial assistance) were sought from formal networks, both public and private. Other types of support, such as childcare, were sought from both informal and formal networks simultaneously (e.g., as respite, through formal networks, and as babysitting, through informal networks).

Exploring all avenues was not described as a passive activity, but rather as one that required a tremendous quantity of time, energy, and perseverance on the part of mothers and fathers. As Victor and Bridgette suggested, the need to be pro-active and persistent:

> *I would credit Helene, because Helene is just not a person who's going to sit idly by. Okay. She would research. She would call. She would contact people. She would ask the questions. She is very, very on top of her game. I don't want to say it's just her, per say. But I just think... you know, not sitting back and waiting for things to actually happen.* (Victor)

> *So the uhm you know, it was really hard. And, so that's when I started calling every day... and I said to the woman on the phone, I was like, 'I am extremely stubborn and I will call you every day until you have someone come to my home because I'm telling you, I need help. I don't care what kind of waiting list you have. I don't care how long it takes. But I will call you every day'... and they said*

> *'madame (last name), you know you're, like you really need to stop calling'... and I was like 'no. I will call you every day. I. Need. Help'.* (Bridgette)

An aspect of *exploring all avenues* was the delicate balance of quantity and timing of help sought and provided, more particularly around the time of their child's diagnosis process, when the experience of their child's condition was both clearly apparent, yet frighteningly unfamiliar, and their engagement in a process of seeking answers and support was necessary, yet wrought with trepidation into unchartered territory. In early quests for help, mothers and fathers reported not always being certain they truly comprehended what the problem was, nor did they always know exactly what they were looking for. They knew they needed help, but they did not always know where to turn, or where to seek. Simone shared of a time during her son's diagnosis process about the unfamiliarity that surrounded her seeking help that was shared by other mothers and fathers in this study:

> *And this is why you, you could be very knowledgeable, very intelligent but if you don't know, you don't know. And you can't say, 'let's find the solution', you don't even know what's going on (emphasis). To find a solution you have to know the problem.* (Simone)

Help was experienced as both too much, and insufficient, depending on what type of help it was, and on when it was offered. Thus *exploring all avenues* meant that mothers and fathers sometimes received help they had sought, but did not experience it as helpful, leading to them sometimes needing to seek for the same information again, at a later time. Informational help, provided before a mother or father felt they were ready to absorb it, or provided in too great quantity, was experienced as ineffective and counterproductive, especially when a diagnosis and the ensuing seeking were new, leaving mothers and fathers feeling overwhelmed. Anne explained it this way:

> *one of the things I think they're trying to do is help people early on... and we did have it because we definitely had someone come to the house early on with a big (emphasis) envelope of stuff. But I think, at that point, it was way (emphasis) too early (laughs). Like, we weren't ready! But, just, if there was some way. Because that's a big thing, some times, you don't, like, you need to know to ask, right? Even like money. Like that disability tax credit. We didn't apply for that right away because we didn't know, so, if you don't know what to ask for, you don't know to ask.* (Anne)

Yet the opposite was also true when the help provided was for personal care, or for specific treatments and interventions aimed at increasing their child's functioning. Mothers and fathers spoke about how this direct type of help was often insufficient to meet the needs it had been requested for. When help was insufficient, mothers and fathers needed to find ways to fill in the gaps, or they pushed, and tried to ask for more. Marc described the help his daughter received for her personal care in this manner, suggesting that as a parent, seeking did not stop once help had been received, but actually continued in order to ensure it was provided in the right amount. His description also suggested that when a discrepancy in the number of hours allotted to care and what he felt was needed, could be influenced.

> Marc: *If the (organization) is telling you, 'I can only be with you a certain number of times per week', try and get more. They're able to do it. You know. With the (organization), I went from 10-hours per week of support to 24.*
>
> Interviewer: *How did you manage that?*

> Marc: *Well, you gotta stress the severity of the situation that you're in. Some of them don't get it.* (Marc)

When mothers and fathers described their involvement in the element of *exploring all avenues* they spoke of themselves as being advocates for their child. They spoke of seeking as something for which their involvement was imperative, and that without them remaining on top of things, being persistent, and strategizing, their expectation was that help would have taken longer to locate and understand, longer to acquire (once it was offered), and that at times, it may not have occurred at all. Nathalie and Nicole spoke about persistence and strategizing in this way:

> *I feel that it's my responsibility to stay on top of it. It's not, they, they've got a lot, 500 patients or whatever it is, Annabelle's my only priority... My daughter's not more important than any other kid. For me she is, but for them she's not... so, she has to be my #1 priority so, I (emphasis) need to be on top of it, and that's the philosophy I take. I'm persistent in that way... So if someone tells me they're going to get back to me, I jot it down, and I put it, like in a week later I'll be like following it up with so and so. That's all that's in my agenda so that things don't get lost. It's a little bit, some people are like, 'ah, that's a lot of energy', well, it's energy spent. It's worth it for me because it'll, for me it will avoid frustration.* (Nathalie)

> *The other thing, I'm just remembering that I've always done (laughs), I don't know if it's conscious or subconscious, I have always implicated myself wherever he is. So, I was on the governing board at the elementary school. The minute we switched to high school we switched school boards, so right away. Governing board, special needs committee, parent's committee. To, like, get in, get known. So*

> *that if there is a problem, they already know who I am. They know who my child is. It's a lot easier to ask for, like I think it's my sneaky way, like, if I'm volunteering all these hours and now I'm asking you to help my child, it's an easier ask because I feel like I'm giving you something as well* (Nicole)

Exploring all avenues was experienced with varying degrees of success by mothers and fathers. At times, it resulted in mothers and fathers acquiring the help they sought. At other times, it meant they may have located a specific type of help for which their child met the eligibility criteria, but due to lack of availability, they were placed on wait lists. At other times still, they found help but their child did not meet the eligibility criteria. And so, a mother or father's engagement in the element of *exploring all avenues* was impacted not only by their own agency, but also by the criteria governing availability and access to help. When parents needed to wait for help that their child was eligible for, but for which availability was limited, their active seeking sometimes ended for that particular need, and they waited for it to became available. When parents' success was prevented by unmet eligibility criteria, they sometimes continued seeking, in the hopes of gaining a re-evaluation or of finding something they had not yet investigated, or their seeking for that particular need ended, and, having *explored all avenues*, they moved into the next element, *dealing with today*. The highlight of *exploring all avenues* within the process of seeking is that it continued until mothers and fathers had exhausted every source of support possible for that particular need, at which point they entered the element of *dealing with today*.

Dealing with Today

Dealing with today is the final element in the process of seeking, and relates to what happened once mothers and fathers had sought all the help they could for a specific need. What happened in life post-seeking? The label for this element was inspired by Marc who had been actively engaged in a complex seeking of help for his child that included dealing with medical and developmental concerns, mostly from his formal network of support. Having sought and received help from both informal and formal networks for aspects of his daughter's development, he was able to move on with daily life albeit with the knowledge that, as other needs arose he could be "*right back to where I started*":

> *I've done my research. Like there might be some new stuff coming out and I'll learn about it, but right now I'm happy with the progress that she's made. I'm happy with the interventions that I've put in place to get her to where she is today, and now I'm just dealing with today.* (Marc)

When Marc spoke of this phase of life, there was a sense of relief and of peace about him having done everything he possibly could, and that his role now was to pay attention to day-to-day life. But while Marc and other parents did experience times when they had settled back into life, where "*...in fact, at some point, we stay like, we stay like this, and it's like we're on, uh, as if the car is rolling and uh, and we're on uh, a little bit on auto pilot"* (George), it was sometimes short lived as other needs came up that required seeking. Or, at other times, it seemed as though those times were simply accompanied by a sense of unsettlement, that just around the corner, something might come up (something new or familiar), that they needed to remain vigilant, observant, and prepared for the unexpected. During this time, there may not have been any active seeking taking place, just an awareness that something might come up that they would need to begin a seeking process for once again. Anne explained the period of *dealing with today* in terms of how it typically seemed to occur in between moment of crisis in her home:

> *It's like when you come out of a crisis. In our case it seems to always follow a crisis. You know. There's the crisis of diagnosis. There's the crisis of, you know, increasing aggression at school. Then the crisis of having to put him on (name of medication). Which was really devastating to me. But then we got some help. You know. And there was a period where it did seem to help. And then there was another crisis when he was having problems with his teeth.* (Anne)

When mothers and fathers entered the element of d*ealing with today* they did so after an active seeking phase from which various results were possible. Some parents sought and received the help they sought for. For these parents, the time spent in this element of the *process* meant they integrated the acquired help into their every day life, organizing, scheduling, attending appointments, and at times engaging with helpers who worked with their child within their home. It may not be the help that they had anticipated, but it was help, and parents often described that, "*it might not be what I wanted originally, but you know what, it's going, it's moving along, I'm happy.* (Nathalie) Charles explained that having his son attend specialized treatment sessions was wonderful for him, but it also meant that he and his child's mothers needed not only to get him to his weekly appointments, but also needed to learn the exercises his son was learning, and organize time at home to practice them and ensure his son maintained the skills he acquired. Thus, the work involved in seeking, when successful, also translated into more work:

> *… but you have to accept, work, do their homework too. They're gonna give you some stuff to do. I mean, you want to see improvement, you have to do your part. Not only their part. Some people think 'I put him with a therapist and it's fine'. No. You have your own responsibility.* (Charles)

Sometimes mothers and fathers entered *dealing with today* without help. At times this was because they had located help that their child was eligible for but were on a wait list, thus, their seeking had ended, but they had not yet begun integrating new help into their every day lives. At other times this occurred because help was sought, and it was never located. For parents who experienced this, seeking for that particular need came to a halt, and they resumed daily life.

Most mothers and fathers who entered *dealing with today*, whether their seeking had been fruitful or not, had a sense of wanting to give back, of wanting to share the experience and knowledge they had gained through their journey with other parents, in the hopes that it would facilitate theirs. There were various ways that this occurred. Sometimes it was in a simple exchange in a waiting room where they and other parents awaited therapies with their child. Other times it was through face-to-face contact with parents they knew, or on-line, in parent support groups or chat forums. Helene, explained it this way:

> *And then, as a parent who, you know, in and around special needs at the schooling level or at the community level or hospital level, you're going to meet other parents. And then someone is going to approach you and you're going to share your ideas. That, that's how it happens.* (Helene)

Temporality

When mothers and fathers in this study spoke about their experience of seeking help, they spoke about it as a reoccurring entity, as something that was ongoing, and long term in their lives. The *process* of help-seeking is ignited each time a need arises, meaning that parents can have several processes, each addressing a different need, unfolding simultaneously. For example, mothers and fathers in this study spoke about changes in their child's needs as they aged, sometimes related to developmental and functional capacities such as communication, or to life transitions such as entering or leaving school. So as time passed by, the types of needs they sought help for changed. In addition they also described that certain transformations occurred within them, as individuals that impacted the way they sought. While the roles each adopted in their seeking remained steady over time, they gained experience with seeking and so, while roles remained, their familiarity with the networks and the processes helped them anticipate what the process might be like. Other times they spoke about specific situations that reoccurred for their child, for which they sought help frequently, as fresh episodes occurred e.g., aggressive behaviour. As time progressed, mothers and fathers could actually be in one stage, perhaps *dealing with today*, for one need, while simultaneously anticipating future seeking processes, thus moving into *what*'s *happening here*, for another need. Mothers and fathers also remained in particular elements of the *process* for different amounts of time, at times longer in one than the other, and they also moved back and forth within elements, as they learned more, or as needs changed. Thus the *cyclical process model of help-seeking* is a *process* that occurs in relationship to time, that is non-linear and fluid, as mothers and fathers move from, within, and through elements. And it is *cyclical* in that it is evoked recurrently, through the cycle of life.

Both Nicole and Victor provide examples of being in two stages at one time in relation to being grounded in *dealing with today*, yet simultaneously anticipating future transitions. For Nicole, it was thinking about her child (aged 12-years at the time of the interview in 2018) transitioning to the adult medical world, and alternative living arrangements. For Victor, it was anticipating his son (aged 10-years at the time of the interview in 2018) entering high school:

> *... when children are transitioning out of the kid system .... you can't go to a pediatrician anymore. You have to find yourself an adult doctor. And for some of these kids, that's something that I worry about, is he going to be able to live on his own? I don't know. And that's, you know, once he hits that (emphasis) age, like now (emphasis) I'm thinking about it! That's going to be another stressful period because, if he's not, I'm going to have to understand what's out there, and who can I ask for help, and what help is out there. But for me, there are definitely these milestone things that happen.* (Nicole)

> *We've weathered the storm and we've come out of it so it's good, but, I mean. There's going to be, just going into another chapter, where, when he, technically goes into high school.* (Victor)

The process of seeking is depicted above a time continuum that is presented as looping, meaning to reflect the spiralling journey of life filled with ups and downs, as opposed to a linear life experience. The line shows three starting points at which the mothers and fathers in this study began their seeking journey. At the pre-birth starting point, help-seeking began before the birth of a child due to complications detected in-utero. Seeking during this time was more medical in nature as mothers and fathers sought to understand what was happening and what it meant for their unborn child. For other mothers and fathers, seeking commenced immediately at birth, when medical complications became apparent. Here, again, seeking was initially medically based, and was very much crisis-oriented. Seeking that had its starting point pre- or immediately at the birth of a child tended to begin with sources from formal networks, mainly with medical interventionists. Most mothers and fathers in this study engaged in help-seeking some time later in their child's life, after their child was born. Their seeking typically originated from their own observations and doubts about heir child's development or behaviour, or from an observer external to them. For these parents, it was often help from informal sources such as family and friends that they first sought as they tried to understand their concern.

The temporality line also shows an ending point to seeking that reflects mothers' and fathers' impression that seeking help will never end. While 'what' they seek, and 'where' they may seek may change as situations evolve, seeking is perceived as something that, "... *never ends, never ends"* (Marc).

> *I would guess that it sort of gets less as the child gets older... I think that there might always be the need for another kind of help.* (Nicole)

> *It would seem like we are always, always in a, constantly searching for help, even when he is doing well... it's like it never ends, it never ends, help-seeking* (Victor)

> *Now I see it as ongoing maintenance that we're going to have to do for the rest of our lives.* (Trevor)

Perhaps the most emphatic description of help-seeking ending came from Anne, and clearly depicts the intensity and longevity of help-seeking. In her interview, Anne, without hesitation, said:

> *When he's dead. Yeah (said in a whisper). Or when I'm dead. (laughs). I think uh, because of what we've learned, and I knew it was a problem. All (emphasis) parents with this uh, with a child with these challenges think like that. You know. Of, of keeping, it would be better, the optimum situation is if he dies before me. That's how parents think.* (Anne)

The final temporal aspect of help-seeking shared by mothers and fathers related to the effect of time on their informal networks of support. Mothers and fathers spoke about how they had received help from members of their own family, in particular help from their own parents who spent time with their grandchild while mothers and fathers had some time off. Over time, mothers and fathers became aware that, as their child aged, so did their own parents. Mothers and fathers became aware having made adjustments regarding the types of help they asked for, the frequency of their asking, and well as the length of time /duration of each help provided e.g., in terms of baby-sitting, as grandparents aged, they were asked less frequently, and for shorter periods of time. Anne described her adjustment this way:

> *I mean, things have (emphasis) changed. Like, George's dad has passed away. My parents are older than they were years ago. They're still physically fit and very involved but I'm conscious of the fact that they're older, so I try to, you know, ask a little bit less. I'm more conscious of that...* (Anne)

Discussion

The *Cyclical Process Model of Help-Seeking* (CPMHS) is a model that represents the help-seeking of mothers and fathers of children with ND. It stems from *The Journey of Ladders and Snakes*, a ConGT that was developed through a study conducted with co-parenting mothers and fathers. The model is composed of three stages that mothers and fathers expressed having gone through in their quest to seek help for their child (and sometimes for themselves). The first stage, *What's going on here?* depicts the start of the journey, the time during which mothers and fathers determine that there is something they are unable to address themselves for which they need external input. The second stage, *Exploring all avenues*, refers to the period during which mothers and fathers engage in seeking. And *Dealing with today*, the final stage, is the time during which mothers and fathers re-establish a daily family life post-seeking. The process is characterised as being a cycle during which processes of seeking are evoked every time a new need arises, thus, the cycle can contain several simultaneous processes at once.

The objective of this study was to gain an understanding of the process mothers and fathers of children with ND experienced as they sought help, and this model provides a useful practice tool that clearly illustrates that. Within this model are some elements that resonate with existing models, in particular with the recent model by Gibson (2016), who described the experiences of parents who sought help for their child (young youth, and adults) with Down syndrome, through a three-stage process related specifically to seeking informational support. While elements of the model described in this article resemble the Gibson (2016) model in that it presents the experience of parents seeking help for their child, there are also several important differences: (1) it is not diagnosis-specific and thus includes the experience of parents who have children with various diagnoses under the umbrella term ND, (2) it is not focused on one specific type of help, but describes the experience of parents seeking for a variety of types of support, (3) it describes an entire seeking process that includes a period of adjustment post-seeking, (4) it adds a nuance of co-seeking decision-making, that is absent from all models. These elements are unique to this model, adding to what is known about help-seeking, and providing a lens through which to picture what a whole process might be like for mothers and fathers who are engaging in seeking. A discussion of these elements follows with a focus on what the CPMHS adds to the current literature, as well as how it might apply to mothers and fathers in a practice context (e.g., social work and other HCPs).

The most obvious link between the CPMHS and all help-seeking models is help-seeking. Within existing models, scholars identified element(s) of decision-making and/or behaviour that influenced individuals' decisions to seek help. It is in the first stage of CPMHS that mothers and fathers in this study identified that something required assistance from outside of their co-parenting dyad, and that a decision-making process ensued. In this study the vast majority of discussions about decision-making were about mothers' and fathers' decisions to seek help for their child. This is contrary to other models that focus on individuals seeking for themselves. For example, Chan (2013) analysed psychological literature (social, educational, counselling, clinical) and developed a theoretical model that describes the pre-help-seeking factors, personal and public, that impact an individual's *intentions* to seek help. Morawska and Sultan (2016) focused on the personal *attitudes* that impacted one's decision to seek help, while Cohen (1999a) and White, Clough, and Casey (2018) focused on elements that impacted individual *motivation*. Each of these characteristics provided insight about pre-seeking conditions that influenced help-seeking on an individual basis.

What parents in this study revealed was that for the most part, despite acknowledging that they may have needed help, most did not seek it for themselves. Overwhelmingly, the message that was received from both mothers and fathers was that if they could secure help for their child, and if they gained a sense that their child was doing well, then they, themselves, were also okay. Helping their child, in a sense, also helped them. Even when specifically prompted to speak about helping seeking for themselves, they veered back toward speak about help seeking for their child. This has major practice implications. On the surface, it seems like a win-win situation: help the child, and parents are helped also. However, helping their child was not always reported as a task that was easily accomplished. Mothers and fathers reported that locating, qualifying for, and securing many types of help they sought for their child was complex, complicated and constraining. This, they described, was due to health and social service systems that were difficult to navigate, supports that were diagnosis-contingent and lacking in availability. Many parents and their children, if they qualified for help, needing to wait, on lists with numerous other similar families, till more help became available. HCPs who were the providers of help needed to remain closely attuned to the win-win relationship between helping the child and parent because when children were waiting for a specific type of help, the waiting became a lose-lose for both. Being a provider of help must go beyond evaluating needs and referring to appropriate services, to ensuring that support is available for parents while a waiting period unfolds, or while an active searching period is underway.

In contrast to most other models, the help-seeking in this model focused on seeking for their child. This seeking is in line with Gibson (2016) whose 3-stage seeking model, as previously mentioned, is specific to parents seeking help for their child with Down's Syndrome. These two models share several elements. They both reflect the experiences of parents as seekers of help for their child, although 'child' in CPMHS referred to children between the ages of 5 and 17 years of age, while Gibson (2016) included parents whose children were also adults. Both models also reflected help that was sought specifically related to a neurodisability, although Gibson (2016) focused specifically on Down's Syndrome, while CPMHS focused on ND in general. Both models also introduced the element of time, and the impact it had on the help-seeking process. In Gibson (2016), parents' ability to seek information about the diagnosis, and their capacity to absorb the information they found increased as time passed, making it possible for them to move through three identified stages: information overload/avoidance, passive acceptance/seeking, active information seeking.

In the model produced in this study, the passage of time highlighted three elements; (1) changes in the type of help needed, (2) changes in parents themselves, (3) consistency in the seeking roles established within co-seeking dyads. The first element, changes in needs, is quite straightforward. As with all children, growth and aging lead to different developmental milestones and life transitions that naturally prompted the need for different skills and involvement. Parents in this study described changing needs based on transition periods that were also present in current literature e.g., transitions to kindergarten (Fontil & Petrakos, 2015; McIntyre, Blacher, & Baker, 2006; McIntyre, Eckert, Fiese, Reed, & Wildenger, 2010; Quintero & McIntyre, 2011), entering high school (Letrello & Miles, 2003; Wigfield, Eccles, Mac Iver, Reuman, & Midgley, 1991), and then transitioning out of school (Kraemer & Blacher, 2001; Stewart, 2009; Volkmar, Jackson, & Hart, 2017). Thus, this model depicts a process of seeking that was triggered as these different developmental and transitional needs occurred. The second element that occurred through the passage of time, transformations in parents, is in line with the discussion in Chan (2013), who reported that individuals sometimes acquired new skills through their seeking that became useful tools in their future seeking. Similarly, mothers and fathers in this study reported having gone through some personal changes where they may have developed skills such as perseverance, determination etc., and these skills were reported as having changed the way parents experienced seeking: being more familiar with what to expect of the process enabled them to go into seeking more prepared and with expectations they thought were more realistic; having a better understanding of the formal network assisted them in navigating its complexity, and helped them identify what their resources were, where to find them, and how to engage with them, making seeking more predictable and easier to organize.

However, while parents may have transformed on a personal level, the roles they adopted early on in their co-seeking process, the third element of change, were described as relatively unchanged despite the passage of time. This finding has important implications for clinical practice. Becoming aware that roles each has adopted and enacted through their co-seeking will most likely not vary significantly through time, clinicians can help parents identify the roles they adopt early on in their seeking process, not only as a means of becoming aware of who has taken on what role, but to ensure that these roles make sense to them. In this study, while both mothers and fathers were able to provide details about the types of responsibilities they had taken on within their parenting dyad, remarkably, examining how these roles had been adopted is not something they had ever discussed with any one else. They had not thought of it as a topic of discussion, and they had never been asked about it through contact within either informal or formal networks. This highlights how silently such an important aspect of seeking transpires, and reinforces the importance for clinicians to bring the topic to the forefront. While parents may declare being satisfied with their roles, in the event that they are not, an open discussion with them could facilitate changes where needed.

Making the decision to seek help for their child was met with much less hesitance than was seeking for themselves, and it introduced a 'co-seeking process' that seemed unique to this model. When either parent identified a concern, or if one was brought to their attention from the outside, mothers and fathers described that all decisions to either move forward with seeking, or to hold off, were the result of discussions, and at times negotiations, between the two. Never did one or the other engage in seeking without the other knowing. Here, a 'co-decision-making process' ensued, ignited by parents responding to immediate concerns or situations (e.g., developmental concerns, behaviour problems, crises), preparing for imminent situations (e.g., transitions into of out of school), or anticipating future events (e.g., post-secondary education, vocational concerns, future living arrangements). It is important to note that this process described by parents in this study may be relevant to parents who have found a way to work together and do not appear to be in high conflict. It provides some insights into what happens between co-parents whose roles are not necessarily sources of disappointment or frustration. For practitioners, this model becomes a useful tool for keeping track of help seeking processes that are currently in place, but knowing that seeking processes are also ignited in anticipation of up-coming events, this model can also be used in preparation for these, and thus, perhaps alleviating concerns about the future that left unresolved, may become more problematic.

Once mothers and fathers had made their decision to seek, a co-seeking process was ignited, and mothers and fathers embarked into the next stage of CPMHS, *exploring all avenues*, an element that is not present in other models. As described earlier, during this stage of the process parents sought help from two main networks of support: an informal network, comprised of individuals within a close circle to the parents and included individuals such as their child's other parent, their own parents (the child's grand parents) and other family members, friends, neighbours, and co-workers, and a formal network, comprised of for example, healthcare professionals (HCP) such as social workers, psychologists, occupational and physiotherapists, speech and language pathologists, who provided help from pediatric hospitals and rehabilitation centres, health and social services organizations, and schools. Of particular interest for practitioners is the uncertainty with which parents talked about seeking in terms of knowing what to ask for, and where to ask from. This was equally true for parents whose help-seeking had begun early on in their child's life, (e.g., after having received a diagnosis for their child from a HCP immediately after birth), as it was for parents for whom a diagnosis came later, after their own observations about their child had triggered initial concerns. It might seem likely that parents whose first contact in help-seeking was from helpers in their own informal networks would be experienced as difficult. Without any prior necessity to utilize support, it makes sense that neither parents or their informal helpers would be aware of such help and they possibly would not have been aware of what route to take in order to get answers to their first suspicions. However, the same should not hold true for parents whose first help-seeking contacts were with HCP, individuals who work within a formal network of care whose purpose it is to provide help. This raises a question about how information about the different types of support is provided to parents. In this study, parents' help-seeking was triggered at three different starting points and depending on when their seeking began, their first contacts were with either formal, informal, or sometimes both networks of support. Parents whose child was diagnosed while in utero typically first sought help from both informal (child's other parent, family friends) and formal (HCP). This was similar for parents whose child was diagnosed at birth as their first source of support and requests for help would have come from HCP and their child's other parent. Parents who became suspicious and concerned about their child following observations of their own, later on in their child's life, typically consulted with family and friends from their informal networks first, before eventually making contact with HCP. The types of help parents received from each network varied as well, with informational and instrumental support typically coming from formal networks, and emotional support typically mostly from informal. For practitioners, it is important to be aware that parents express having difficulty knowing what to ask about, what to ask for, and where to ask from. As such, it is incumbent on HCP to engage in a conversation that assesses what parents may need and what is available, in as overt a manner as possible, so that parents can get access to the help they need as efficiently as possible.

The final stage of CPMHS, that again, distinguishes it from other models, is that it presents a post-seeking stage that represents what occurs after the seeking (*Dealing with today)*. In this study, mothers and fathers spoke about a time during which their active seeking about a particular concern had ended, and during which they resumed their daily family routines either with newly found help, or without it after having sought and not acquired what they hoped for. The post-seeking element is also an important one for HCP as it is a period of adjustment during which many parents are still in need of support. Parents from this study entered this stage under three different conditions.

(1) Some parents entered this stage because they had sought help and they had acquired the help they hoped for. For these parents, this stage of the process became focused on integrating the help into their daily routines. For most parents, this required a restructuring of routines in order to accommodate for regular appointments outside the

home for specialized therapies and programs. It also meant attending meetings with HCP teams during which evaluations and implementation goals were established. Often times, these plans lead to techniques that parents needed to learn and then integrate into their homes (e.g., specialized behaviour programs). And so, while these parents acquired the help they sought, having acquired it placed a great deal of strain on them and required enormous adaptation on their part. This phenomenon is also present in current literature.

Scholars have consistently documented the negative impacts that having a child with ND has on parents, highlighting increased symptoms of depression (Blankenship, 2010; Grant et al., 2013; Kilic et al., 2013; Singh et al., 2017), anxiety (Grant et al., 2013; Kilic et al., 2013), and stress (Grant et al., 2013; Theule et al., 2011; Wang et al., 2013) as the main contributors to psychological and physical strain. Many mothers and fathers invest immeasurable amounts of time and personal resources ensuring their child's best care (Oh & Lee, 2009), interacting with professionals in the health, social service and education sectors. There are both direct costs (e.g., medication, physical therapy, behavioural and educational supports) and indirect costs (e.g., availability for employment) (Stabile & Allin, 2012) associated with this. In their day-to-day interactions, they report feeling more ineffective, less positive in their interactions, and less able to be consistent than do parents of children without NDD (Arim et al., 2012; Garner et al., 2013). Thus, for parents who have acquired the help they sought, the post-seeking process highlights the importance of regular follow-ups by HCP to ensure that their adaptation process is progressing smoothly.

(2) Some parents who enter this stage of the help-seeking process have sought for help and have been eligible for it, but they were on wait lists, as the help was not readily available. While having secured help is a positive, the waiting periods were often reported as long, frustrating, and difficult. Recent research conducted in the province of Québec by

Raymond and colleagues (2016) conquers with these parents' experience. Based on data collected from occupational therapists within 55 different home care programmes throughout the province, wait lists were shown to have between 2.9-130 people waiting (median = 23.4) and the wait times were reported to as between 2 – 108 months (9 years), with an average wait of 18 months. The study also highlights that, as many organizations operate on a priority-based delivery system, some individuals with the lowest priorities did not ever receive the help they were waiting for. Despite the fact that no parent in this study reported such exorbitant waiting periods, this does not diminish the weight of the waiting on them and their child. Connolly and Gersch (2013) recognized this period of waiting in their sample of parents who were awaiting a diagnosis for their child. Their findings suggested and demonstrated that inviting parents to attend a short-term education program, during the waiting process, helped to alleviate some of the negative impacts of waiting. Thus, from a practice standpoint, it is clear that once the evaluation and referral process have been completed, there remains a need for support while parents (and their child) wait, and support that is framed as being beneficial to their child, may be more compelling.

(3) Finally, some parents enter this phase of the seeking model, having been unsuccessful with their seeking. There are many reasons why this may have occurred, but the one most often highlighted by parents in this study was not meeting eligibility criteria for diagnostic specific support. This is problematic on many levels.

i. First of all, the right to full participation in society is a human right. The rights of individuals with disabilities to have access to the supports they need in order to participate to their fullest capacity are protected and clearly stipulated through several legislative documents: chapter 15 of the *Canadian Charter of Human Rights and Freedoms*

(Government of Canada, 2018a), chapter 10 of the *Charte des droits et libertés de la personne* (Publication Québec, 2018) for the province of Québec and for children from First Nations communities, *Jordan's Principle* (Government of Canada, 2018b). Further to this, the rights of children with disabilities are stipulated in article 23.3 of the *UN Convention on the Rights of the Child* (United Nations, 2018), and in articles 25 b, and 26.1 in the *UN Convention on the Rights of Persons with Disability* (United Nations, n.d.). Thus, a service delivery practice that systematically and systemically prevents access to needed supports, goes against basic human rights.

ii. The current trend in the scholarship on disability emphasizes the place of functionality over diagnosis, as a greater indicator of child and family well being (Miller, Shen, & Mâsse, 2016; Ritzema et al., 2016). Such a non-categorical approach, which underlines the research in this article, highlights commonalities in the functional capacities of individuals regardless of their diagnosis (Miller et al., 2016). This has been collaborated by parents in this study who, despite having children with different diagnoses under the umbrella term ND, had children who experienced similar functional needs. Unfortunately, while the children of these parents required similar types of support, eligibility for the existing supports were often diagnosis-contingent, resulting in some children being denied the support they also needed.

From a practice perspective, this also has huge implications, particularly in the field of social work. Social workers can play an important role as advocates for the human rights of the parents and children they encounter in practice. Understanding that even the most willing social workers enact their role within the structures of the organization in which they work, it is contingent upon them to consider the ways in which structures impede their professional obligations, and to push for equity within programs and accessibility to these. Of course, this is a complicated and highly systemic endeavour that requires the involvement of policy makers at various levels of government, and it far exceeds the purpose of this article. But at its most basic, social workers and other HCP would do well by ensuring that they remain focused on the human rights basis of the support they are providing, to ensure they are doing so in the best manner possible.

Limitations and future research

This model represents an important contribution to the current literature about help-seeking. It is specific to mothers and fathers of children with ND and thus provides the perspective and experience that is particular to these parents, while most other models reflect help-seeking in general, or for medical, psychological or mental health reasons. It reflects seeking that is not only for one's self but mainly for others, adding the element of co-seeking, while most models are about individuals making decisions about seeking for themselves. This model represents an entire seeking process, from identifying a need and deciding to seek, to the actual seeking, to the post-seeking, while most models reflect only factors related to the decision-making process, and do not discuss the actual seeking, or what happens post-seeking. And this model incorporates the element of time, the relationality of seeking (between mothers and fathers), and seeking from informal and formal networks, elements that are only seen in few other models. Despite these contributions, there are limitations that need to be mentioned that also suggest directions for future research.

- This model captures the experience of mothers and fathers who were similar in terms of age, marital status, relationship to their child, and income. These are mothers and fathers whose journey through help-seeking began many years prior to the study, were (mostly) in married relationships with their child's other parent, were (mostly) biological parents to their child, and who all had similar, elevated family incomes. The model could be strengthened by adding the perspective of younger parents who may have just begun their seeking journey, or that of older parents whose children had transitioned from the pediatric to adult support. Single parents, parents who had remarried, and adoptive parents and other legal guardians may also have experienced seeking differently and their perspective could also provide added insight into the model. As well, the perspectives of parents with lower income status, no income, and parents who receive monthly government support could inform the model regarding the impact of available finances on the access to support. This model did not include the perspectives of any First Nations parent. Considering the discrepancy between access to supports for First Nations individuals on and off reserve, despite the access regulations stipulated in *Jordan's Principle* (Government of Canada, 2018b), this model would likely be different had their perspectives been included.

- Parents in this study were all involved, or had been involved in heterosexual relationships, and so this model does not account for the experience of same-sex parents or of parents with other gender identities who may have experienced co-seeking differently.
- Most parents in this study were healthy, with no other ailments, disabilities or chronic health conditions. They were also highly functional parents, whether or not they resided together, and so their co-seeking experience may be different from that of parents with health issues, or parents who experience contentious relationships

with their child's other parent. This model may look different in relation to these conditions.

- Furthermore, all parents who participated in the study were long-term residents of Montreal where they shared familiarity with the city and similar geographical access to health and social service sectors. While language was a barrier for some, this was offset by the bilingual status of this parent's spouse. This might not be the case for a family who do not speak the language in which services are typically sought. This model may look different if it had included perspectives of parents who had recently immigrated to Montreal and who were unfamiliar with language, culture, and the nature of health and social service delivery as well as the social climate and understanding of disability. Also, parents from rural areas of the province, and with varying distances to urban centres may experience access to support differently than the parents who participated in this study.

Conclusion

This article has introduced the *Cyclical Process Model of Help-Seeking* (CPMHS), a help-seeking model stemming from a ConGT study in the field of social work, that represents the help-seeking of mothers and fathers of children with ND. The model depicts a three-stage process consisting of *what's going on here*? the moment(s) in time during which a seeking need is identified; *exploring all avenues,* the active seeking process; and *dealing with today*, the post-seeking stage. The model fills gaps in the current knowledge about help-seeking by adding elements that are particular to the experiences of mothers and fathers of children with ND. In addition, this model reflects a full seeking process (problem identification, active seeking, post-seeking) that transpires through a collaborative co-seeking relationship between mothers and fathers. Further, it includes seeking for others, from both informal and formal networks of support. The authors consider this model to be a useful tool for social workers and other HCP in the discussion with parents and in the provision of help to them.

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Chapter 6: General Discussion, Implications, and Concluding Statement

This dissertation is composed of two manuscripts that each presented unique elements of the substantive constructivist grounded theory that was constructed through the course of this doctoral study. The first manuscript, the *Journey of Ladders and Snakes* described the experiential elements of the substantive theory, highlighting the help-seeking process as a highly affective process, and as a lifelong journey. During this journey mothers and fathers encountered *ladders* that facilitated their seeking process (a sense of transformation, a sense of privilege, a sense of complementarity, a sense of relationship), and *snakes* that rendered it more difficult (difficult relationships, difficult navigation, difficulty in consistency of care providers). The second manuscript, the *Cyclical Process Model of Help-Seeking* presented a practical application of the experiential elements presented in manuscript 1, into a three-stage, co-seeking process that was ignited for each concern mothers and fathers had throughout the life course. The model described how mothers and fathers identified the concerns they would seek help for (What's going on here?), how they actively sought for help within formal and informal networks of support (Exploring all avenues), and how they subsequently resumed daily routines, post-seeking (Dealing with today). Clinical and policy implications, as well as directions for future research were described within each manuscript, and will be summarized below.

General Practice Implications

1. While help-seeking can be seen as a concrete activity that is geared towards mothers and fathers acquiring support, it is also a highly affective process that mothers and fathers experienced; it is a process that stems from a place of grief and sadness. HCPs need to be mindful of this element and must open up space to have a discussion with mothers

and fathers that encourages them to explore the affective aspect of how they experience 'being' a parent of a child with ND. This will not only signal to them that this type of conversation is one that can be held in the practice context, it will give voice to their grief.

2. Mothers and fathers identified that they often engage in their journey unaware of what their needs are, and that when they have identified what they think they need, they often do not know what help is available, who they can ask, or where they can to go to access help. HCPs need to engage parents in a conversation that helps them to identify their needs, and should not assume that parents already know what their needs are. HCPs need to accompany parents as they navigate the complex formal systems of support so that the most appropriate help is located in a transparent, efficient and timely manner. Needs change through the passage of time and so, too, does the help required. HCPs need to provide regular re-evaluations with mothers and fathers so that needs that may not have been clear at one time point may be identified at another. In this way, parents will have an ongoing opportunity to express new needs as they arise and no need gets left unaddressed.
3. Mothers and fathers reported benefitting from help they received from informal networks, thus, HCPs need to be aware of the extent to which mothers and fathers belong to an informal network (or not) in order to understand the nature of this extra source of help - who provides what type of help, when, and how often. In addition, HCPs need to be aware of how the passage of time might impact the availability of sources of support and their capacity to continue providing help. As sources of help age, they may be less available and/or capable of providing the help mothers and fathers

once benefited from, and so a need that was previously addressed by their involvement, may resurface as unmet.

4. Mothers and fathers clearly demonstrated that help-seeking was not only an individual journey but also a co-seeking one in which each parent adopted different roles. Yet, they also expressed never having been asked about these roles, how they had come about, or about why they had been adopted. Mothers and fathers also clearly identified that while they may have changed as time passed, and while they may have become more aware of what to expect from seeking, the roles they adopted early on in their co-seeking journey remained relatively stable over time. Thus, it is imperative that HCPs invite both mothers and fathers into discussions about help-seeking for their child, and that they facilitate discussions about their mutual roles. Parents can then identify roles they adopted early on in their seeking process, and reflect on the extent to which these roles still make sense to them as time goes on.
5. The study presented a model of help-seeking that reflects an entire help-seeking process for parents of children with ND (from identifying a need, to actively seeking, to adjusting to routines post-seeking). It highlights a co-seeking decision-making process, and also the anticipatory nature of seeking, in that parents not only seek for current issues but they are also seeking for future needs. HCPs can utilize the model when having discussions with parents related to their current seeking processes as well as to assist parents in their preparation for the future. HCPs can also utilize the model themselves, to anticipate the types of needs parents may have in the future so that they, can be prepared for responding to these needs, thus perhaps alleviating future concerns. In addition, the post-seeking period was a time of adjustment (to newly acquired help, or to having not acquired help) and also, at times, a period during which parents waited for

support to be available. HCPs must provide help during these periods of adjustment and of waiting.

General Policy Implications

1. Study results have organizational implications as well, in terms of addressing the needs of both mothers and fathers. 'Needing' help, and 'being' helped are experienced differently by mothers and fathers; with fathers, in particular, feeling inadequately supported. Thus, organizational policy related to service development, promotion, and access should include provisions for creativity, flexibility, and adaptability to ensure that meaningful support is available to both, in manners and at times that meets their individual needs and that each finds helpful.
2. Full participation in society is a human right that is recognized in several legislative documents (Canadian Charter of Human Rights and Freedoms, the Charte des droits et libertés de la personne (Publication Québec, 2018) for the province of Québec, Jordan's Principle, UN Convention on the Rights of the Child, the UN Convention on the Rights of Persons with Disability), yet mothers and fathers overwhelmingly report not having access to help that would benefit their child in their quests for participation. It is imperative that service provision organizations respect human rights, and recognize that failing to provide necessary help equates to an infringement on human rights. Getting at the root of this systemic problem requires the involvement of high-level policy makers, directors and managers of government organizations, NGOs and parents. With a commitment to improving access to services that provide support, the rights of children with ND will be more likely to be respected.

General Research Implications

Research about the help-seeking of mothers and fathers of children with ND is scarce, and so continued inquiries to further and deepen knowledge are recommended.

1. Mothers and fathers in this study participated in a one-time interview that captured their current and retrospective experiences about help-seeking. While results show that seeking roles did not change over time, they indicated that needs did, and that parents began anticipating the needs their child might have when they became adults while they were still young children. Future research conducted with mothers and fathers of young adults to explore how help-seeking related to this transition might be experienced (pre-transition, during transition, and post-transition), could clarify not only what parents anticipate needing but also what mechanisms need to be in place to facilitate a seamless transition from child to adult support systems.
2. The voices of more vulnerable and marginalized mothers and fathers, those from different geographical areas of the province of Québec, within nearer or further proximities to help, different gender identifications and couple relationships, and those who shared less cooperative co-parenting relationships with one another could add depth to what is now known. A greater understanding of the particular needs that might be experienced by these groups (e.g., cultural, linguistic, religious) could ensure that current supports are adjusted accordingly (or that more appropriate supports are created), and that clear access mechanisms are in place that ensure individuals are not only aware of what support exists, but that they can also access them with as much ease as possible.
3. In this study the vast majority of discussions about decision-making were about mothers' and fathers' decisions to seek help for their child. As mothers and fathers also

recognized that they, too, sometimes needed help, further research could focus specifically on how parents seek for their own needs. Gaining insight into what parents seek for themselves, when and why they seek it, and what supports they consider most helpful, will help ensure that the right combination and balance of support and access mechanisms, are present so that their needs are addressed.

4. The current study described the experiences of mothers and fathers as co-seekers of help related to their child with ND. Future research could seek the voices of HCPs to better understand how they experience their roles as help providers, what they know about parents' help-seeking, and how they utilise this knowledge within their practice. In addition, based on what HCPs know, training modules could be developed to increase and refine knowledge where necessary, and the monitoring of these modules could inform on the extent to which they improve the experience of mothers and fathers.

Concluding Statement

This doctoral dissertation presented details about a constructivist grounded theory, conducted with mothers and fathers of children with ND that sought to better understand their process of help-seeking. Parents experienced the seeking process as a lifelong, co-seeking journey that occurred cyclically, as new needs arose through the passage of time. What is evident from their accounts is that help-seeking was impacted by personal characteristics and beliefs, and by systemic and societal factors, and that decisions they made concerning seeking (or not seeking) were made together, as co-seeking dyads. The model that was developed can serve as a tool with which to open the discussion about help-seeking with parents, and it can be used by HCP as a tracking tool regarding needs, requests, and progress of help-seeking processes.

Appendices

Appendix 1: Consent Form

ID:____________________

Consent Form

Title: Help-Seeking: A constructivist grounded-theory study of mothers and fathers of children with neurodisabilities

Principal Investigator:	Gina Glidden, Master of Social Work (MSW), PhD Candidate Centre for Research on Children and Families McGill University, School of Social Work 3506 University Street, Suite 106, Room D Montreal, Quebec H3A 2A7 (514) 398-2107 gina.glidden@mail.mcgill.ca
Faculty supervisor:	Lucyna Lach, MSW, PhD McGill University, School of Social Work

Sponsor: This study is made possible by funding from the Fonds de Recherche du Québec: Société et Culture (FRQSC)

Introduction:

You are being asked to participate in a research project involving your experience as a parent of a child with a neurodisability (ND). Before agreeing to participate in this research project, please take the time to read and carefully consider the following information. This consent form describes the aims of the study, the procedures, the advantages, risks and inconveniences of participation as well as provides information about the person to contact, should you need to.

This consent form may contain terms that are not clear to you. I invite you to ask me any questions that you deem useful and to ask me for explanations about any word(s) or information that is not clear to you.

This Informed Consent form has two (2) parts:

1. *Information about your participation in the study*
2. *Consent (signature section if you agree to participate)*

PART I: Information about your participation in the study

Purpose of the study

I am requesting your participation in a research study. The purpose of this study is to better understand what seeking help is like for mothers and fathers who co-parent children with ND who are either entering primary school or exiting high school. The information you share will be useful and important for clinicians who will be better prepared to provide help to you in a manner that you consider meaningful and effective.

What do I have to do?

There is no preparation required for participation in this study. Once you have indicated that you are interested and willing to participate, you will be asked to sign this consent form, and to complete 2 questionnaires: a demographic questionnaire that will provide me with information about you, and a questionnaire called *About my Child*, that will give me an idea about the functional level of your child. Completion of these questionnaires will require approximately 15 minutes. Following this, an interview will be scheduled with you at a date, time and place that is the most convenient for you. The interview will last about 45-90 minutes, during which I will ask you questions about what asking for help in relation to your child has been like for you. I will audio record the interview and then it will be transcribed so that I can remain as true and accurate to your information as possible throughout the analysis and interpretation.

What are the Potential Risks?

There are no known risks associated with taking part in this study, but some parents may find the interview elicits difficult emotions or sadness. Should you find the discussions upsetting or distressing you will be referred to an appropriate resource for further support. As interviews will require a time investment, some parents may the interviews inconvenient.

What are the Potential Benefits?

You may not benefit directly from taking part in this study. However, many people find it satisfying to share their personal experiences, in the hope that they will help others facing similar circumstances.

Do I Have to Participate?

Participation in this study is voluntary. You are not obliged to answer any question(s) that you do not want to, and you have the right to withdraw from the study at any time. If you wish to withdraw from the study after having participated in the interview, your interview will not be used in the analysis and your transcript will be deleted. While agreeing to participate in this study, you will not give up any of your legal rights nor release the researchers, sponsors or institutions involved of their legal and professional obligations.

Will my records be kept confidential?

All information I collect from you for this study will be kept confidential. The only exception is in the case where it becomes clear that a child or another person is currently at risk of harm – in which case the proper authorities and professionals would be notified in order to keep the child/person safe. However, even if confidentiality needs to be broken in these types of situations, full details of your research information will remain confidential, although the reason for concern will be shared.

All information and data collected from you will be protected for confidentiality by assigning a non-identifiable code for each participant. Any discussion pertaining to the analysis of the information, and any reports and publications will never identify you. Data will be stored in a password-protected file on a computer located in the Centre for Research on Children and Families (CRCF), and all paper documents and audio recordings will be kept in a locked filing cabinet at the CRCF. Audio recordings will be deleted from the recorder after the interviews have been transcribed and paper documents will remain at the CRCF for 7-years following the termination of the study, after which they will be shredded. At any time, the McGill Institutional Review Board or a person designated by the Board may access the study data to verify the ethical conduct of this study.

Should you have any questions or concerns regarding this study or about your participation in it, please contact the McGill Research Ethics Manager, Lynda McNeil, at 514-398-6831 or lynda.mcneil@mcgill.ca. You may also contact my doctoral supervisor Dr. Lucyna Lach, Associate Professor, McGill University, School of Social Work and Associate Dean, Student Affairs, McGill University Faculty of Arts at: 514-398-4206 or lucy.lach@mcgill.ca

PART II: Consent

I state that I have read this consent form. I acknowledge that this study, the nature and extent of my participation, as well as the benefits and risks/inconveniences to which I will be exposed have been explained to me in this form. I have been given the opportunity to ask questions concerning any aspects of the study and have received answers to my satisfaction.

I, the undersigned, voluntarily agree to take part in this study. I can withdraw from the study at any time without prejudice of any kind. I certify that I have had sufficient time to consider my decision to participate in this study. A signed copy of this consent form will be kept in a secure data lab. A signed copy of this consent form will be given to me.

I agree to be re-contacted to further the discussion of specific themes or to elaborate and contribute to others ☐ Yes ☐ No

I agree to be re-contacted for other research projects in the future. ☐ Yes ☐ No

Date: ________________________________

________________________ ________________________________
Name of participant Signature of participant

________________________ ________________________________
Name of researcher Signature of researcher

Appendix 2: Facebook Recruitment

Invitation to Participate in Research
Seeking Help:
Mothers and fathers of a child with a neurodisability

I am a doctoral candidate conducting research with parents of children with neurodisabilities in Montreal and

YOU CAN HELP

What research? In my doctoral research, I want to better understand how mothers and fathers *seek help* for themselves and for their child with a neurodisability (ND): how they determine *who* will seek, for *what* type of help, and under what circumstances (*when*)?
Who Can Participate? Mothers and fathers, living together or apart, who co-parent a child with a ND who is between 5 and 17 years of age. **Note:** To be eligible, both parents - mother(s) and/or father(s)- must participate.
What's involved? This study involves each parent participating in one individual interview lasting approximately 45-90 minutes. (Each parent is interviewed separately.)
What are the Benefits? Participation in this study will help clinicians, service providers, and policy makers understand how mothers and fathers *seek help* in order to ensure that *help* is offered in a way that is most meaningful and beneficial to them.
Who do I contact for more info?
Gina Glidden, SCC, BSW, MSW, PhD(c) gina.glidden@mail.mcgill.ca

NOTE: To maintain your confidentiality, please respond to me privately.

Thank you for your help!

McGill | School of Social Work

Fonds de recherche sur la société et la culture Québec

CENTRE FOR RESEARCH ON CHILDREN AND FAMILIES
CENTRE DE RECHERCHE SUR L'ENFANCE ET LA FAMILLE

Appendix 3: Interview Guide

Initial Interview Guide

Interview Question: How do mothers and fathers who co-parent their child with ND seek help from sources within informal and formal networks?

Preamble: The purpose of this interview is to better understand what seeking help for you and your child has been like for you. I'm really trying to get a better understanding of what it's like for moms and for dads;

What might be the same?
What might be different?
How things work between both

Do you have any questions before we begin?

Family Context

1. What would you like to tell me about yourself?
2. What would you like to tell me about your child?
    Probe: Name, age, position in family, likes/dislikes
3. Understanding of term help-seeking.

Asking for Help

4. a) If you take a moment and think back in time, can you tell me about the first time you asked for help for your child?

b) Can you tell me what is it about this particular time that lead you to ask for help?

c) How would you were to describe to me how you went about seeking the help?

What did you have to do?
How did that work for you?

d) How did it come to be that it is you who asked and not your child's other parent?

e) How did you and your child's other parent decide who would seek for what, who would *do* what?

e.g., What I am hearing from mothers and fathers so far is that mothers do a lot of the 'caring' piece (appointments, therapies, overseeing things) and fathers do more hands on things (research, care for other kids in the house, shopping).

Can you help me understand that? How does that sit with you?
Why do you think that is?
Does that work for you?
How could this be different?

f) What do you do when it is your child's other parent who is seeking?

Characteristics of Help-Seeking

5. If you take a moment to think about who you are as a person, what do you think it might be that is specific to you, that makes you ask for help the way you do? (for child)
6. If we take 2 parents, same child, same needs, will they ask for help in the same way?

7. If you think about the people from whom you sought help for your child, how would you describe your relationship with them? Did you need to do anything specific to establish a relationship? Were roles different?

Same for formal and informal?

8. Is help-seeking the same/different for moms and dads? Why do you think that is? Does that work for you? How could this be different?

Spousal Help-Seeking

9. How do you think the way you seek help influences how your partner seeks help? How does the way your partner seeks help influence the way you seek help?

Help-Seeking Over Time

10. How do you think your help-seeking has changed over the years? Tell me how. Why do you think that is? Does that work for you? How could this be different?

Help for self

11. We've talked a lot about seeking help for your child, what about seeking help for yourself?

e.g., What I am hearing from parents so far is that their priority is their child. Parents have a hard time talking about help for themselves. Parents seem to seek very little help for themselves.

Can you help me understand that? How does that sit with you?

Why do you think that is?

Does that work for you?

How could this be different?

Guiding Others

12. How do you think you would guide another (mother/father) who was seeking help for a child with ND?

Probe: Would your guidance be the same for a (mother/father) seeking help for themselves? Explain. If different, why?

Concluding Thoughts

13. Is there anything else you would like to share with me that would help me understand what seeking help has been like for you?

Closing Remarks

I want to thank you for participating in this interview and for sharing your personal experience with me. If you have any questions, please do not hesitate to contact me (business card will be given).

Appendix 4: Demographic Questionnaire

Date Completed________________(Day/Month/year) ID: ___________________

DEMOGRAPHIC QUESTIONNAIRE

Help-Seeking: A constructivist grounded-theory study of
mothers and fathers of children with neurodisabilities

Thank you for agreeing to participate in this important study. Your responses are very important to us, as they will help us to understand the experiences of raising a child with a neurodevelopmental disorder, and the help you have experienced and hoped for.

Research plays a large role in the improvement of health and social services. When families like yours participate in research, we can answer questions that will lead to further improvements in the quality of care for children and families.

We ask that you take your time in completing this questionnaire, as your responses are extremely important to us.

Thank you again for your time and interest.

If, at any time, you have any questions/comments about the study in general contact Dr. Lucyna Lach (514) 398-4206.

Before you begin, there are a couple of important things that you should know:

1. **The term, neurodevelopmental disorder (NDD) may be new to you.** In this study, children with a neurodevelopmental disorder may be diagnosed with spina bifida, cerebral palsy, epilepsy, fetal alcohol spectrum disorder, autism spectrum disorder, Down syndrome, cognitive disabilities [including mild, moderate and severe], global developmental delay or any other diagnosis that influences how a child gets around, communicates their ideas, processes what they hear, or remembers things.

2. The term *demographics* refers to the characteristics of a particular group. The following questionnaire asks about the unique characteristics of you and your family such as the age of your family members, the area in which you live, your marital status, and your financial or socio-economic status. These questions are asked in order for us to be able to understand the various aspects of yours and your child's life and how the characteristics of your life may differ from other groups.

3. **If you are a parent of two (or more) children with a neurodevelopmental disorder, please pick one as a reference point.** For the purposes of this study, your answers should be based on your experiences with this child only.

Demographic Questionnaire

Please complete the following background questions about your child with a neurodevelopmental disorder (NDD) and your family.

1. Date of birth of child enrolled in the study (MM/YYYY): _____ / ____________

2. Date of birth of parent or caregiver completing the questionnaire: (MM/YYY): _____ / ____________

3. Parent age ____________

4. Sex of parent or caregiver completing the questionnaire:
    a. Female
    b. Male

5. Current Marital status:
    a. Married
    b. Common law
    c. Separated
    d. Divorced
    e. Widowed
    f. Single (never married)
    g. For how long (years and/or months): _________

6. How many children do you have? (Include both biological children and those under your guardianship) ________

7. How many children currently live with you? _________

8. In the table below, please list and provide information for all of your children. Please start with firstborn:

Child	Age	Sex		Neurodevel-opmental Impairment or Diagnosis		Type of Neurodevelopmental Impairment or Diagnosis, if applicable (e.g., Autism, Down Syndrome, speech delay, epilepsy, unknown)	Nature of Relationship to child*
		M	F	Yes	No		
1							
2							
3							
4							
5							
6							
7							

*Using the descriptions that follow, choose one that describes the nature of your relationship:

A. biological mother
B. biological father
C. adoptive mother
D. adoptive father
E. step mother
F. step father
G. foster mother
H. foster father
I. other related female (e.g., grandmother, aunt, etc.)
J. other related male (e.g., grandfather, uncle, etc.)
K. unrelated female
L. unrelated male
M. other (please specify) __________________

9. From the table in question #8, indicate the identifying number of the child enrolled in the study: _____

10. In any given month, how many days does the child (identified in Question #9) live with you (versus in another setting)? ________

11. How old was your child when you (or someone else) first became concerned about their development? Check one only.
    a. Before birth
    b. Immediately at birth
    c. Before 12 months
    d. 12 to 23 months (1 yr. old)
    e. 24 to 35 months old (2 yrs. old)
    f. 3 to 5 years old
    g. 6 years or older

12. How old was your child when he/she received her/his diagnosis? ___________(yrs./mo.)

13. How long ago was that? ________(yrs.)

14. Please indicate your family composition. Check one only.
    a. Two parent family
    b. Single parent family
    c. Other (please specify): ____

15. If you are a two-parent family, is the second parent the biological parent of the child with a neurodevelopmental disorder?
    a. Yes
    b. No

16. How were you referred to this study? Check one only:
    a. Pediatric hospital (please specify): ____
    b. Rehabilitation Hospital/Centre (please specify): - ____________________________________
    c. CLSC (please specify):- ____
    d. Other (please specify): ____

17.

From which of the following centres does **your child** receive services? **Check all that apply**		How long has **your child** been receiving services from this centre? (years, months)	How often did **your child** receive any services from this centre within the last year?				
			Once a week or more	More than once a month	Once a month	A few times a year	Once a year or less
Montreal Children's Hospital	☐		☐	☐	☐	☐	☐
CRDI *(e.g.: Miriam Home, CROM, CRDI-TED Montreal) (please specify):* ____________________	☐		☐	☐	☐	☐	☐
CRDP *(e.g.: MAB-Mackay, Marie Enfant) (please specify):* ____________________	☐		☐	☐	☐	☐	☐
CLSC *(please specify):* ____________________	☐		☐	☐	☐	☐	☐
Corporation l'Espoir	☐		☐	☐	☐	☐	☐
West Island Association for the Intellectually Handicapped (WIAIH)	☐		☐	☐	☐	☐	☐
Étoile de Pacho	☐		☐	☐	☐	☐	☐
Centre Philou	☐		☐	☐	☐	☐	☐
Other Community Center *(please specify):*________________	☐		☐	☐	☐	☐	☐
Summit School	☐		☐	☐	☐	☐	☐
Peter Hall	☐		☐	☐	☐	☐	☐
École Victor-Dore	☐		☐	☐	☐	☐	☐
École Joseph-Charbonneau	☐		☐	☐	☐	☐	☐
Other:	☐		☐	☐	☐	☐	☐
Other:	☐		☐	☐	☐	☐	☐

18.

From which of the following centres **do you** receive services? **Check all that apply**		How long have **you** been receiving services from this centre? (years, months)	How often did **you** receive any services from this centre within the last year?				
			Once a week or more	More than once a month	Once a month	A few times a year	Once a year or less
Montreal Children's Hospital	☐		☐	☐	☐	☐	☐
CRDI (*(e.g.: Miriam Home, CROM, CRDI-TED Montreal) (please specify):-* ____________________	☐		☐	☐	☐	☐	☐
CRDP (Please specify) *(e.g.: MAB-Mackay, Marie Enfant)*____________	☐		☐	☐	☐	☐	☐
CLSC *(please specify):* ________ ____________________	☐		☐	☐	☐	☐	☐
Corporation l'Espoir	☐		☐	☐	☐	☐	☐
West Island Association for the Intellectually Handicapped (WIAIH)	☐		☐	☐	☐	☐	☐
Étoile de Pacho	☐		☐	☐	☐	☐	☐
Centre Philou	☐		☐	☐	☐	☐	☐
Other community Centers *(please specify):*____________	☐		☐	☐	☐	☐	☐
Summit School	☐		☐	☐	☐	☐	☐
Peter Hall	☐		☐	☐	☐	☐	☐
École Victor-Dore	☐		☐	☐	☐	☐	☐
École Joseph-Charbonneau	☐		☐	☐	☐	☐	☐
Other:	☐		☐	☐	☐	☐	☐
Counselling services: *(please specify)*________________	☐		☐	☐	☐	☐	☐
Physicians *(please specify)* ____________________	☐		☐	☐	☐	☐	☐
Other specialists *(e.g., massage, acupuncture, naturopath) (please specify):*______________	☐		☐	☐	☐	☐	☐
Spiritual Counselling	☐		☐	☐	☐	☐	☐

19. What type of school setting does your child attend? Check all that apply.
    - a. No school
    - b. Preschool
    - c. Day care
    - d. Home school
    - e. Regular school, regular program
    - f. Regular school, regular program, assistance in classroom
    - g. Regular school, regular program, assistance/resource out of classroom
    - h. Regular school, special education program
    - i. Special education school
    - j. Adult education
    - k. Other, please specify: ____

20. What is your postal code? __________________________

21. What language(s) is spoken at home? Check all that apply.
    - a. English
    - b. French
    - c. Other, please specify: __________________________

22. What is the highest level of education that you and your current spouse/partner have completed? Check **one** level for each parent. Answer only for yourself if you are a single parent.

You	Your spouse or partner	Education
☐	☐	a. No schooling
☐	☐	b. Elementary school
☐	☐	c. Some high school
☐	☐	d. Completed high school
☐	☐	e. Some college or technical training (at least 1 year)
☐	☐	f. Completed college or technical training
☐	☐	g. Some university (at least 1 year)
☐	☐	h. Completed university degree

23. What do you consider to be your current main activity(ies)? Check all that apply.
    - ☐ Caring for family
    - ☐ Working full-time for pay or profit
    - ☐ Working part-time for pay or profit
    - ☐ Recovering from illness or disability
    - ☐ Looking for work
    - ☐ Going to school
    - ☐ Retired
    - ☐ Other, please specify: ____

24. What is your annual household income? Check one only.

- ☐ Under 10,000
- ☐ 10,000-19,999
- ☐ 20,000-29,999
- ☐ 30,000-39,999
- ☐ 40,000-49,999
- ☐ 50,000-59,999
- ☐ 60,000-69,999
- ☐ 70,000-79,999
- ☐ 80,000+

Is there anything else you would like to share with the research team about help you have received or would have liked to receive for your child and family?

Appendix 5: About my Child

Date_____________(Day/Month/year) ID: _______

Our Concerns about Our Child's Function

- Please fill in every row by ticking either "yes" or "no" on each line

Compared to other children of the same age, I am concerned about my child's:		**If YES, does this impact on their ability to participate in everyday activities?**
1. Ability to move around at home, school and community	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
2. Ability to use their hands and arms to do the things they want to do	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
Daily Activities *such as*		
3. Feeding / eating	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
4. Toileting	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
5. Dressing/undressing	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
6. Sleeping	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
7. Seeing	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
8. Hearing	☐ Yes → ☐ No (go to	☐ not at all ☐ a little ☐ somewhat ☐ a lot

	next question	

Compared to other children of the same age, I am concerned about my child's:		If YES, does this impact on their ability to participate in everyday activities?
Ability to communicate		
9. Ability to understand other people	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
10. Ability to tell people what they want	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
11. Clarity of speech/language	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
Behaviour: My child is often…		
12. Aggressive toward others	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
13. Overactive and too 'busy'	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
14. Too quiet and shy	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
Mood: My child is often…		
15. Irritable and cranky	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
16. Anxious and worried	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
17. Sad and moody	☐ Yes → ☐ No (go to	☐ not at all ☐ a little ☐ somewhat ☐ a lot

	next question	
Compared to other children of the same age, I am concerned about my child's:		**If YES, does this impact on their ability to participate in everyday activities?**
Thinking and learning abilities: My child has…		
18. Trouble to learn new things	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
19. Trouble to remember things they know	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
20. Trouble to say what they mean	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
Social skills with children: My child is often…		
21. Shy	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
22. Slow to make friends	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
23. Aggressive	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
Social skills with adults: My child is often…		
24. Rude	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
Participation in activities outside of school		
25. My child is a loner	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot

Compared to other children of the same age, I am concerned about my child's:		**If YES, does this impact on their ability to participate in everyday activities?**
Participation in activities outside of school		
26. My child doesn't want to do outside activities	☐ Yes → ☐ No (go to next question	☐ not at all ☐ a little ☐ somewhat ☐ a lot
Are there any other functional/behavioural problems which worry you? Please describe these in your own words.		